Perceptions and Barriers to Disclosure of HIV Status of Children by Caregivers at Donkerhook Clinic, Windhoek, Khomas Region, Namibia

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Abstract

Background: Disclosure of HIV status in general and to children in particular has remained a challenge along the continuum of HIV prevention, treatment care and support. Failure to disclose often brings several challenges for both the caregiver and the children involved.

Method: The study used a qualitative research approach whereby 35 parents and caregivers were interviewed using a semi-structured interview guide at Donkerhoek clinic in Windhoek. Moreover, in-depth interviews were held with the parents and caregivers who volunteered to participate in the study after giving consent to participate in the study.

Results: The study found out that caregivers face multiple challenges related to disclosure of HIV status to children. One major barrier is finding an age-appropriate way to explain HIV, fearing children may misunderstand it as a punishment or fail to grasp the need for medication adherence. There is also fear of emotional and psychological reactions, with caregivers worrying that children may become depressed, angry, or isolated, potentially leading to denial or refusal to take medication. Another barrier they face is responding to difficult questions, particularly around how the child contracted HIV, they fear this can trigger guilt and anxiety, especially if the caregiver transmitted the virus. Stigma and discrimination are significant concerns; caregivers fear the child might disclose their status to others, resulting in rejection or bullying. Adherence to medication is another challenge, as some children may resist treatment after disclosure.

Conclusions: Caring for children living with HIV poses significant challenges, primarily due to societal stigma, the need for continuous health management, and the emotional toll on both the child and caregiver. Although early disclosure and education about HIV status have shown positive impacts, many caregivers remain uncertain about how to approach disclosure and navigate the related emotional complexities. The findings indicate a need for improved support systems for caregivers and children, aimed at reducing stigma, providing education, and ensuring emotional well-being.

Keywords: Disclosure, HIV Status, Perceptions, Barriers, Caregivers, Children

I. Introduction

HIV and AIDS remains a significant public health challenge globally, with Sub-Saharan Africa bearing the highest burden of the disease (UNAIDS, 2021). Namibia, just like all countries in Sub-Saharan African countries, the HIV epidemic has had and continues to have negative implications for individuals, families, and communities. Despite substantial progress in combating the disease through various prevention, treatment, and care and support programs, challenges persist, particularly regarding pediatric HIV.

Disclosure of HIV status to children by their caregivers is a complex and sensitive issue with far-reaching implications for the well-being of both the child and the family unit. Studies have shown that timely and appropriate disclosure of HIV status to children is associated with improved adherence to treatment, better psychosocial outcomes, and enhanced coping mechanisms (Vreeman et al., 2013).

This study seeks to delve into the perceptions and barriers surrounding HIV status disclosure among caregivers of children accessing services at Donkerhoek Clinic. By exploring the lived experiences, beliefs, and challenges faced by caregivers in disclosing HIV status to children, this research aims to contribute valuable insights that can inform the development of tailored interventions and support mechanisms to enhance disclosure practices and improve outcomes for children living with HIV in Namibia.

Namibia, situated in this region, is no exception, grappling with the multifaceted impacts of HIV/AIDS on its population. Within this context, understanding the perceptions and barriers to disclosure of HIV status among children by their caregivers is crucial for designing effective interventions and support systems. This study aims to explore these dynamics specifically within the setting of Donkerhoek Clinic, located in Windhoek, Khomas Region, Namibia. In According to UNAIDS, an estimated 3,400 children under the age of 15 were living with HIV in Namibia in 2020, highlighting the continued importance of addressing pediatric HIV within the country's public health agenda (UNAIDS, 2021).

II. Method

Study Design

The study used a qualitative research design because it allows issues to be examined in detail and in depth, the data based on human experience is more powerful and more compelling than the quantitative data and the research framework.

In this study data was collected using open ended questions. Open ended allowed unlimited responses, provided more details, allowed respondents to express themselves freely and offered a deeper qualitative data on the researcher's topic.

Study Setting

This study was conducted at Donkerhoek Clinic at the ART clinic in Windhoek, Khomas Region, Namibia. Donkerhoek Clinic is in Windhoek, the capital city of Namibia. The clinic serves as a vital healthcare facility providing primary health care as well as comprehensive care HIV/AIDS services to the local community.

According to the UN 95% of the population must be tested for HIV, 95% of those tested must be put on ARV treatment, and those on treatment must achieve 95 % adherence.

As such understanding the factors influencing disclosure practices at this clinic is of critical importance for the purposes of optimizing pediatric HIV care and support services in the Khomas Region and the country. This is in line with the Vision 2030 of the 95-95-95.

Study Population

The population of study involves all the caregivers of children undergoing HAART at the Donkerhoek clinic in Windhoek, Khomas Region, Namibia. The study was limited to those who are taking care of children within the age range of 12 to 18 will make up the research group. The research population included all adults who provide care for children and adolescents who are receiving HAART at the clinic.

Sampling

Sample

A sample of 40 to 60 respondents will be drawn from the population. A non-probability sampling approach was used, and a purposive or judgmental sampling technique will be used to approach respondents for the purposes of collecting data. Study participants were drawn on their similar characteristics in that they are taking care of children who are living with HIV and are currently undergoing HAART at Donkerhoek Clinic.

Data Collection/Methods & Tools

In this study, data was gathered using in-depth, semi-structured interviews with caregivers at Donkerhoek Clinic. Using a phenomenological approach, the researcher conducted face-to-face interviews to allow caregivers to share personal stories, experiences, and emotions related to disclosing HIV status to their children. The semi-structured format provided a flexible framework where the researcher could explore specific topics while also allowing participants the freedom to discuss additional concerns, thoughts, or challenges that emerged naturally during the conversation.

Each interview included open-ended questions, inviting caregivers to describe their views, struggles, and perceptions about disclosure in detail. This approach facilitated a deeper understanding of the caregivers' perspectives, helping to capture the complex emotional and psychological factors involved in the disclosure process. The researcher also paid close attention to the caregivers' tone, pauses, and non-verbal cues, which offered additional insights into their feelings and hesitations about HIV disclosure.

Consent was obtained from all participants, ensuring ethical considerations were addressed, and interviews were conducted in a safe and confidential environment. By using qualitative methods like in-depth, semi-structured interviews, the researcher could gather comprehensive, firsthand insights into the barriers and perspectives surrounding HIV disclosure, aligning with the phenomenological aim of understanding participants' lived experiences.

III. Results

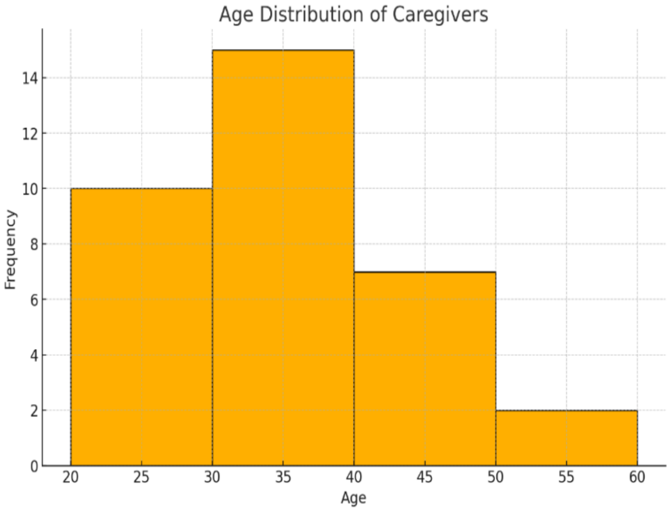
Using thematic analysis, the chapter identifies key themes that emerged from the data, offering a detailed understanding disclosure challenges they face, and the strategies they use to overcome these challenges.

Section A

Age range

Age	Frequency	Percentage
20-30	10	28.6

31-40	15	42.9
41-50	7	20
51-60	2	5.7
Total	**35**	**100**



IV. Discussion on age-related implications

Age can significantly influence caregivers' experiences and approaches to disclosing HIV status to children. The following are some of the key considerations.

Support needs

This group may benefit from additional support, such as educational resources or mentoring from experienced caregivers, to build their knowledge and communication skills.

Younger caregivers

Challenges in disclosure

Younger caregivers may have limited experience in dealing with sensitive health issues, which can impact their confidence in discussing HIV status with children.

Influence of social dynamics

Younger caregivers might be more susceptible to societal stigma, which could affect their willingness or readiness to disclose.

Middle-aged caregivers

Increased life experience

Middle-aged individuals might have more experience handling challenging conversations and could therefore approach disclosure more confidently.

Professional and family responsibilities

Balancing professional commitments and family responsibilities may also impact their ability to provide the necessary emotional support during the disclosure process.

Older Caregivers

Traditional views and stigma

This age group may hold more traditional views, which can sometimes lead to a more cautious or even hesitant approach to disclosure. Older caregivers may need targeted support to address any potential biases as well as fears about discussing HIV.

Potential health challenges

Older caregivers might also face their own health challenges, which could impact the way they handle disclosure-related stress and provide continuous support.

Senior Caregivers

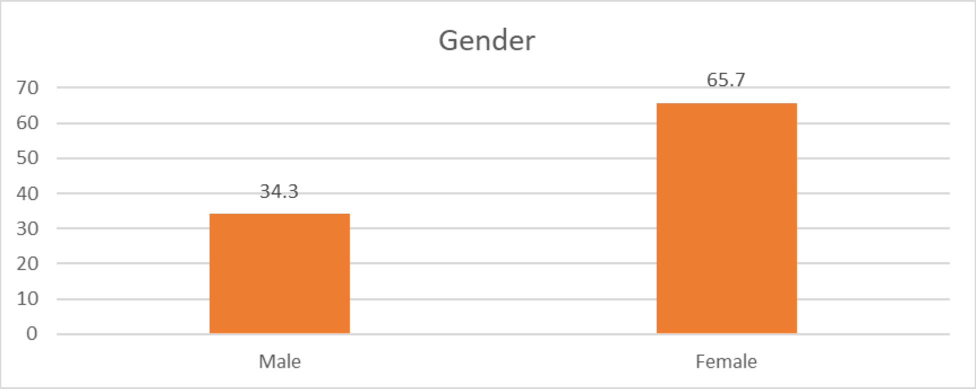
Role of extended family

Older caregivers, particularly grandparents, may take on caregiving roles for their grandchildren. Their approach to disclosure may be influenced by generational beliefs and the protective instincts often associated with older family members.

Need for emotional and social support

Given that this group may face isolation or physical health limitations, they might benefit from peer support networks and health services tailored to their unique needs.

Gender



Discussion on gender-related implications in disclosure

Gender dynamics can influence how caregivers' approach and experience the process of disclosing HIV status to children. Here are some key considerations:

Female caregivers

Primary caregiver role

Females often assume the primary caregiving responsibilities in many societies, which can lead them to be more involved in health-related conversations, including disclosing sensitive information like HIV status.

Emotional and psychological burden

The responsibility of managing disclosure often falls more heavily on female caregivers, which may increase their emotional and psychological burden. This can impact their own mental health as well as the quality of the support they provide.

Communication style

Female caregivers may feel more comfortable with emotional expression and empathy, which can facilitate open, supportive disclosure. However, they may also experience higher anxiety due to the perceived responsibility for the child's emotional response.

Male Caregivers

Social expectations and stigma

Cultural and social expectations can influence male caregivers' involvement in caregiving and their approach to sensitive topics. They might feel additional pressure to maintain a sense of "strength" or stoicism, which could hinder open communication.

Reluctance toward disclosure

Some male caregivers may feel less equipped or comfortable discussing sensitive health information, possibly leading to delayed disclosure or avoidance. This reluctance can affect the child's understanding and management of their condition.

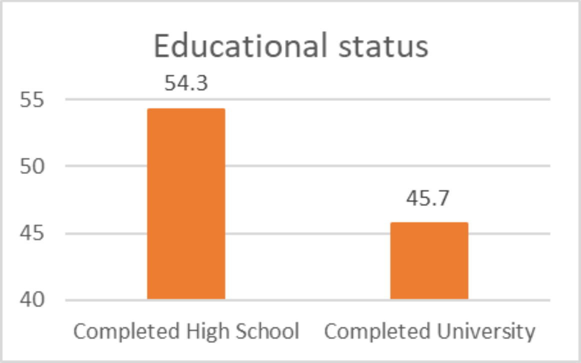
Discussion on educational status implications in disclosure

High school education

Understanding and health literacy

Caregivers with a high school education may have foundational knowledge in health but might lack in-depth understanding of HIV and its implications for long-term health. This could impact their confidence and ability to provide comprehensive information when disclosing a child's HIV status.

Educational status



Need for Support and Training

Male caregivers may benefit from targeted support that emphasizes the importance of emotional involvement in caregiving and helps them develop effective communication skills for handling difficult topics like HIV disclosure

Disclosure preparedness

Caregivers with only high school education may feel less equipped to handle the psychological and emotional challenges that accompany HIV disclosure, especially if they lack access to additional resources and support networks.

Possible barriers

They might experience difficulties in explaining complex medical concepts to children and in addressing concerns that arise post-disclosure. They may also face more challenges if they do not feel empowered to engage in medical discussions or navigate healthcare systems effectively.

University education

Increased health literacy

University-educated caregivers may possess greater health literacy and a better understanding of HIV management. This knowledge could increase their confidence in discussing HIV openly and providing detailed information to children.

Section B

What do you understand by disclosure?

Preparedness and access to resources

These caregivers are more likely to have access to informational resources and support networks that can help them prepare for disclosure. They may also feel more comfortable engaging with healthcare providers and seeking guidance.

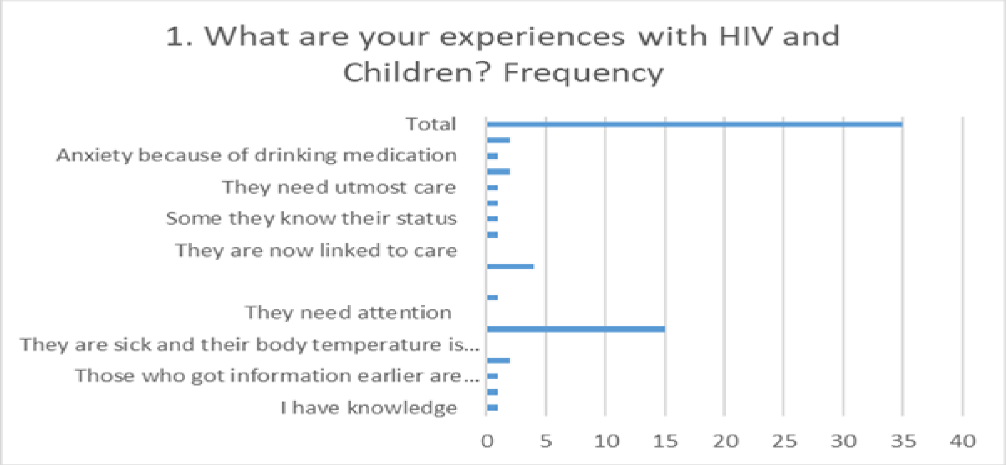
Communication skills

University-educated caregivers may have stronger communication skills, which can help them convey sensitive information in a clear, supportive manner. This can contribute to a more positive disclosure experience for both the caregiver and the child.

The understanding of "disclosure" among participants largely revolves around the concept of revealing previously unknown or confidential information, particularly in the context of sensitive topics such as HIV status. Key themes identified in the responses include Definition and Interpretation: Most participants (83%) interpreted disclosure as the act of sharing confidential or secret information that someone was previously unaware of. This encompasses revealing personal health information, such as one's HIV status, to trusted individuals.

Emphasis on Trust and Confidentiality: Many responses highlighted the importance of trust in the disclosure process, with participants noting that disclosure often involves sharing information with people who will maintain confidentiality. Complexity of the Disclosure Process: Some responses recognized that disclosure is not just a one-time event but an ongoing process that requires sensitive communication and adaptation as children grow and develop a better understanding of their condition.

What are your experiences with HIV and Children?

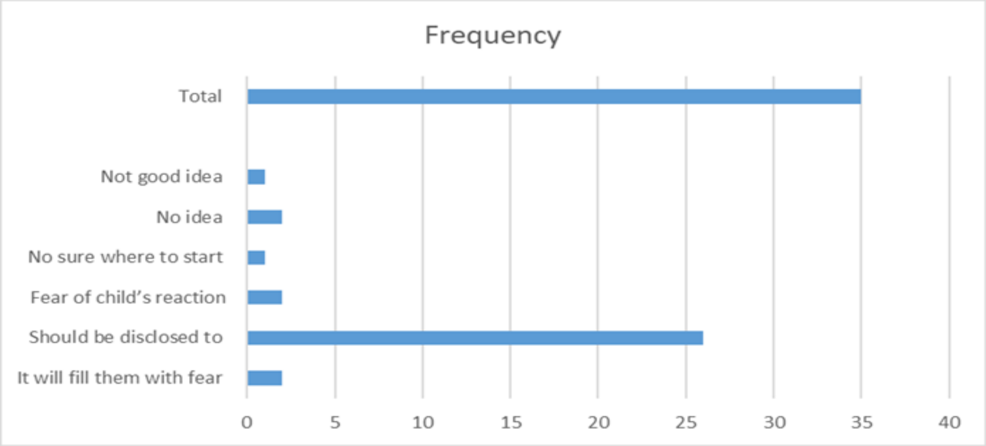


The study found that caregivers and guardians report a variety of experiences when caring for children living with HIV (CLHIV), reflecting both the emotional and social challenges these children face. Key themes include, stigma and social isolation, many caregivers (43%) report that children with HIV face stigma, leading to social withdrawal, lack of confidence, and feelings of neglect or shame. The other finding was on health and emotional needs, children often exhibit symptoms like high temperatures, frequent illness, and general sadness.

Summary of findings

They require regular care, which adds complexity to the caregiver role. The other findings were on early disclosure benefits, some caregivers observed that children who received early information about their HIV status adjusted better, showing that timely disclosure might promote acceptance and self-care. Difficulties for caregivers also emerged, caregivers experience emotional challenges, including feelings of powerlessness and anxiety, as they help children manage HIV-related health care, including medication adherence and emotional support.

What are your views about disclosing HIV to children?

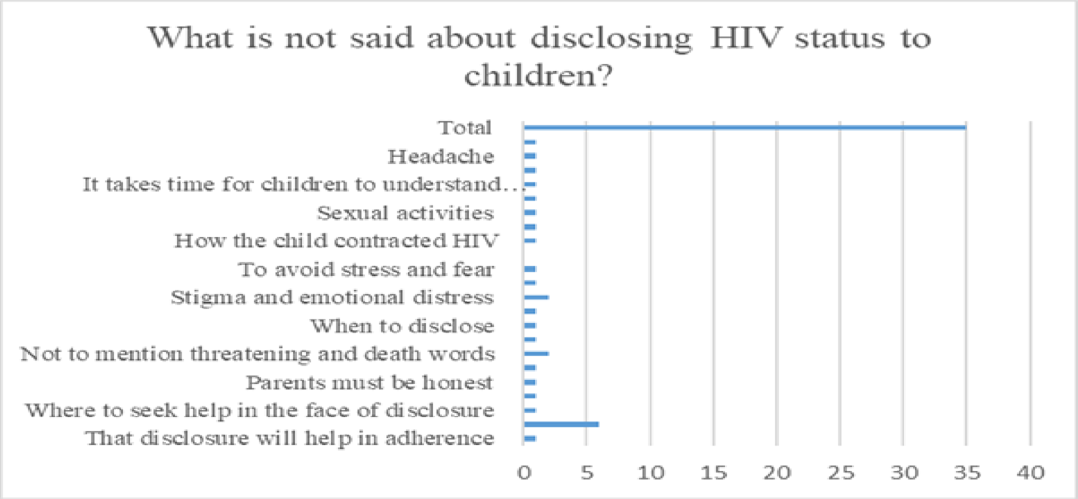


The data shows that caregivers predominantly view disclosing HIV status to children as necessary but also complex and challenging. Some of the key findings include support for disclosure, a significant majority (26 caregivers, 74.3%) believe that disclosure is important for the child's well-being and for promoting treatment adherence. There were concerns about disclosure, caregivers have concerned that disclosure might fill children with fear (2 caregivers) or result in an adverse reaction, potentially leading to trauma or emotional distress.

Summary of findings

Timing and approach were found to be an issue faced by caregivers. Some caregivers think disclosure should happen at a young age, but opinions vary, with suggestions to wait until children reach an age of understanding, such as early adolescence. Emotional complexity was also found to be an issue, as some caregivers expressed mixed emotions, including fear of how the child will respond and the potential for blame, depression, or stigma.

What is not said about disclosing HIV status to children?

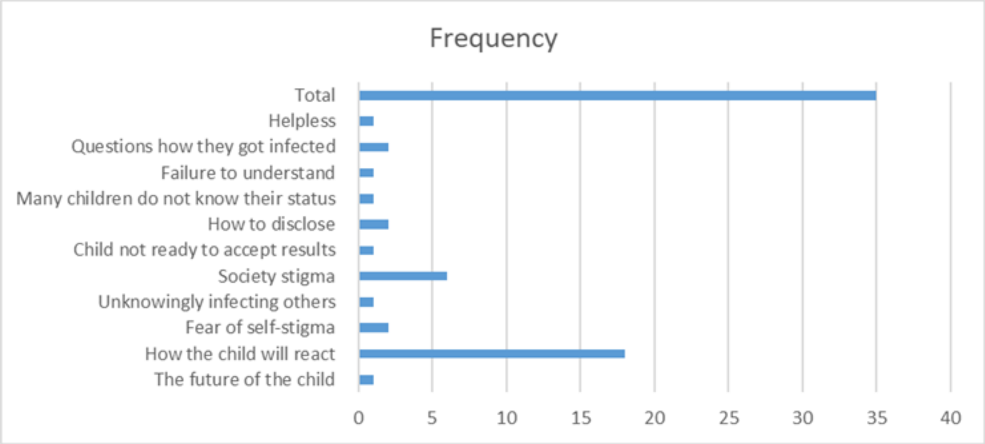


Summary of findings

The data reflects that caregivers find certain aspects of disclosing HIV status to children are often underemphasized or unclear. Key areas that are not adequately addressed include the importance and benefits of disclosure. Six caregivers (17.1%) indicated that the positive impacts of disclosure, such as improved treatment adherence and self-care, are not well communicated. Guidance on how and when to disclose, a lack of clarity exists regarding the appropriate age and timing for disclosure, as well as strategies for explaining the diagnosis without instilling fear.

Emotional preparedness and stigma, several caregivers highlighted that emotional distress, stigma, and the psychological toll on children are often overlooked in discussions about disclosure. Support systems and where to seek help, only one caregiver noted a lack of guidance on available support systems or resources when facing challenges related to disclosure. Sensitive language, some caregivers mentioned the need for guidance on avoiding fear-inducing language or references to death, which could traumatize children during disclosure.

What worries you about disclosure to children?

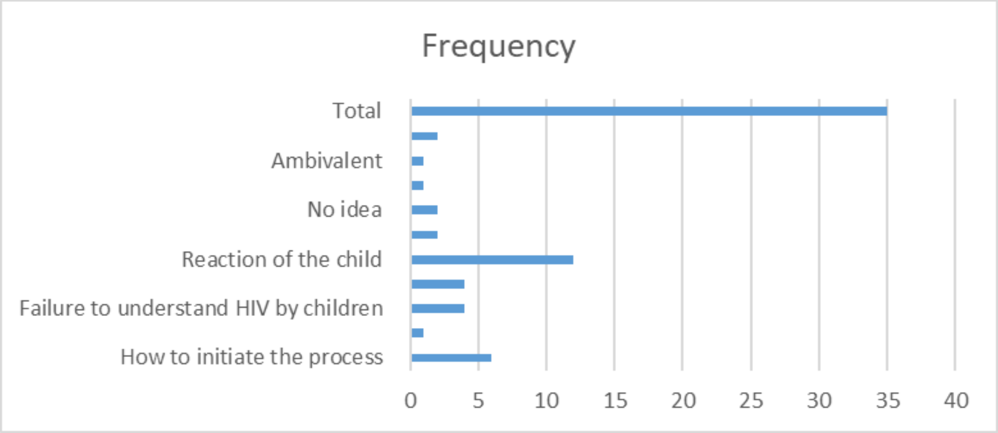


This study found that caregivers face significant worries about disclosing HIV status to children, the following are some of the major concerns. Child's reaction, the most frequently cited worry (18 responses, 51.4%) was the anticipated reaction of the child, including potential emotional distress, isolation, depression, or even suicide. Societal stigma, a substantial number of caregivers

(6 responses, 17.1%) feared societal discrimination and stigma, worried that children would be treated differently by peers and the community.

Fear of self-stigma and guilt, some caregivers (2 responses, 5.7%) were concerned that disclosure might lead to self-stigma or self-blame. Challenges with understanding and acceptance: Concerns that children might not be ready to understand or accept the diagnosis were noted, along with worries about how to handle difficult questions regarding how the child contracted HIV (2 responses, 5.7%). Disclosure process, A few caregivers (2 responses, 5.7%) reported anxiety about how to approach disclosure, indicating uncertainty about the best method for initiating the conversation.

What challenges do you face when disclosing HIV status to children?

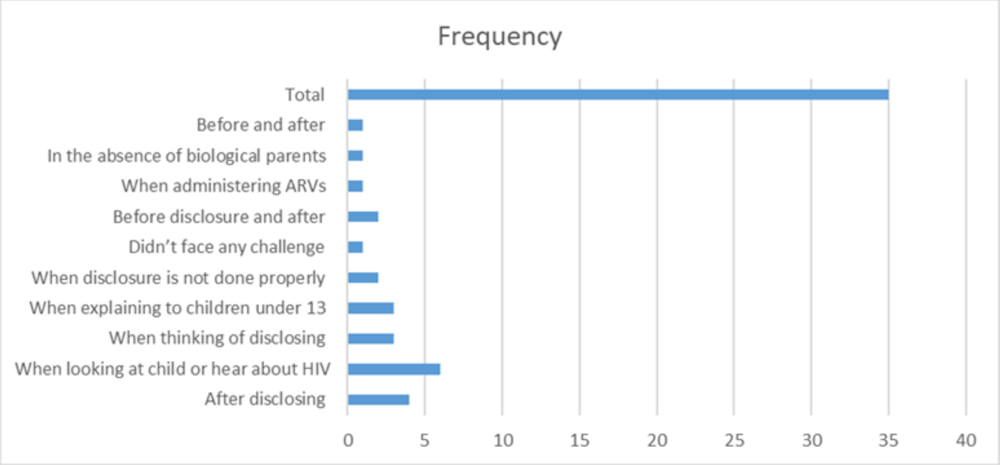


Summary of Findings

This study highlights the multifaceted challenges caregivers face when disclosing HIV status to children. The main challenges can be categorized as follows: Initiating disclosure, the challenge of knowing how to start the conversation was the most frequently cited issue (6 responses, 17.1%), reflecting the difficulty caregivers face in beginning such a sensitive topic. The other challenges had to do with children's reaction, concerns about the child's potential reaction—such as emotional distress, anger, or denial—were significant (12 responses, 34.3%).

The study found challenges related to understanding and comprehension, some caregivers worry that children will not fully grasp the meaning of HIV or the importance of adhering to treatment (4 responses, 11.4%). Answering Questions was found to be a challenge, **c**aregivers expressed difficulty in addressing challenging questions that children may ask, such as how they contracted HIV (4 responses, 11.4%). The fear of losing trust, caregivers fear that disclosing HIV status may lead to a loss of trust or feelings of blame (2 responses, 5.7%). Stigma and discrimination, concerns about potential stigma or discrimination from peers or within the community were raised by several respondents (2 responses, 5.7%). Additional concerns included ambivalence, fear that children might share sensitive information with others, and a general lack of ideas on how to handle disclosure.

When do you face these challenges when disclosing HIV status to children?

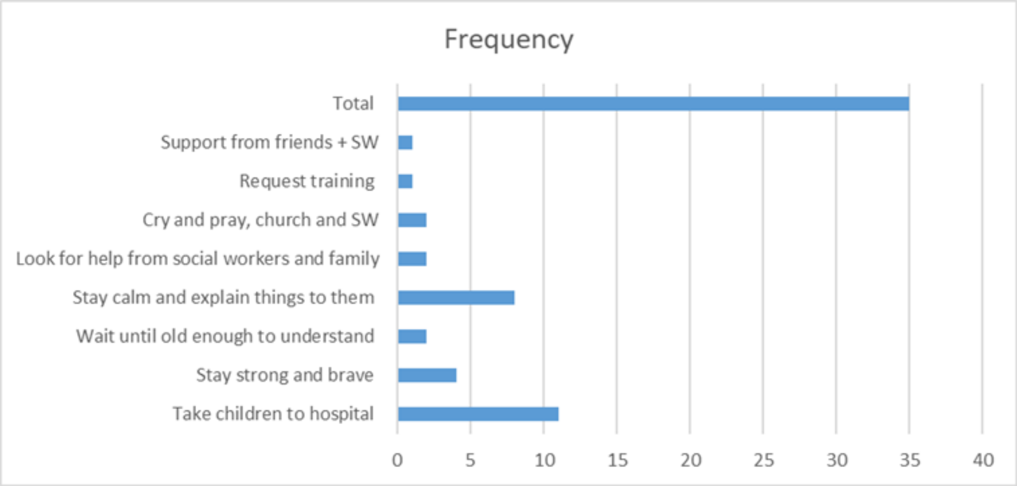


These findings highlight the emotional and logistical challenges caregivers face when disclosing an HIV-positive status to children. Many caregivers are affected deeply by daily reminders of HIV, indicating that the emotional toll of managing a child's health condition is a consistent source of stress. This finding suggests that caregivers may benefit from continuous emotional support rather than only at the time of disclosure.

The results also underscore that younger children pose a particular challenge for caregivers, who may struggle to find age-appropriate ways to explain the concept of HIV. This is further complicated by the limited ability of children to fully understand the implications of living with HIV, potentially resulting in confusion, stigma, or fear. For adolescents, caregivers report facing challenges related to the teen's increased awareness of isolation and potential stigma associated with the condition.

Another key finding is the difficulty that arises when disclosure is unplanned or poorly handled. This can create trust issues or feelings of betrayal in children, emphasizing the importance of a structured and sensitive approach to disclosure.

What do you when you are facing these challenges?



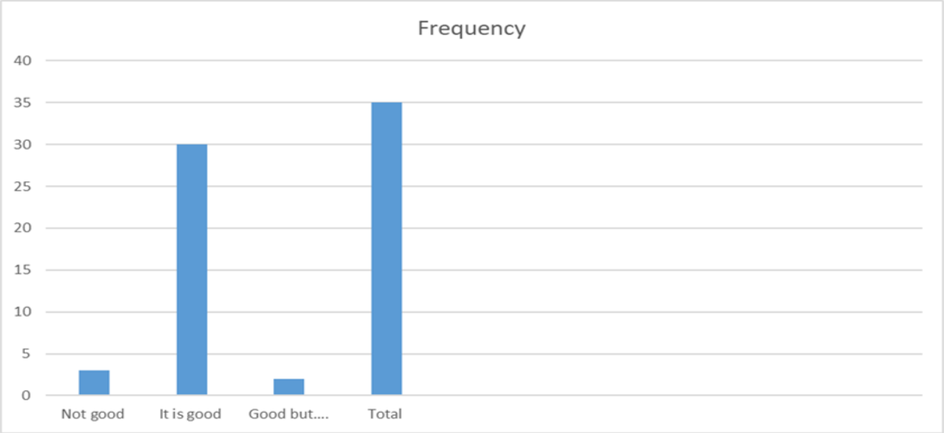
Summary of Findings

The responses to this question reveal a variety of strategies used by caregivers when faced with challenges related to HIV disclosure to children. Most respondents focus on medical support, resilience, calm communication, and seeking external help as key actions. Medical Support, 11 caregivers (31.4%) prioritize taking the child to the hospital to receive disclosure support from healthcare professionals.

As for emotional resilience, 4 caregivers (11.4%) the importance of staying strong and brave in the face of challenges. Communication and Patience**,** 8 respondents (22.9%) mention staying calm and explaining the situation to the child, while others (5.7%) believe in waiting until the child is mature enough to understand. Seeking Support, a portion of respondents (11.4%) seek assistance from social workers, family members, or friends, and a few (5.7%) mention the support of religious and community resources as an essential aspect of coping.

Self-Care and Emotional Processing**,** some respondents (5.7%) mention crying, praying, or venting to family members as methods for dealing with stress. Request for Professional Guidance**,** 2.9% requested additional training to better handle these challenges, reflecting a need for skill-building in effective communication and support techniques.

What can you say about the support you receive from others e.g. clinic or community counsellors?



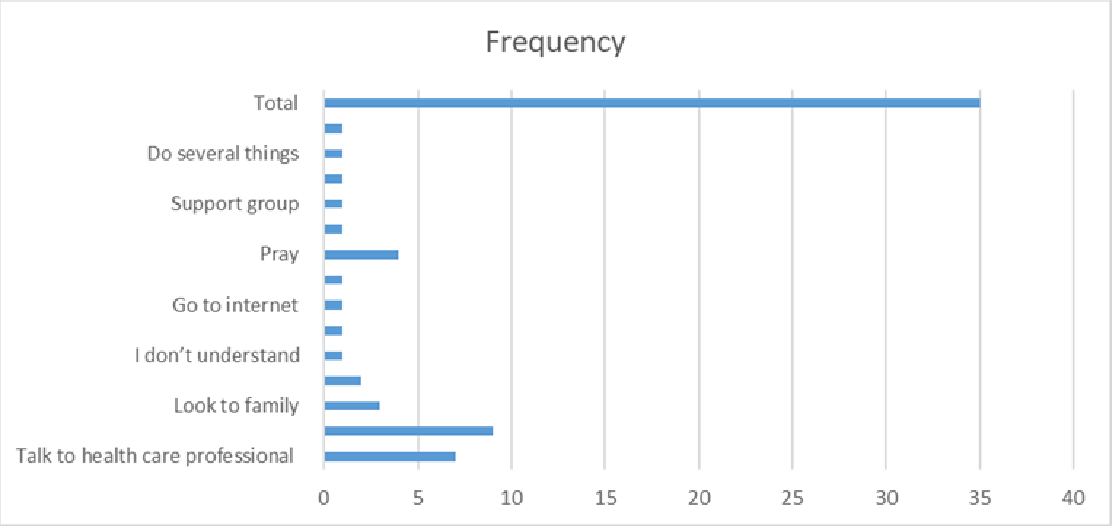
Summary of key findings

The study found that overall, the support they receive from others thus family, clinic and community counselors is favourable. Positive feedback accounted for (85.7%), most caregivers reported positive experiences, describing support from family, community, and clinics as "helpful," "motivating," and "excellent." This indicates that most caregivers feel supported, particularly through health education, counseling, and family encouragement.

There was also negative feedback thus (8.6%), a few respondents felt the support was inadequate, citing issues such as stigma and a perceived lack of empathy from healthcare workers who may not share the same experiences as the caregivers.

The data from the study came up with mixed feedback (5.7%), some caregivers felt support was generally helpful but mentioned occasional challenges, such as fluctuating attitudes from healthcare providers.

How do you cope with these challenges?

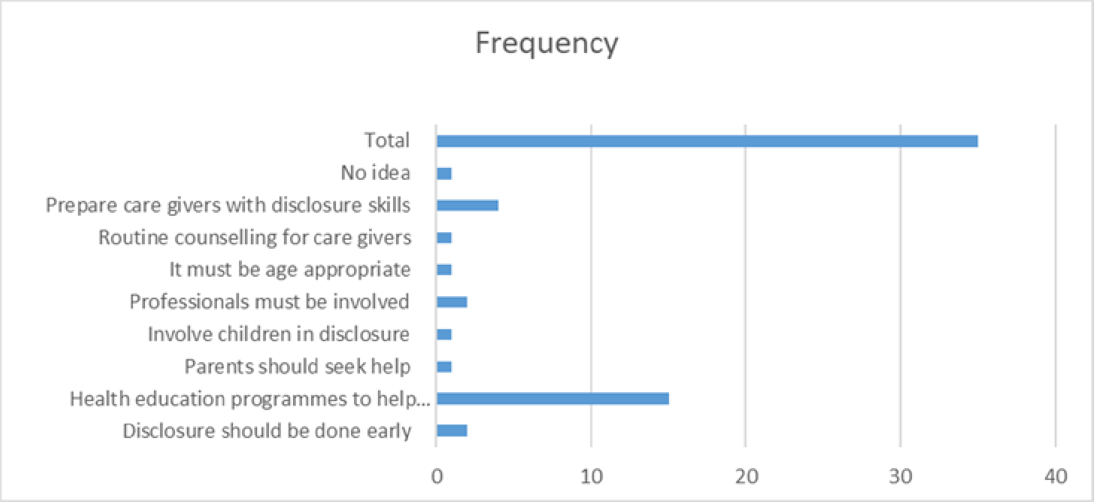


Summary of key findings

The study found that care givers have several ways of coping with the challenges of disclosing their HIV status. Self-Reliance and resilience accounted for (25.7%), many respondents indicated that they look to themselves for resilience, encouraging themselves to stay strong or focus on a positive outlook. Other caregivers cope by seeking help from health professionals which accounted for (20%, a significant number of respondents rely on healthcare professionals, including counselors, for guidance and support.

Some caregivers depend on family support amounting up to (8.6%) and prayer (11.4%), turning to family or religious practices are common coping mechanisms that provide emotional and moral support. The study also found that empowerment and community is one way of coping with disclosure issue, a few respondents highlighted empowering others and seeking peer support to deal with their challenges.

What should be done to improve the disclosure of the HIV status of children by caregivers?

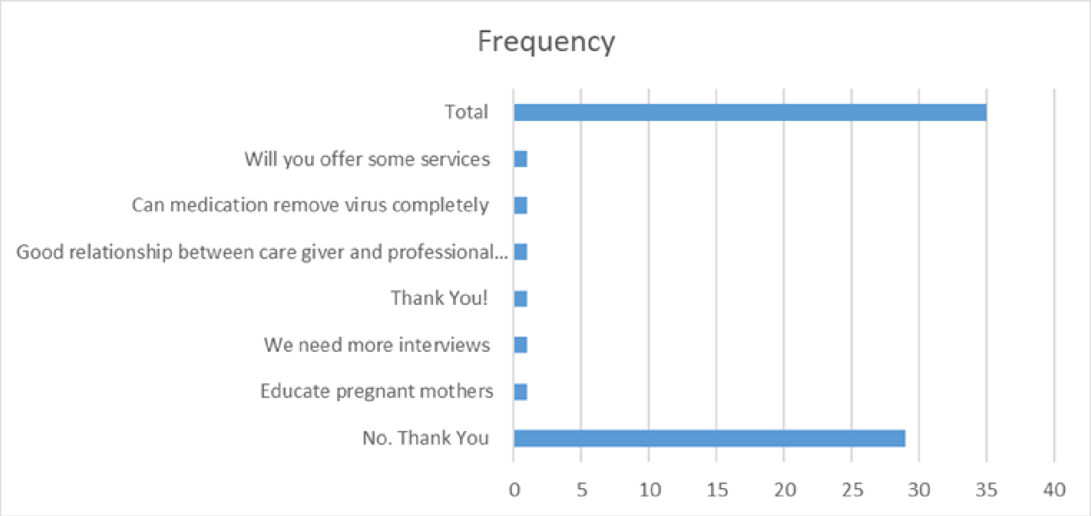


Summary of findings

The findings highlight a variety of approaches caregivers and professionals believe would enhance the disclosure process for children living with HIV. These suggestions include, health education programmes, 15 respondents recommended health education initiatives to help caregivers and children understand HIV better. The other approach is disclosure timing, 2 respondents advocated for early disclosure.

Professional support was another approach which was suggested by respondents, 2 respondents believe that professionals should be directly involved in the disclosure process. The issue of caregiver Preparation was one of the approaches, which was established in the study, 4 respondents mentioned the need for caregiver training on disclosure skills.

Child Involvement and Age-Appropriate Approach: Some respondents stressed involving children directly in the process and ensuring that disclosure is tailored to the child's developmental level Routine counseling and support through was one of the approached suggested, one respondent each suggested routine counseling for caregivers and professional guidance in disclosure situations.



Summary of findings

The findings of the study show that the majority (82.9%) of respondents did not have any further comments, while the remaining responses raised suggestions or questions related to patient education, treatment efficacy, and service provision. The responses to the closing question in the interviews reveal that most caregivers felt satisfied with the interview process, with 29 out of 35 participants expressing gratitude and declining to add further comments. This indicates an overall positive reception to the interview process and suggests that most caregivers felt they had shared all relevant information.

V. Conclusion

This study presents and analyses the findings from interviews with caregivers on the topic of disclosing HIV status to children and adolescents receiving HAART at Donkerhoek Clinic in Windhoek, Namibia. The data is organized by key themes, including caregivers' understanding of disclosure, their experiences with HIV-positive children, and the perceived barriers to disclosure.

Key findings reveal that while many caregivers recognize the importance of disclosure, significant barriers persist, including fears of stigma, emotional distress, and uncertainty about the right timing and method for disclosure. Additionally, age, gender, and education levels influenced perspectives on disclosure, with younger caregivers and those with higher education levels more open to early disclosure.

Suggestions for improving disclosure practices highlighted the need for early, age-appropriate discussions, increased health education, routine counseling, and professional support. Overall, the findings emphasize a need for targeted support systems to prepare caregivers for effective and sensitive disclosure, alongside community education initiatives to address stigma and promote understanding.

HIV- Human Immunodeficiency Virus

AIDS- Acquired Immune Deficiency Syndrome

WHO- World Health Organization Organization

DAPP- Development Aid from People to People

ARV- Anti Retroviral

ART- Anti Retroviral Therapy

HAART- Highly Active Anti-Retroviral Therapy

USAID- United States for International Development

MoHSS- Ministry of Health and Social Services

MGECW- Ministry of Gender Equality and Child Welfare Abbreviations

UNICEF- United Nation International Children's Emergency Fund Abbreviations

CBOs- Community-Based Organizations

CSOs- Civil Society Organizations

HCW- Health Care Worker

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First and foremost, I would like to humbly express my profound gratitude to my living God for blessing me with the utmost strength, wisdom, courage and for being my guidance in my every path I took that made it possible for me to complete this research because without Him, this study would have not remained productive.

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Author's contribution

Ndinomukulili N Lomboleni was entirely responsible for this study's design, data collection, data analysis, and the interpretation of the results.

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This study was not funded by any external funder in any way possible,

Availability of data

The data to back up the findings stipulated in this study are available upon request from the enlisted authors. However, the data is restricted to public access without the authors' permission due to limitations, which includes the presence of sensitive information that may compromise the privacy of research participants.

Declarations

Ethical approval and consent to participate

The Post Graduate Studies Committee of the University of Namibia reviewed the study proposal for ethical approval. The Ministry of Health and Social Services (MoHSS) Research Committee and the Donkerhoek Clinic Management additionally provided further approval for ethical clearance. The main populations and partakers were told of the study's objectives, then those who are willing to take part will be asked for their written consent before the study may proceed. The goal of informed consent was to make sure that participants are willing to engage in the research and conform to its rules and regulations. They were assured that their participation is optional and will remain anonymous. The researcher ensured that every facet of the study is handled in a way that fully considers participant requirements as well as respect for human rights. The confidentiality of the data was guaranteed to the participants, and they were made aware of their ability to withdraw from the research at any time without penalty. They were also guaranteed that declining to take part in the trial will not prevent them from getting ARVs in the future. The participant received a guarantee from the researcher that the data collected will only be utilized for this study's research goals.

Consent for publication

This is not applicable to this study.

Competing interests

The author is not aware of any completing interest, therefore there is no competing interest know to the author.

Author details

Ndinomukulili Ndaedeelao Lomboleni

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