

Experiences of Caregivers in Disclosing HIV Status to Children Infected with HIV in Mopani District, South Africa



Muditambi Nndavheleseni Nathaniel¹, Mamogobo M Pamela^{1,*} and Mutshatshi E Takalani¹

¹Department of Nursing Science, School of Health Care Sciences, University of Limpopo, Polokwane, South Africa

Abstract:

Background: Caregivers are confronted with difficulties in determining the ideal period to initiate HIV disclosure to the child infected with HIV. Moreover, caregivers are uncertain about how to facilitate the HIV disclosure process, and opportunities to start the discussion are frequently missed until a later stage. Caregivers often fear that the child will be affected psychologically and have poor cognitive ability to comprehend the nature of the illness.

Objective: The objective of the study is to explore and describe the experiences of primary caregivers regarding HIV disclosure to children infected with HIV.

Methods: A qualitative, explorative, and descriptive study was conducted at 4 selected ART facilities in the Mopani district. Where face-to-face semi-structured interviews were conducted until data saturation with 16 primary caregivers. Data was analysed and coded using the ATLAS.ti 9 program, according to the thematic method of analysis.

Results: Analysis of data identified three main themes that described the experience of caregivers regarding HIV disclosure in children, which are cues to disclose HIV status to children, experiences of the event of HIV status disclosure to children, and caregiver's experiences of healthcare providers' role in HIV disclosure process.

Conclusion: Caregivers revealed that they initiated the HIV disclosure process to the children because of their personal and child-related factors. However, they perceived HIV disclosure as a difficult process to initiate, because of lack of skills, knowledge, and support from healthcare providers. Caregivers perceived children as too young to receive HIV disclosure information and they feared that the child would react negatively.

Keywords: Disclosure, HIV status, Children, Experience, Caregivers, Primary.

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*Address correspondence to this author at the Department of Nursing Science, School of Health Care Sciences, University of Limpopo, Polokwane, South Africa; Tel: 0791343285; E-mail: pamela.mamogobo@ul.ac.za

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1. INTRODUCTION AND BACKGROUND

The global increased access to Antiretroviral Treatment (ART) improved the quality of life for people living with HIV and as a result, the number of children living with HIV is increasing as well. In 2021, an estimated 38.4 million people were living with HIV worldwide, of which, 2.73 million were children aged between 0 - 18 years [1,2]. Children infected with HIV are growing up to

an adolescent age where the disclosure of HIV status is inevitable [3,4]. HIV disclosure is a complex social issue that is often faced with HIV-related stigma, this has made the disclosure process more complicated. HIV disclosure is a challenge for caregivers to decide when and how to disclose HIV status to children, hence caregivers frequently postpone HIV disclosure because they wish to protect the child from psychological impact and

discrimination [5, 6]. Caregivers and healthcare providers regularly are reluctant to inform children of their HIV status. HIV disclosure to children infected with HIV is becoming a fundamental issue in the clinical management of children living with HIV [7].

Primary caregivers are responsible for initiating the process of HIV disclosure, moreover, evidence indicate that disclosure is frequently done at home [7, 8]. Caregivers need to be able to determine the cognitive and developmental age that is appropriate to initiate the process [7]. The delays in HIV-positive status disclosure can lead to negative psychological and poor adaptation to appropriate health promotion activities [7]. Therefore, it is crucial for caregivers to provide appropriate information to children regarding their HIV-positive status. The provision of such information would assist in protecting the health rights of the children [4]. Unfortunately, despite evidence supporting the benefits of developmentally appropriate HIV disclosure, many of the children are unaware of their HIV status, do not understand the importance of remaining adherent to antiretroviral therapy, and they enter adolescence age without the knowledge that they could infect others with HIV [5, 6]. Existing literature indicated that out of 190 children, only 45 (23.7%) received disclosure of their HIV status, of whom 28 (14.7%) were partially disclosed and 17 (8.9%) were fully disclosed [7].

Caregivers disclose the HIV status because of the children's desire to know and concerns that children might initiate sexual activity before knowing their HIV status [8]. Additionally, caregivers disclose HIV status only if the child starts to ask why they are taking HIV medication, threats by children not to take HIV medication, and the desire to promote treatment self-efficacy amongst children [9]. Unfortunately, some of the caregivers delay disclosure because they have doubts related to the right timing of disclosure and the amount of information to be disclosed to the children [10]. Contributing factors to low disclosure include mental maturity, specific age category, and fear of HIV status being disclosed to others by children leading to stigma and discrimination [11]. The researcher wished to better understand and improve the HIV disclosure process; therefore, the study envisages describing the experiences and challenges encountered by caregivers during the disclosure of HIV status to children infected with HIV.

2. MATERIALS AND METHODS

2.1. Study Design

The study employed a qualitative, explorative, and descriptive design using phenomenology research technique to explore and describe the experience of primary caregivers regarding the disclosure of HIV status to children infected with HIV. Phenomenological studies are ideal to deeply understand human nature and individuals' lived experiences and perspectives on a given situation [12]. No intervention was introduced, data was collected in a natural environment.

2.2. Study Setting

The study was conducted in Mopani District, Limpopo Province, South Africa, in four selected Primary Health care facilities which are located in Greater Tzaneen Sub-district. Mopani District which is situated in the North-eastern part of the Limpopo Province.

2.3. Population and Sampling

The study population consist of all primary caregivers who were accompanying their children for ART collection in the primary health care facilities. The researcher purposively selected four primary health facilities with high number of children collecting ART and the researcher identified the facility date when children are coming for ART collection in those facilities. A non-probability purposive sampling method was used to select primary caregivers for the interview in those facilities on different dates. Primary caregivers of children infected with HIV, collecting ART in four selected clinics in Greater Tzaneen Subdistrict, who have been living with the child since the child was 5 years old and are willing to participate in the study were included in the study.

2.4. Pilot Test

The researcher piloted the interview guide in a similar environment to that of the actual study. A pilot study was performed at the Lenyenye clinic which was not part of the clinics to be used in the main study. During pilot study, the researcher selected participants meeting the selection criteria to conduct interviews. Study information was given in the waiting area of the ART clinic and 4 caregivers volunteered to participate in the pilot. Information regarding the study was provided to individuals, and a consent form was signed. The interview question opened the conversation with individual participants, "The interview took an average of 35-45 minutes to complete the interview session including the use of probing question session. At the end of the pilot, the researcher requested participants to give honest feedback on the questions to identify challenges experienced during the process. The researcher identified that there were two similar questions, one was removed and replaced by a different question. A gap was identified when interviewing a caregiver who already disclosed, so two additional questions when added to explore more from these caregivers.

2.5. Data Collection Process

The researcher (Mr Muditambi NN) was a student of Master's in nursing supervised by PM Mamogobo and TE Mutshatshi. The researcher collected data with the support and supervision of PM Mamogobo and TE Mutshatshi who both have a degree of Doctor of Nursing Philosophy. Furthermore, the researcher attended a workshop on qualitative data collection and analysis as part of the Master's in nursing skill development process. Once the research study was granted ethical clearance through the Turfloop Research and Ethics Committee, the researcher obtained permission from the Limpopo

Provincial Department of Health to conduct a study. Access to health facilities was obtained from the Mopani district health office. Arrangements were made with the facilities manager regarding the date to start with data collection process and the flow of participants in the facility was outlined. Interaction with the participants was only established with eligible participants during the recruitment process. Study information leaflets written in English and local language were provided, followed by an oral presentation about the objectives of the study. A self-developed semi-structured interview guide was developed and pre-tested before the actual study. Verbal, followed by written informed consent was obtained before the interview. Face-to-face interviews were conducted to collect data from caregivers who meet the criteria. The researcher interviewed 16 participants until data saturation was reached, because there was no new information given by participants and the information sounded the same. Interviews were audio recorded and fields notes were captured manually. The duration of each interview lasted 45 to an hour and at the end of each interview session, the researcher paraphrased and summarised the conversation, including replaying the audio recordings to the participants. Recording and fields notes were shared with external expert in the field for data analysis and coding, and themes emanated from the study as interpreted by the researcher were discussed and agreed upon.

2.6. Data Analysis

Data analysis was initiated concurrently during the data collection process and audio recordings were transcribed verbatim. The researcher read and re-read the transcribed data and with the assistance of an independent coder data was coded using the ATLAS.ti 9 program where consensus was reached on the identified themes and sub-themes. Through thematic analysis of transcribed data, repeated patterns of meaning were identified, and themes and sub-themes were developed.

2.7. Trustworthiness in the Study

To improve confidence and quality in the methods applied, the researcher used measures that include credibility, dependability, transferability, and confirmability [12]. To improve data quality, the researcher spent enough

time with participants when collecting data. Furthermore, by listening to the audio-recorded interview several times, reading and re-reading of transcripts were done to be fully engaged with the data.

2.8. Description of the Caregivers ¹

The total number of participants included in the study were 16 caregivers, biological parents were 13 and guardian were 3. The age of caregivers was between 28 and 60 years. Caregivers who attended school between grades 1-4 were 4, between grades 5-11 were 5, those who attended matric were 3, and only 3 never attended school. Most of the participants were unemployed (14) and only 2 were employed, Table 1.

3. RESULTS

Three themes and ten sub-themes were generated highlighting caregivers’ experiences regarding disclosure of HIV status to infected children. See Table 2 below for details:

3.1. Theme 1: Cues to Disclose HIV Status to Children¹

The findings of the study suggest that caregivers feel unprepared and coerced to disclose HIV status to the child because of their individual and child-related factors.

3.1.1. Sub-theme 1.1: Caregiver-related Cues to HIV Disclosure

Caregivers revealed that they are encouraged to disclose HIV status because they want their children to know the truth about their condition and the desire for the child to understand the treatment they are taking. Moreover, caregivers wanted their children to be independent, so that even if they themselves are not around, the child must be able to take care of themselves.

Participant 08 said: *“If I can die first and he remains, he won’t know the truth about how he was infected with HIV. I must tell him while am still alive about HIV”.* (Biological Parent of 10 years old child)

Participant 10 said: *“But it was a must that I disclose to him, because if am not around he must not stop taking treatment. Life goes on and he is growing and if he finds out from others it will hurt him, so it was a must I tell him”.* (Biological Parent of 12 years old child).

Table 1. Caregiver’s demographic details total N= 16.

Variables	Characteristic	Frequency (%)
Caregiver’s relationship to the child	Parent	13 (72.3)
	Guardian	3 (16.7)
Caregiver’s age	20 - 30	2 (12.5)
	31 - 40	8 (50)
	41 - 50	4 (25)
	51 - 60	2 (12.5)
Caregiver’s level of education	Grade 1 - 4	5 (31.5)
	Grade 5 - 11	6 (37.5)
	Matric	3 (19)
	Never attended School	2 (12.5)

(Table 1) contd....

Variables	Characteristic	Frequency (%)
Caregiver's employment status	Employed	2 (12.5)
	Unemployed	14 (87.5)

Note: ¹Guardians (1 grandfather and 2 grandmother).

Table 2. Themes and sub-themes identified from caregiver's interviews.

Themes (3)	Sub-themes (10)
1. Cues to disclose HIV status to children	1.1. Caregiver-related cues to HIV disclosure
	1.2. Child-related cues to HIV disclosure
2. Experiences of the event of HIV status disclosure to children	2.1. Child's age to disclose HIV status
	2.2. The person responsible for HIV status disclosure
	2.3. Caregiver's perceived self-efficacy for HIV status disclosure
	2.4. Information provided during HIV disclosure
	2.5. Caregiver's experience of the disclosure event
	2.6. Child's response to the disclosure event
3. Caregiver's experiences of healthcare providers' role in HIV status disclosure to children	3.1. Support from healthcare providers
	3.2. Support required from healthcare providers

3.1.2. Sub-theme 1.2: Child-related Cues to HIV Disclosure

Caregivers disclosed the HIV status to the child because the child was starting to ask questions about the illness and treatment they were taking. Additionally, caregivers feared that the child had grown up and would start to engage in sexual activities and could potentially infect others with HIV.

Participant 01 said: "I saw that anytime from now he will start having sex because he is grown up now and I must tell him to use a condom, so when I tell him to use a condom, he will ask me why I should use a condom". (Biological Parent of 18 years old child).

Participant 10 said: "He was refusing treatment and asking me a lot of questions, he asked me when I would be cured and stop taking treatment. I used to tell him that he is having flu, but he asked me when he will I be cured, so I disclosed to him that this was not flu but HIV. So, you should take treatment for life and on time". (Guardian of 12 years old child).

3.2. Theme 2: Experiences of the Event of HIV Status Disclosure to Children

The study revealed that caregivers experienced uncertainty regarding appropriate time, child's age and the responsible person to disclose status to initiate and how to facilitate the disclosure process to a child infected with HIV.

3.2.1. Sub-theme 2.1: Child's Age to Disclose HIV Status

Findings indicated that caregivers acknowledged that children should be told about their HIV status, however, they were not sure of the appropriate age to start with the HIV disclosure process.

Participant 03 said: "The child must be told, but they said we must not tell them until they are 10 years. Until

the child is 10 years, we must not tell them, now the child doesn't know why he is taking treatment". (Biological Parent of a 6-year-old child).

Participant 04 said: "when the child is 11 years" (Biological Parent of 9 years old child).

3.2.2. Sub-theme 2.2: The Person Responsible for HIV Status Disclosure

Caregivers indicated that it was their responsibility as parents to disclose HIV status to their children. They further stated that they did not want their children to find out about their HIV status from someone else other than them.

Participant 03 said: "Me as a parent, it must be me as a parent to disclose HIV status to my child, not anyone to tell my child, because they might not tell truth to the child". (Biological Parent of 6 years old child).

Participant 05 said: "Me because I give birth to him, and I am the one who infected the child and is my responsibility to sit down and disclose to the child so that the child must not found out from people gossiping". (Biological Parent of 11 years old child).

3.2.3. Sub-theme 2.3: Caregiver's Perceived Self-efficacy for HIV Status Disclosure

Caregivers expressed that they were not so sure on how to initiate HIV disclosure to the infected child. They indicated that they did not have knowledge.

Participant 09 said: "No, I do not have the knowledge or skills" (Biological Parent of 8 years old child).

Participant 15 said: "On this one, I do not have knowledge/skills" (Biological Parent of 7 years old child).

3.2.4. Sub-theme 2.4: Information Provided during HIV Disclosure

Caregivers who had engaged their children in HIV disclosure have explained to the child how the child was infected with HIV. Furthermore, caregivers explained to the

child that they would have to take treatment for the rest of their life to remain healthy.

Participant 08 said: *“when I started disclosing, I told him if you do not take treatment, you will get sick and you will not live long, treatment will help you. if you do not take you will get sick and even if I am not around you must take your treatment on time at 18:00. If you do not take treatment, you will always complain of chest pain because you do not take treatment”*. (Biological Parent of 10 years old child)

Participant 09 said: *“The treatment you are taking is because you are HIV positive. HIV is a virus that lives in your blood, I was waiting for the ideal time to tell you that the treatment you are taking is for the rest of your life. Even when I die you should take this treatment because it will boost your immune system so that you do not get sick. He knows that previously he was sick always and I told him now that you are on treatment, you are no longer sick as always, you live like other children”*. (Biological Parent of 8 years old child).

3.2.5. Sub-theme 2.5: Caregiver's Experience of the Disclosure Event

Caregivers indicated that it was difficult to initiate the HIV disclosure process to the child, however, after disclosure, caregivers felt good and relieved because they did not have to keep it a secret anymore.

Participant 09 said: *“On my side it was a relief as well because I have disclosed the secret to him, because he was always asking me why he is taking the treatment”*. (Biological Parent of 8 years old child).

Participant 10 said: *“To the child, I did not see a problem and to me, it was a relief because it was a pain to me, I did not know how to tell him. After disclosure, both of us did not have a problem and I told the child that nothing will change, I did not see any problem after disclosing even I did not have a problem”*. (Guardian of 12 years old child).

3.2.6. Sub-theme 2.6: Child's Response to the Disclosure Event

Caregivers indicated that after disclosure children accepted and appreciated that the caregivers eventually disclosed their HIV status to them. Caregivers also indicated that after disclosure, the child was more responsible to take their treatment.

Participant 01 said: *“The child is fine and because he is kind, friendly person. “The child said I thank you for telling me the truth, from now I will take care of myself”*. (Biological Parent of 18 years old child).

Participant 09 said: *“ehh”, to him at first it was difficult for the child to accept, but not that much because we started while he is young but eventually accepted. It was difficult, he even asks if he will take treatment for life, I asked him he if want to be sick like before, which one is better, and he said now is better. Now he knows time to take treatment even if I am not around. Now the child is free, now he even knows the time for treatment I can see*

now”. (Biological Parent of 8 years old child).

3.3. Theme 3: Experiences of Healthcare Providers' Role in HIV Status Disclosure to Children

The finding indicated that caregivers did not receive enough support from the healthcare provider on how to handle the HIV disclosure process. Caregivers stated that they required assistance from healthcare providers to facilitate the HIV disclosure process to the child living with HIV.

3.3.1. Sub-theme 3.1: Support from Healthcare Providers

Caregivers state that they did not receive any training on how to initiate HIV disclosure, however, caregivers indicated that the healthcare provider did advise them to disclose their HIV status to their children despite a lack of proper support.

Participant 05 said: *“eish” No, I have not received any training/support”*. (Biological Parent of 11 years old child)

Participant 14 said: *“No, they have not educated me”* (Biological Parent of 7 years old child)

3.3.2. Sub-theme 3.2: Support Required from Healthcare Providers

Caregivers stated that they did not know when and how to disclose HIV status to the child, and they stated that they would need assistance from healthcare provider. Some caregivers even indicated that nurses should conduct disclosure because they have more knowledge on how to disclose.

Participant 06 said: *“Yes, I do not know how to explain it, but I will need help on guidance on how to disclose to my child, maybe It will be better”*. (Biological Parent of 6 years old child).

Participant 09 said: *“the health department should assist us because they know more than us. I can tell him, but more information is with nurses”*. (Biological Parent of 9 years old child).

4. DISCUSSION

The study revealed that caregivers acknowledge the significance of disclosing HIV status to the child because they desire the children to know the truth about their condition and the child to understand the treatment they are taking. Moreover, caregivers disclosed HIV status to the child because they felt that the child had grown up and they will start to engage in sexual activities. Caregivers also disclosed it because children would stop treatment if they had not been given appropriate answers to the questions they would ask related to the treatment they are taking. This finding was similar to other studies [27, 29, 37, 39], which revealed that HIV disclosure is associated with ART adherence and increases the odds of having a good quality life. Additionally, caregivers disclosed it because they were afraid that children would get information from others, and they wished to disclose it to the child themselves. These findings are congruent with

other studies [13-15] that found that caregivers disclosed it because they believed that children were mature, they would know their HIV status, would take the treatment as prescribed by the physician, and they would be responsible for their well-being.

This study also revealed that caregivers do not initiate HIV disclosure or delay HIV disclosure, because they are not sure when, how and what level of information to disclose to the child. These results are similar to other study results. In a study [16], caregivers delayed HIV disclosure due to lack of skills or knowledge of how to appropriately disclose this news. Caregivers in this study further indicated that they would only tell their children to take treatment without disclosing the actual reason for taking treatment. This finding is similar to other studies that found that caregivers expressed fear about HIV disclosure conversation, so they hid the actual reason why the child is taking treatment [17, 18,38]. Caregivers state that they are not positioned to initiate the HIV disclosure process, however, caregivers acknowledge that the healthcare provider encourages them to disclose HIV status to their children, without giving details or support during the disclosure process. These findings are congruent with other studies [19, 20,34] which found that the majority of the caregivers lacked knowledge of the process of HIV disclosure and most caregivers never received guidance about the disclosure process from their healthcare providers. Some caregivers even indicated that nurses should conduct disclosure because they believe that they have more knowledge regarding HIV disclosure process.

Caregivers indicated that HIV disclosure should be initiated around the age of 10 years. These findings suggest that caregivers do not understand the ideal age to initiate HIV disclosure to the child. These findings are identical to other studies [14,30,36] which found that the mean age at disclosure was 10 years. Additionally, similar studies found that caregivers suggested that the ideal age to disclose is between the age of 10-15 years [9, 21, 22]. Caregivers indicated that it is their responsibility as parents to disclose HIV status to their children. They further state that they do not want their children to find out about their HIV status from someone else other than them. A similar study [20] found that caregivers felt it was their responsibility to initiate HIV disclosure to their children.

The findings further highlight that caregivers wish to initiate HIV disclosure however they do not have enough skills or knowledge to initiate it. Caregivers who had put their children in HIV disclosure process have explained how the child was infected with HIV. During disclosure, caregivers further indicated that the child was infected with the HIV, and the virus existed in their blood. Caregivers explained to the child that they would take treatment for the rest of their lives to remain healthy. However, this findings were contrary to other studies [23, 24, 28] where results showed that the majority of caregivers unfortunately withheld specific information or deceived the child in disclosing an HIV-positive status.

However, caregivers indicated that their experience of HIV disclosure process was good. Additionally, after disclosure, caregivers further indicated that children appreciated that the caregivers eventually disclosed their HIV status to them. These findings are supported by other studies [25, 26,33] which reported that caregivers felt relieved after disclosing, they observed that the child was more independent and responsible with their health, and this was also satisfying to the caregivers.

5. LIMITATIONS OF THE STUDY

Due to financial constraints, the study was only conducted at 4 PHC facilities in the Mopani district within Greater Tzaneen subdistrict. So, the results cannot be generalized to other areas in the district and the province . The researcher recommends that the same study should be conducted in the same context, focusing on the experience of children living with HIV and the HIV disclosure process.

6. IMPLICATION OF THE FINDINGS

The findings of the study suggest that caregivers need more support and knowledge from nurses regarding the HIV disclosure process and the appropriate age to initiate the process. The support will empower caregivers to conduct the process effectively and timely.

6.1. Professional Nurses

The professional nurses as the custodian of patient care, must be knowledgeable and support caregivers on the HIV disclosure process.

6.2. Limpopo Department of Health

The department of health needs to ensure that healthcare providers are trained and mentored on HIV disclosure guidelines.

CONCLUSION

The study concludes that HIV disclosure to children infected with HIV is a difficult process for caregivers to carry out. Moreover, caregiver experience is exacerbated by a lack of skills and support from healthcare providers on how to go about the process. As a result, caregivers delays the disclosure process and even deceive the child because they do not know exactly what to tell the child during the process of disclosure. Caregivers believe that it is their responsibility to conduct HIV disclosure, but come caregivers suggested that healthcare providers should conduct HIV disclosure because they have more knowledge on how to disclose HIV to the child. This study contributes critical knowledge in understanding challenges faced by caregivers during HIV disclosures in children infected with HIV. These findings will be important in guiding policy makers to develop appropriate interventions to assist healthcare providers with appropriate support to the primary caregiver.

DISCLOSURE

Part of this article has previously been published in "Disclosure of positive human immunodeficiency virus

status to children diagnosed with the infection and on antiretroviral treatment: experiences of primary care givers at selected clinics in mopani district, Limpopo Province”.

http://ulspace.ul.ac.za/bitstream/handle/10386/4335/muditambi_nn_2023.pdf?isAllowed=y&sequence=1

ABBREVIATIONS

ART = Antiretroviral Treatment

TREC = Turfloop Research Ethics Committee

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

The protocol was approved by the Turfloop Research Ethics Committee (TREC) with approval number (FHDC2020/7). Limpopo Provincial Department of Health’s research ethics committee granted permission to conduct the study. The university approval and letter of permission were submitted to the district to get access to ART facilities.

HUMAN AND ANIMAL RIGHTS

No animals were used in this study. All human research procedures performed in this study were in accordance with the ethical standards of institutions, and research committees and with the Helsinki Declaration of 1975, as revised in 2013.

CONSENT FOR PUBLICATION

Caregivers acknowledge to participate by signing a consent form and confidentiality was maintained throughout the study.

STANDARDS OF REPORTING

COREQ guidelines were followed.

AVAILABILITY OF DATA AND MATERIALS

The data supporting the findings of the article is available in the muditambi_nn_2023.pdf (ul.ac.za).

FUNDING

None.

CONFLICT OF INTEREST

The authors declare no conflict of interest either financially or otherwise.

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