ORIGINAL ARTICLE

I, too, Need Care: Narratives of Caregivers Raising a Child with HIV – An Input for Life Coaching Approaches

Donna P. Sombrea, MS, RPsy and Loyd Brendan P. Norella, MD, MPHM

Ateneo de Davao University

ABSTRACT

Objectives. The present study explored the experiences of caregivers raising a child with perinatal HIV infection through a narrative inquiry approach. It uncovered how caregivers learned about their children's diagnosis, the challenges that they experience in raising their children, and how they cope with the ordeal caused by HIV infection.

Methods. A total of ten participants joined the study – five caregivers participated in the key informant interviews (KIIs), with their respective child diagnosed to have perinatal HIV infection joining the focus group discussion (FGD) (n=5). Semi-structured individual interviews were carried out to examine in-depth narratives from the caregivers. We thoroughly analyzed the verbatim interview transcripts using reflexive thematic analysis (RTA) by the six-phase process outlined by Braun and Clarke (2019). NVivo 12 was utilized in the process of data analysis. The transcribed data were uploaded, coded, and analyzed individually. The software helped the organization and expression of the codes and themes.

Result. In this study, three major themes and four sub-themes in each theme were generated: *a) becoming known: the journey towards testing and treatment*, which includes reasons for testing, cause of acquiring HIV, reactions, and treatment, *b) passing through challenging times*, which cover preparing the child to understand illness, child's awareness and understanding of illness, physical health, and discrimination, and *c) receiving essential support* which includes an understanding of illness, building hope, needs received, and sources of support.

Conclusions. Caregivers with children living with HIV face challenges such as preparing the illness to be known and understood by their child, managing the child's physical health, and discriminating against others. However, they can live healthy and meaningful lives if they are given comprehensive support from the government, access to quality healthcare and education, and psychosocial interventions. The government and private sectors must make efforts to promote physical, emotional, and mental health care underpinning the well-being of caregivers and children with HIV. The retention of the programs offered by certain organizations (e.g., testing and treatment needs, nutritional and basic needs support, educational supply, and livelihood program for caregivers) and the increase in the number of psychoeducational and support group activities were suggested to significantly help in addressing the concerns of both caregivers and their child with perinatal HIV infection.

Keywords: HIV, perinatal transmission, life coaching, caregivers

eISSN 2094-9278 (Online)
Published: December 18, 2024
https://doi.org/10.47895/amp.vi0.8398

Corresponding author: Donna P. Sombrea, MS, RPsy
Ateneo de Davao University, Roxas Avenue, Poblacion District, Davao City, 8000, Davao del Sur, Philippines
Email: donnapsombrea@gmail.com
ORCiD: https://orcid.org/0000-0001-5349-2115

INTRODUCTION

Perinatal transmission of HIV, also known as mother-to-child (HIV) transmission (MTCT), results when a person living with HIV transmits the virus to their baby.[1] Each year, there are 1.3 million women and girls infected with HIV who become pregnant globally.[2] The transmission can happen during pregnancy, delivery, and breastfeeding. Among mothers not receiving treatment, about 25 to 30 percent of their children are likely to acquire the virus.[2,3] This estimate may drop to two percent or less if mothers are aware of their status and have undergone treatment.[3] That said, the mothers' lack of awareness of their HIV status (e.g., testing and screening were not done during the early phase of pregnancy) almost doubles the rate of HIV transmission[4] and consequently increases the rate of mortality amongst their offspring.[5] In the Philippines, the government has taken measures to address this concern by implementing rapid HIV screening and delivery of test results and providing treatment such as antiretroviral (ARV) for those infected.[6]

Caregivers of Children with HIV Infection

When children are diagnosed as HIV-positive, their caregivers tend to experience psychological distress.[7] Prior research suggests that biological parents of infected children were found to experience high psychological problems compared to other relatives or foster caregivers.[8] In general, clinical depression (28%) among caregivers of HIV-infected children was found significantly high compared to the WHO estimate (5.4%).[9] Low monthly household income, poverty, and environmental stress were among the factors contributing to the caregiver's psychological distress.[7,9] However, caregivers with regular work or better monthly income have lower adherence to child treatment compared to lower-income or unemployed caregivers, probably due to time availability in providing care.[10]

Another dilemma of caregivers includes the idea and process of disclosing HIV to positive children. The difficulty of the caregivers in disclosing HIV status to the infected child led to most of the children learning about their HIV infection from their healthcare providers.[11] A recent study identified that HIV-negative caregivers are twice as likely to disclose HIV status to the infected child compared to HIV-positive caregivers.[12] Considering the disadvantages of disclosure contributed to the delay of disclosing the HIV status to the child. These concerns commonly include fears of the reaction, disclosure of the child to others about his/her infection, lack of knowledge, stigma, and discrimination.[11] Additionally, the age of the child was considered by most of the caregivers. They felt that they, caregivers, are the appropriate people to disclose the HIV status to the infected child, yet they claim to wait until the child reaches mid-teenage or mid-adolescence, or until the child becomes mature.[12,13] Some of the recommendations provided in previous studies related to caregivers of HIV-infected children were the implementation of programs and policies to provide support for the caregivers of HIV-infected children. As most children mainly depend on the caregiver, it was recommended in prior research that programs should focus on caregivers' education and treatment adherence for the HIV-infected child.[10] The inclusion of programs reducing social barriers to HIV status disclosure is an important component in implementing community-based programs, especially in resource-limited settings.[11,13] Since caregivers have experienced a mild-to-severe caregiver burden, policymakers and stakeholders should be aware of how vital it is to implement programs specially tailored for caregivers and HIV-infected children.[8] Governments are expected to make efforts to meet the needs of caregivers, especially female caregivers, by providing information on the HIV infection diagnosis, accessing emotional support from professionals, practical help, and financial aid.[14]

Despite the efforts in testing and treatment, there exist limitations. Most studies about the experiences of individuals with HIV – particularly parents and caregivers of children with HIV focused on statistics, testing, treatment, and populations including youths and adults. Qualitative data were limited, and a quantitative approach is often used to inquire. Despite the count of mother-to-child infections in the HIV statistics, the researcher has shown interest in starting with the minority to prevent the increasing number. Another concern found in the literature review was the limited number of studies related to the perinatal transmission of HIV in the country. Along with the seeming lack of studies, the literature seems to be outdated as well. Additionally, few investigated the psychological experiences of caregivers raising a child with perinatal HIV. Therefore, it is essential to write research exploring the experiences, challenges, and needs of caregivers and children with perinatal HIV infection.

The present research explores the experiences of caregivers raising a child with perinatal HIV. Specifically, it uncovers how caregivers learned about their children's diagnosis, the challenges that they experienced in raising their children, and how they cope with the ordeal caused by HIV infection. This study contributes to the limited number of studies related to the perinatal transmission of HIV. Hence, this study led to inputs on further improving the life coaching approaches essential to the well-being of People Living with HIV (PLHIV), ultimately aiding the advocacy on helping curb the rising number of HIV cases.

METHODS

Design

A narrative inquiry was carried out through individual face-to-face interviews. Following constructivist epistemology, meaning, and meaningfulness are produced from the language and the depth of caregiver experiences in care and support to children diagnosed with the perinatal transmission of HIV.[15,16] Adopting an experiential orientation and inductive approach, we further explored and aimed to understand the experiences of the participants in each phenomenon and within the context of the data as to how they communicated it. Their thoughts, feelings, and experiences are regarded as internal reflections of caregivers' personal states.[17] In the inductive approach of analysis, the data were treated free from preconceived theory or conceptual framework.[18,19]

Participants

A total of ten participants joined the study – five caregivers participated in the key informant interviews (KII), with their respective child diagnosed to have perinatal HIV

Table 1. Participants' Profile

Caregiver	Sex	Age	Civil Status	Highest Educational Attainment	Child	Age	Caregiver–Child Relationship	Year of Diagnosis	Year of Treatment	Age in Treatment	Knowledgeable of Status
P1	F	33	Single	High School Graduate	P1C1	13	Mother	2011	2011	5 years old	Yes
P2	M	51	Single	College Graduate	P2C2	10	Uncle/Adoptive parent	2011	2011	2 years old	No
P3	F	32	Married	College level	P3C3	12	Mother	2008	2011	4 years old	No
P4	F	58	Married	College Graduate	P4C4	14	Grandmother	2010	2010	5 years old	Yes
P5	F	37	Single	Vocational	P5C5	9	Mother	2014	2014	4 years old	No

infection joining the focus group discussion (FGD) (n=5). Caregivers (n=5) range in age from 32 to 58 years (mean: 42.2 years). Three biological mothers, a grandmother, and an adoptive parent participated in the individual, semi-structured interview. Two caregivers completed a bachelor's degree, two are high school graduates, and one finished a vocational course. All children were infected with HIV through perinatal transmission and have been receiving treatment for more than five years. (Table 1)

Non-probability purposive sampling technique was used in the selection process. Participants who were considered eligible to participate in the study were caregivers (a) either biological parents, guardians, relatives, or adoptive parents with the primary responsibility of raising their children with perinatal HIV infection, (b) residents of Metro Manila, Philippines, and (c) the child is receiving treatment. Participants with a child diagnosed with HIV age 5 and below, and newly enrolled for treatment were excluded from the study. After exhaustive interviews with five participants and reviewing the research problem, we made an initial decision that saturation was reached.[20] Through an inductive thematic saturation approach, we conducted a preliminary analysis to confirm the emergence of new or repeated codes and themes.[21] After careful evaluation, no new codes and themes were generated amongst the participants' narratives.

Research Setting and Data Collection

The interview sessions were done from November 2019 to February 2020 in the community clinic located in Manila, Philippines where children with HIV and their caregivers are affiliated. The HIV clinic is a non-stock, non-profit foundation registered under the Securities and Exchange Commission of the Philippines. They created a program focused on supporting children with HIV addressing issues including Philippine Health (PhilHealth) membership of mothers to extend the package covering children's need for HIV treatment, assist medical needs, and maintenance of overall health for one year during and post-hospitalization (e.g., milk formula, diapers, clothes and toys, and vitamins). The program caters to newborn babies to 17 years old with HIV.

Following the recommendation of Colorado State University- Education Research Method[22] in conducting Narrative Research Design, we employed a narrative inquiry and performed several procedures. First, we identified the phenomenon to explore, that is, the experiences of caregivers raising a child with HIV. This step enabled us to understand the personal and social experiences of the caregivers. Second, we selected participants based on the selection criteria that we set. Third, to encourage storytelling, we collected stories using a semi-structured interview schedule with open-ended questions. We asked probing questions to allow the participants to share more about their experiences. We also conducted an FGD and obtained field text to triangulate the stories that we collected from the primary participants. For the group interview with children, we limit inquiry to the interests, provided activities they enjoy, and activity suggestions they wish to receive in future programs. The children's HIV status was not mentioned during the FGD as instructed by the program coordinator and caregivers, and observance of protocol set by the organization. Fourth, we reread and retell each participant's story. Then, we identified, organized, and sequenced the elements we obtained from the stories of the caregivers. We also coded the significant stories after re-reading the narratives. We placed the codes in a logical category that reflects the themes and represents the major findings of the study. We also included the setting, characters, problems, actions, and resolutions for added context. Fifth, we collaborated with the storyteller in all phases of the research process. We continuously collaborated with the study participants to ensure that we would accurately portray their stories in the manuscript. Finally, we wrote a story about the experiences of caregivers. This helps readers to understand the caregiver's life experiences through a written story. We highlighted the themes that we identified throughout the story. To validate the accuracy of the report, we utilized the steps to collect data as identified in the third step (i.e., qualitative documents and FGD). This is known as methodological triangulation.[23,24]

Data Analysis

We recorded each interview which lasted for approximately 30 minutes. NVivo 12, a qualitative analysis software package, was utilized in the process of data analysis. The transcribed data were uploaded, coded, and analyzed individually. The software helped with the organization and expression of the codes and themes. We thoroughly analyzed the verbatim interview transcripts using reflexive thematic analysis (RTA) which is in accordance with the six-phase process outlined by Braun and Clarke.[17] We started the analysis through familiarization of data from the transcription, then initially we generated codes and new patterns of meaning (semantic and latent) throughout the initial interpretation. We then transferred the initial codes to a spreadsheet with identifying labels for each participant and later combined them according to meanings to form themes and sub-themes. Finally, we reviewed and defined all the themes and finalized them in the report. Similarly, we qualitatively analyzed the transcripts obtained from the FGD and the documents we gained from a clinic for children with HIV based in Manila, Philippines to gain an in-depth understanding of the programs already offered. These were used to validate and support caregivers' narration of their experiences.

Trustworthiness

To ensure rigor and increase authenticity in our methodology, we used two kinds of triangulation: an FGD with the child of caregivers infected with perinatal transmission of HIV, and qualitative documentation. FGD further inquired about the programs enjoyed by children from the organization and activities provided by the HIV community clinic. Qualitative documents are important guides in contributing ideas on life coaching approaches and this helps validate the narratives of the caregivers regarding the benefits received, and the program and policies available. The researcher assigned to conduct the interviews is a psychologist and a volunteer counselor in one of the non-profit, non-government HIV clinics in Metro Manila catering to the adult population for testing, counseling, and treatment. Researchers visited the community HIV clinic where participants and their children are affiliated and attended two program activities. This was done before, during, and a few months after conducting the interviews. This will allow researchers to effectively understand the dynamic of the clinic's programs and the organization itself. All participants were invited through the endorsement of the HIV clinic program manager to ensure the authenticity of participant affiliations. All caregivers who expressed their willingness to join the study were initially considered, followed by a screening based on inclusion and exclusion criteria to reduce bias in selection. The research panel from the psychology department, with rich knowledge of the narrative inquiry method, assessed and approved thoroughly the data collection technique, procedure, and analysis. We provided substantial descriptions of the themes to ensure a thorough interpretation of the context presented which also reflects the reality of the caregiver's experience.

Ethical Considerations

Following the approval of the first and second authors' institution's research ethics committee (MS-20-07), we handed a letter of request to the HIV clinic coordinator requesting approval to invite participants from their members. In compliance with the Philippine HIV and AIDS Policy Act of 2018 (Republic Act 11166)[25] on confidentiality, we obtained HIV-related information after we discussed written consent from the participants which they then signed. This consent form specifically asked for their permission to allow the researchers to use an audio recording device to document the interviews, their involvement, and their child participation. The form also briefly discussed the rights of participants, benefits, and risks of participating in the study, confidentiality and anonymity measures, data sharing, and other ethical concerns that may arise during the study, including the participation of their child. The developmental level and ability of the child to understand research involvement were individually assessed, inquired to their caregivers, and reviewed and approved by the university research ethics board before the FGD with children proceeded. An informed assent with simplified written information about the child's participation in the study (i.e., FGD) and their rights, was distributed to, verbally discussed upon, and signed by the child through writing their full names in the document followed by counter signature made by their caregiver. Due to the sensitivity and vulnerability of participants, the name of the clinic where participants are affiliated is not disclosed to secure anonymity and protection. Debriefing after interview sessions was employed and all information gathered was secured in one digital folder with a password and storage limit of five years. After that, all data shall be permanently deleted. No distress was reported during post-research interview sessions, hence, contact details of the researchers and the Institution Research Board (IRB) for complaints and other reports.

RESULTS

There are three major themes identified in the narratives of the caregivers, (1) *becoming known: the journey of testing and treatment*, (2) *passing through challenging times*, and (3) *receiving essential support*. These themes are vital to understanding caregivers' experiences and how the research may help in designing a life-coaching approach for caregivers and children with perinatal HIV infection.

Becoming known: the journey of testing and treatment

The first theme is the process of undergoing testing for possible infection to HIV and what treatment they received. All the biological mothers of the children tested positive for HIV and infected their children with the virus upon giving birth.

Reasons for testing

Two biological mother-caregivers knew about their status when they were applying for work abroad. As mentioned by P1, *"I applied for work abroad and one of the requirements includes a medical check-up. My application got declined due to my reactive HIV result."* P5, also a biological mother of a child with HIV, learned about her status when the health office declared HIV testing mandatory for pregnant women in their locality. As she mentioned, *"HIV testing becomes mandatory in the center for pregnant women."*

On the other hand, two caregivers – both adoptive parents – knew about the status of the child when they observed symptoms in the skin and the child's health declined.

> *"He had shingles, so I decided to admit him in the hospital where I am currently connected with."* (P4)

> *"When the kid was given to us, I observed that she was too slim, and had a thick crust formed in her skin. I also saw tiny abscess in her body and a big abscess formed in her head."* (P2)

Cause of acquiring HIV

Although some participants declined to disclose the reason for acquiring the virus or were admittedly confused about when and where they acquired such, it was then revealed that four of the participants were infected during sexual intercourse. Among the participants, only P1 acquired the virus through a blood transfusion when giving birth to her eldest son through cesarean delivery (C-section).

> *"I was informed by the hospital staff that the possible reason for acquiring the virus was due to blood transfusion."* (P1)

Reactions

The third subtheme identified is the reaction of the caregivers and/or family upon knowing the HIV status of both the child and mother. Upon knowing their status, they were in denial of the diagnosis, and they slowly started to accept it towards treatment so they could live longer for their family, especially the child (*c.1. Acceptance and Denial*), caregivers mentioned that they experienced arguing with their partner and starting to question why, among all people, they were the victim of an illness that has no cure yet (*c.2. Argument*).

Treatment

This is a vital part of the theme of Testing. All the children who participated in the study underwent ARV treatment:

> *"When we had our eldest son tested, he immediately received a reactive HIV result. I can't accept the diagnosis yet nor believe we had it. Until my son and I underwent confirmatory testing. My husband refused to undergo tests, until his immune system declined in 2017."* (P3)

> *"Certainly, conflict will arise especially when you discuss to your partner the illness, who was first infected with the virus."* (P5)

However, not all participants underwent ARV despite knowing their status; only three participants adhered to the treatment. P2C2's biological mother, according to P2 (P2C2's caregiver/adoptive parent), died due to health complications and did not have a chance to undergo treatment nor confirmed with HIV infection.

> *"That's when I learned about the death of the mother since the child tested positive for HIV."* (P2)

According to the caregiver (grandmother) of P4C4, his biological mother is aware of the diagnosis, yet did not bother undergoing treatment.

From the gathered documents, the available clinic programs offered medical assistance to children with HIV-AIDS. The assistance includes the provision of medicine, vaccinations, laboratory examinations, antiretroviral assistance, and hospitalization. Nutritional support for children with HIV-AIDS, weekly food assistance during the COVID-19 pandemic, and other supplementary needs were also provided by the program.

Since the FGD with children infected with perinatal HIV was limited to discussing hobbies, perceived challenges, and performance, the data from FGD cannot validate results in the theme of Testing.

Synthesis

Testing is vital in the journey of caregivers. The narratives showed similarities in the testing, diagnosis, and treatment. Testing was administered due to health complications of the child and mandatory testing (i.e., at work and as a step in prenatal check-ups). The late diagnosis led to late treatment. Only a few caregivers were open to specifying the cause of acquiring HIV. Reasons for acquiring the virus have been a challenging topic, especially among the biological mothers of children with HIV. Reactions include denial, displacement (typically in the form of arguments), and doubting their partner and/or themselves. These negative reactions become hindrances to treatment. At a later phase, the participants expressed their belief that adhering to treatment is indeed important in the journey; this realization may, however, come in too late.

Passing through challenging times

The second theme identified is the challenges encountered by caregivers. These are the difficulties experienced by the caregivers while raising a child with HIV.

Preparing the child to understand illness

This subtheme communicates how caregivers prepare the child to know and understand their HIV status. Three participants mentioned that their child remains unaware of their status, with the clinic program helping them prepare their child through psychosocial interventions. On the other hand, two caregivers identified the steps they took following future disclosure.

> *"I told my son, 'You will know your condition at the right time... little by little, I will make you understand this."* (P5)

> *"Billy is our companion, he has a similar condition to yours. There are no physical obvious signs of your condition… I am hopeful that society will accept your condition and will not be ashamed of it."* (P4)

Child's awareness and understanding of illness

If the child is already aware of their condition, the concern shifts to how they manage their emotions; a process that is vital to their well-being. This was identified as a challenge for caregivers as their responsibilities doubled. The curiosity of the child will arise and always be eager to find answers.

> *"There are times he is often curious and asks several questions like, 'Why is it taking too long?'"* (P3)

Challenges may also come in ensuring that the children remain healthy as well as in making sure that their child has a good understanding of their health condition. The caregivers were eager to ease the tension by seeking help from the clinic director and staff in helping them prepare their children to understand their condition. Although help is offered, it is noted that their worries as caregivers can often be overwhelming.

Among the five children participating in the FGD, only two were aware of their diagnosis. However, the interview did not include HIV-AIDS-related questions due to the request of caregivers and the program coordinator. Thus, the attempt to triangulate information in this subtheme fell short.

Physical health

This subtheme covers the physical health of the parent and child, including the child's health prior to testing and during treatment. There were positive changes observed in their child while under treatment:

> *"He eats frequently and has gained weight."* (P4)

> *"He is excelling academically and graduated with honors."* (P3)

However, caregivers are still very vigilant to the health of their child as mentioned by P2:

> *"I told her not to play with kids who have coughs and colds. She replied, 'Why, Daddy?' 'Because you are vulnerable to such. Your immune system is weak,' I answered."*

Sleep and temper problems were also noted.

> *"My eldest son had trouble sleeping since he was prescribed different medicine."* (P1)

> *"Yes, he became hot-tempered."* (P5)

Additionally, information on the health of the parents also provides insight on the topic:

> *"Our health was declining until I decided to take ARV treatment. In 2017, my husband's immune system weakened. I told him that we should be fighting together and that I can't allow us to die at a young age. I persuaded my husband to also undergo treatment."* (P3)

No significant concerns regarding the children's physical health were noted during the FGD. Most of the children chose to discuss other aspects of their day-to-day life such as their academic performance. Most of their input was focused on their academic standing, including concerns regarding their academic modules, the distractions they face especially when studying, and how they yearn to go back to face-to-face classes.

> *"... face to face classes are more memorable than the online set-up"* (P4C4)

During the COVID-19 pandemic, the children expressed getting used to staying at home and playing video games. P1C1 mentioned how he feels anxious due to the virus and how this has caused less socialization with others. P4C4 and P5C5 agreed to P1C1 regarding how the child is affected by the pandemic health concerns.

> *"I become more aloof socially and afraid of contact with other people."* (P1C1)

Three agreed that they experienced anxiety expressing:

> *"Children are being affected."* (P5C5)

> *"The [COVID-19] virus."* (P4C4)

> *"... becoming unused to talking with strangers."* (P1C1)

It was noted during the FGD that the children were constrained by their caregivers to play and go outside. P2C2 mentioned when asked about their engagements at home:

> *"None, I often sleep most of the time."*

Discrimination

Discrimination is a common experience of PLHIV. For caregivers, the discrimination is not just a concern of the PLHIV, as the entire family – even extended relatives – may sometimes be made subject to discrimination as well. That, or they may be the ones that perpetrate discriminatory acts.

> *"[…] that night, the mother-in-law of my cousin went to shame us. She was shouting in front of my children, 'Get out of our house, your condition might be infecting your niece and nephews. How about them?' [….] That time, I thought of ending my life."* (P1)

> *"I feel sorry for him (child) especially if someone will know his condition. It would be better if they understood. What if his fellow kids knew about his condition and would be bullied at school? Of course, he might feel emotional about it."* (P4)

The children made no mention of discrimination during the FGD, even when prompted about the possible discrimination they may have experienced. Instead, the children were sharing their emotions and how insights were built amongst individuals.

> *"I agree with [him]. Let us share our knowledge and not judge others when they commit mistakes."* (P3C3)

> *"In education […] It is important that we pass through or share what we learn to others."* (P4C4)

Every individual would need to understand the importance of education and how this could help everyone in alleviating discrimination in the community. As supported in the responses of the children, the knowledge we share with everyone in the community can be used to help educate individuals and shun negative reactions such as discrimination.

Synthesis

The second theme provides an understanding of the challenges encountered by the caregivers of children with perinatal HIV infection. The caregivers expressed similarities in how their journey, whether as biological parents or adoptive parents, was full of challenges.

Although preparing their child to understand their condition may sound helpful for their adjustment, it was identified as a challenge by the caregivers. This was because there was no way of predicting how their child would react, and those negative reactions might lead to more problems in the household.

Challenges were abounding even with the support of the clinic programs. Questions like, *'How long will they be patient in the treatment?'* and *'When will I not worry about the stability of my child's health?'* are the contributing factors that caused them to worry about their current state. Most of these factors were external as most of the participants pointed out, perhaps the greatest of these factors being the possible discrimination that they might receive once a diagnosis is made and communicated to other members of the community.

Receiving essential support

This theme is important in identifying the approaches for life coaching, including coping strategies that already worked for them, as well as ones that might need to be improved. This section covers topics on family support, motivation, and other essential coping strategies that helped them overcome the challenges of being a caregiver of a child with HIV.

Caregiver's knowledge and understanding of illness

Having enough knowledge and understanding of illness could help caregivers take steps to better their lives with the family and maintain their health. This consists of treatment and motivation to live longer.

> *"I ask the nurses and doctors at [RITM]. They told me, 'Continue the medication' considering it as a normal virus in the body."* (P4)

> *"I was teaching Science and Health before, and I have read the facts about HIV in the books. I found that if you continually take your medicine the health will be stable."* (P2)

Relevant points covered in the FGD with the children were identified in support of this sub-theme. One of the main points includes how the child might know about his condition, and how the child might use this to cope with life's challenges in the future.

> *"Every time I make a mistake, I then realize that I am wrong and willingly forgive other people."* (P3C3)

This insight of forgiving and understanding may become a helping factor for the child to draw positive coping strategies and adjustments in his life.

Building hope

Building hope for themselves, their children, and their family strengthens the caregivers' adherence to treatment. This is also a caregiver's way of managing their emotions about their health status. By looking back at the challenges, they have overcome thus far, they can form a positive outlook that helps them move forward with life with optimism.

> *"I want my son to live longer so I can take good care of him. Also, I wish to see him growing happy and that he would reach his dreams."* (P5)

Needs received

Needs are also a theme in the narratives of the caregivers. It is important that caregivers can reflect on and identify their needs and their child's needs so that they are guided in making future life decisions. They reflected on giving emphasis on education regarding HIV:

> *"Provide an educational program about HIV so the parents will be encouraged to get tested, and they would know their status early. Special cases like pregnancy, this might be passed through to the vulnerable child… treatment to reduce incidents of MTCT of HIV."* (P5)

> *"Seminars are beneficial to parents, especially because it helps parents become more open-minded. Also suggesting providing an equivalent to the children, like counseling."* (P1)

Also, boosting the caregiver's and child's mental health through programs was mentioned:

> *"Counseling program for children with perinatal HIV infection so they will become more equipped in understanding their condition." (P4)*

> *"Programs especially for children. I am afraid he might get depressed while growing up with this infection. The reason why I bring him with me is to expound his knowledge and understanding about his condition."* (P1)

Caregivers were hoping to expand the accessibility of health services.

> *"Free health services to the PLHIV. Number of hub facilities and professionals will hopefully increase."* (P5)

Since the caregivers of the participants are active members of the clinic program, we asked about the activities that the children wished to receive from the program.

Some of their responses were as follows:

> *"I think different games like sports."* (P3C3)
>
> *"Arcade-like activities."* (P4C4)
>
> *"Additional games."* (P2C2)

They also expressed what they wish to be retained.

> *"Just like the activities during the Children's Month, there were several games in the program."* (P3C3)

The children also shared their hobbies and interests during the FGD. Some of the notable responses include TikTok (P2C2), Kidzania (P4C4), and active games (P5C5). The older participants, on the other hand, expressed their interest in playing sports like basketball (P4C4), and soccer or baseball (P3C3).

Sources of support

Finally, sources of support have been found vital in caregivers' coping. This may include family support, financial sources of support (e.g., work), and having friends with whom they can talk about their current situation. On family support:

> *"I disclosed our condition to my sisters. Before, I had experienced breakdowns and thought of ending my life. My sisters were there encouraging me to be strong and were keeping in touch with me all the time."* (P3)

Financial and social support from the clinic program proved to be helpful as well:

> *"Now, since I am no longer in my teaching career […] Livelihood program provided by (clinic)... is a big help. Also, I earn through creating doormats."* (P2)
>
> *"Having a support group with similar experiences helps with the adjustment. It is important to keep your circle close so when you need someone, you have shoulders to cry on."* (P1)

While caregivers identified family, financial, and social support as important components in helping them cope with the challenges, the children were consistent in pointing out that the most significant support that they get is the support of their caregivers.

> *"We get to bond with our parents now more than before when they are working."* (P3C3)

Love, encouragement, and good providers were mentioned in describing the support they received from their caregivers.

> *"They accepted me… I received encouragement."* (P4C4)
>
> *"They are providing my needs."* (P1C1)
>
> *"Love."* (P5C5)
>
> *"Food."* (P2C2)

No matter how simple they may seem, these expressions of support are what help the children appreciate and enjoy life.

Synthesis

Concerns about coping were commonly expressed in the narratives of the caregivers. One way to cope was via educating themselves, as this not only helped them understand the illness better but also helped them turn their attention to healthier, more productive ways of managing their stress.

Being hopeful was also helpful in helping them adhere to treatment. They expressed hope that this study may become an avenue to receive interventions they needed as caregivers, especially for their children.

Also mentioned and emphasized in the interviews was how their needs play a huge role in coping. These needs led them to be active in their membership in the program, as well as encouraging them to look forward to future engagements with the program.

Lastly, sources of support helped the caregivers overcome the challenges. The resources they have now (financial and social support from the clinic programs and family support) are significant and could continuously help them in times of challenges.

DISCUSSION

Based on the narratives of the caregivers, it is important to consider how they found out and reacted to their children's diagnosis. The results of the present study revealed that the caregivers learned about their children's HIV status either through testing or from their own observations of their children's declining health. Consistent with the previous studies,[26,27] we found that late testing leads to late treatment. Regardless, the findings of the study suggest that adherence to treatment helps children to have a normal, healthy life. Thus, the treatment should remain viable to appropriately manage the repercussions of late diagnoses. The summary

Table 2. Themes and Intervention Program

Theme	Subtheme	Suggested Intervention Program
Becoming known: the journey of testing and treatment	Reasons for testing	Comprehensive education program for sex and reproductive health. Retain support from the organization and government (e.g., testing and treatment needs, nutritional and basic needs support, educational supply, livelihood program for caregivers).
	Cause of acquiring HIV	
	Reactions a. acceptance and denial b. argument	
	Treatment	
Passing through challenging times	Preparing the child to understand illness	Psychoeducation and cohesive and supportive dynamics in the community
	Child's awareness and understanding of illness	
	Physical Health	
	Discrimination	
Receiving essential support	Caregiver's knowledge and understanding of illness	Tailored organizational psychosocial intervention (e.g., parenting skills training, home management, effective child support). Dialectical Behavioral Therapy: Individual and group (family) counseling sessions.
	Building hope	
	Needs received	
	Sources of support	

of the results and suggested intervention programs to be included in the life coaching approaches are presented in Table 2.

Testing, treatment, and SRH education

Article IV, Section 29 of RA 11166 (2018)[25] states that HIV testing for children aged 15 and below requires the consent of their guardians. Additionally, HIV testing for this age group can only be mandatory for pregnant individuals. Most children in the Philippines, therefore, are not typically tested for HIV. Only 2.4% (372 out of 16,155 respondents) of Filipino women in 2013 have been tested for HIV.[27] In relation to this, the present findings suggest that more efforts be made to promote HIV testing among Filipino women who are often left in the dark about their HIV status. Unless there is no reason for HIV testing to be performed, Filipinos do not typically go for testing.[27] This consequently leads to late diagnosis and treatment. Coherent to the findings in the narratives of the caregivers and as supported by the KII and qualitative documents, expanding education programs on sex and reproductive health (SRH) may improve testing, promote programs that support the needs of caregivers, may further improve the reach of the PLHIV and carers to the support and needs, and reduce the experience and fear of stigma.[28,29]

Support needs of caregivers and children with HIV

The psychological distress experienced by caregivers and their children can also develop into more serious psychological issues. Studies suggest primary caregivers of children with HIV are at a high risk of developing depressive and anxiety symptoms.[30-32] In a study of young parents with HIV, becoming a parent and spending time with their children has played a significant role in their motivation to continue their education and seek employment opportunities.[32] The psychological adjustments of primary caregivers (e.g., grandparents, family/relatives, and foster and adoptive parents) have been a great concern, and awareness of their mortality (mother with HIV) has become their source of motivation to maintain their health and relationship with the children.[32,33] Similar to Filipinos seeking hope through prayers and belief in God, Iranian WLHIV (Women living with Human Immunodeficiency Virus) gather hope through their children and become closer to God which is beneficial for managing the anxiety and depression that arise from the perinatal transmission of HIV and life span uncertainty.[34] From the results of the FGD and qualitative document, it was found that participants were pleading to maintain programs including assistance for the health of children with HIV (e.g., free medication, vaccination, laboratory testing, and food needed). Increasing interest in sports (e.g., e-sports or in-person) may encourage the child and caregiver to make use of available programs.

Psychological services are also deemed to be helpful. The psychological approach, Dialectical Behavioral Therapy, may help an individual or group to change negative thinking patterns and strive for positive behavioral changes.[35] This is something that the researcher finds beneficial to the caregivers as they have experienced discrimination, sometimes perceived discrimination, and are dealing with frequent worry about their own and their child's health. This approach may help improve social functioning, control anger to relate with others or their child, and increase adherence to treatment (their own and/or their child's treatment). Despite the differences among families and communities, sustaining cohesive and supportive dynamics is indeed important, other than educating about transmission risk.[36]

Role of Psychologists in Responding to the HIV Epidemic

The researcher is hopeful that the advocacy for HIV, especially among caregivers and children with perinatal HIV infection, continues to grow. That, and the field of psychology also gets more involved in such advocacy. There is so much ground to cover in terms of integrating psychological topics on HIV such as risk behaviors (e.g., sex, drugs), discrimination, and critical thinking. Advocacies for HIV should not only focus on the physical aspect but also on the psychological well-being of the individual. Taking good care of the family members while they are attending to their health has been challenging, especially for mothers with HIV. Psychosocial interventions were generally effective in reducing anxiety and depressive symptoms in children with perinatal HIV infection, and generally effective in improving the psychological well-being of the caregivers and the child.[37] Therefore, the role of the psychologist and the interventions they provide is vital in the support to this community.

The practical contribution of this present study is to improve and/or provide additional inputs to the community-oriented life coaching approaches for caregivers and children living with HIV-AIDS. This study may encourage professionals in the field of psychology to contribute to this epidemic via the provision of psychological services and research. Additionally, it is also essential to consider the reach of the advocacy in the Philippines; rural areas need to be considered in terms of education, testing, and treatment services. In turn, these services may help reduce discrimination and increase the number of Filipinos willing to undergo testing and treatment. From being taboo, it is hoped that topics pertaining to HIV become a normal part of the conversation. Lastly, the present study strongly implies that providing psychological support to PLHIV and caregivers of these infected individuals is as important as the medication. To increase adherence to treatment, well-being shall be sustained. In effect, the undetectable=untransmissible (U=U) HIV cascade in the Philippines may improve. In hopes for the government to competitively address the HIV epidemic in the country, they must create steps to improve the primary healthcare system and implement a public health approach, through multi-sectoral actions and community engagement.[38] Strengthening the U=U campaign and awareness of information could attenuate fear-related burden to the life of PLHIV and HIV-related stigma from sexual partners and others.[39]

Limitations and Strengths

Due to restrictions set by the Philippine government in response to the COVID-19 pandemic and the number of active members in the clinic, only a limited number of participants and amount of time were considered for the study. Moreover, the study limits its scope to populations living in highly urbanized areas. Thus, future research may consider extending this study in terms of interviewing more participants, especially in rural areas. The study also limits its generalizability with respect to its methodology making it difficult to confirm the level of distress that affected the participants' narratives. Quantitative research that involves the measurement of psychological distress, life satisfaction, and quality of life among caregivers is warranted.

We listed several strengths of our study. First, our findings may contribute to the limited number of research exploring concerns on perinatal HIV infection, including topics on the experiences of caregivers and their children. Second, this can be used as a reference in designing programs for proactive testing and sustainable treatment in the country. The inclusion of professionals in the field of psychology to focus on non-medical aspects, improvement of adherence to treatment, and initiatives that may improve the overall quality of life of people living with HIV. Finally, the researcher believes that the study is especially timely in this pandemic, as people around the world are becoming more concerned about health.

CONCLUSION

This study explored the experiences of caregivers raising a child with perinatal HIV infection. It identified three major themes: (1) *becoming known*: the journey towards testing and treatment, (2) *passing through challenging times*, and (3) *receiving essential support*. The narratives of caregivers raising a child with HIV highlighted testing and treatment, challenges encountered, and coping needs and support. Caregivers with children living with HIV face challenges such as preparing the illness to be known and understood by their child, managing the child's physical health, and discriminating against others. However, they can live healthy and meaningful lives if they are given comprehensive support from the government, access to quality healthcare and education, and psychosocial interventions. Therefore, the government and private sectors must make efforts to promote physical, emotional, and mental health care underpinning the well-being of caregivers and children with HIV. The retention of the programs offered by certain organizations (e.g., testing and treatment needs, nutritional and basic needs support, educational supply, and livelihood program for caregivers) and the increase in the number of psychoeducational and support group activities were suggested to significantly help in addressing the concerns of both the caregivers and their children with perinatal HIV infection. Barriers to HIV care may be addressed by offering interventions to facilitate safe HIV status disclosure, mobilizing social support, and providing more accessible HIV services.[29]

The field of Health Psychology has been at the frontlines in addressing behaviors and lifestyles of individuals toward health and wellness. Professionals (e.g., psychologists) and researchers in the field of psychology may play a significant role in designing behavioral change strategies in response to public health concerns like HIV/AIDS. Professionals may begin by shifting to community and public health perspectives, understanding the experiences of key populations engaged in high-risk behaviors, and identifying how we can contribute to the management of chronic diseases.

Acknowledgments

The researchers would like to acknowledge caregivers of children with HIV who supported and accommodated the researchers. Many thanks to the program coordinator for her active assistance. To Dr. Rhodora Gail T. Ilagan, Dr. Nieto L. Vitto, and Mr. Randolph Reserva of Ateneo de Davao University, big thanks for the timely suggestions and encouragement to continue the research despite the challenges. Also, to Ms. Abegail Bianca Parcon for her dedicated assistance throughout the completion of the project.

Statement of Authorship

Both authors certified fulfillment of ICMJE authorship criteria.

Author Disclosure

Both authors declared no conflicts of interest.

Funding Source

None.

REFERENCES

1. Center for Disease Control and Prevention, Prevent Mother-to-Child Transmission [Internet]. 2022 [cited 2022 Jan]. Available from: www.cdc.gov/hiv/basics/hiv-prevention/mother-to-child.html
2. World Health Organization, Mother-to-Child Transmission of HIV [Internet]. 2022 [cited 2022 Jul]. Available from: www.who.int/teams/global-hiv-hepatitis-and-stis-programmes/hiv/prevention/mother-to-child-transmission-of-hiv on 29 July 2022.
3. Minnesota Department of Health, Perinatal (Mother-to-Child) HIV Transmission [Internet]. 2019 [cited 2019 Mar]. Available from: https://www.health.state.mn.us/diseases/hiv/prevention/perinatal.html
4. Drake AL, Thomson KA, Quinn C, Owiredu MN, Nuwagira IB, Chitembo L, et al. Retest and treat: a review of national HIV retesting guidelines to inform elimination of mother-to-child HIV transmission (EMTCT) efforts. J Int AIDS Soc. 2019 Apr;22(4):e25271. doi: 10.1002/jia2.25271. PMID: 30958644; PMCID: PMC6452920.
5. Alebel A, Engeda EH, Kelkay MM, Petrucka P, Kibret GD, Wagnew F, et al. Mortality rate among HIV-positive children on ART in Northwest Ethiopia: a historical cohort study. BMC Public Health. 2020 Aug 27;20(1):1303. doi: 10.1186/s12889-020-09418-6. PMID: 32854692; PMCID: PMC7457276.
6. Department of Health. Philippines Addresses Rising Trend in New HIV Infections [Internet]. 2022 [cited 2022 Mar]. Available from: https://doh.gov.ph/node/10649#:~:text=The%20government%20has%20also%20taken,600)%20a%20year%20per%20person
7. Bachanas PJ, Kullgren KA, Schwartz KS, McDaniel JS, Smith J, Nesheim S. Psychological adjustment in caregivers of school-age children infected with HIV: stress, coping, and family factors. J Pediatr Psychol. 2001 Sep;26(6):331-42. doi: 10.1093/jpepsy/26.6.331. PMID: 11490034.
8. Asadullah M, Kamath R, Pattanshetty S, Andrews T, Nair NS. Psychological impact on caregivers of HIV-infected children in Udupi district, Karnataka. AIDS Care. 2017 Jun;29(6):787-92. doi: 10.1080/09540121.2016.1263720. PMID: 27915488.
9. Ofori-Atta A, Reynolds NR, Antwi S, Renner L, Nichols JS, Lartey M, et al. Prevalence and correlates of depression among caregivers of children living with HIV in Ghana: findings from the Sankofa pediatric disclosure study. AIDS Care. 2019 Mar;31(3):283-92. doi: 10.1080/09540121.2018.1537463. PMID: 30360643; PMCID: PMC6382516.
10. Ricci G, Netto EM, Luz E, Rodamilans C, Brites C. Adherence to antiretroviral therapy of Brazilian HIV-infected children and their caregivers. Braz J Infect Dis. 2016 Sep-Oct;20(5):429-36. doi: 10.1016/j.bjid.2016.05.009. PMID: 27471126; PMCID: PMC9425490.
11. Ekstrand ML, Heylen E, Mehta K, Sanjeeva GN, Shet A. Disclosure of HIV status to infected children in South India: perspectives of caregivers. J Trop Pediatr. 2018 Aug 1;64(4):342-7. doi: 10.1093/tropej/fmx079. PMID: 29092080; PMCID: PMC6084615.
12. Wariri O, Ajani A, Raymond MP, Iliya A, Lukman O, Okpo E, 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 Mar 20;20(1):373. doi: 10.1186/s12889-020-08506-x. PMID: 32197648; PMCID: PMC7085175.
13. Arun S, Singh AK, Lodha R, Kabra SK. Disclosure of the HIV infection status in children. Indian J Pediatr. 2009 Aug;76(8):805-8. doi: 10.1007/s12098-009-0177-z. PMID: 19802549.
14. Klunklin P, Harrigan RC. Child-rearing practices of primary caregivers of HIV-infected children: An integrative review of the literature. J Pediatr Nurs. 2002 Aug;17(4):289-96. doi: 10.1053/jpdn.2002.126713. PMID: 12219329.
15. Burr V. An Introduction to Social Constructionism, 1st ed. Routledge; 1995.
16. Schwandt T. Constructivist, interpretive approaches to human inquiry. In: Denzin N, Lincoln Y,eds. The Landscape of Qualitative Research: Theories and Issues. Thousand Oaks: Sage Publications; 1998. pp. 221–259.
17. Braun V, Clarke V. Reflecting on reflexive thematic analysis. Qual Res Sport Exerc Health. 2019;11(4):589–97. doi: 10.1080/2159676X.2019.1628806.
18. Braun V, Clarke V. Successful Qualitative Research: A Practical Guide for Beginners. Thousand Oaks: Sage Publications; 2013.
19. Byrne DA. A worked example of Braun and Clarke's approach to reflexive thematic analysis. Qual Quant. 2022;56:1391–412. doi: 10.1007/s11135-021-01182-y.
20. Colorado State University- Education Research Method, Steps in Conducting Narrative Research. 2021 [cited 2021 Aug]. Available from: www.edrm600narrativedesign.weebly.com/steps.html
21. Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. Qual Quant. 2018;52(4):1893-907. doi: 10.1007/s11135-017-0574-8. PMID: 29937585; PMCID: PMC5993836.
22. Strauss A, Corbin J. Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory. 2. Thousand Oaks: Sage; 1998.
23. Guion L Triangulation: Establishing the validity of qualitative studies. EDIS 2002(6). doi: 10.32473/edis-fy394-2002/.
24. Moen T. Reflections on the narrative research approach. Int J Qual Methods. 2006 Dec;5(4):56-69. doi: 10.1177/160940690600500405.
25. The Republic of the Philippines. Republic Act no. 11166 (as amended by Republic Act no. 8504). HIV and AIDS Policy Act of 2018. Metro Manila, Republic of the Philippines [Internet]. 2018 [cited 2018]. Available from: https://www.officialgazette.gov.ph/downloads/2018/12dec/20181220-RA-11166-RRD.pdf
26. Lehman DA, Farquhar C. Biological mechanisms of vertical human immunodeficiency virus (HIV-1) transmission. Rev Med Virol. 2007 Nov-Dec;17(6):381-403. doi: 10.1002/rmv.543. PMID: 17542053.
27. Pepito VCF, Newton S. Determinants of HIV testing among Filipino women: Results from the 2013 Philippine National Demographic and Health Survey. PLoS One. 2020 May 12;15(5):e0232620. doi: 10.1371/journal.pone.0232620. PMID: 32396559; PMCID: PMC7217462. Erratum in: PLoS One. 2021 Jan 26;16(1):e0246013. PMID: 33497401.
28. Hamilton M, Botfield J, Persson A, Newman C, Bryant J, Valentine K, et al. Hidden carers? A scoping review of the needs of carers of people with HIV in the contemporary treatment era. Int J Care Caring. 2018;2(4):529–49. doi:10.1332/239788218X15411705099442.

29. O'Laughlin KN, Greenwald K, Rahman SK, Faustin ZM, Ashaba S, Tsai AC, et al. A social-ecological framework to understand barriers to HIV clinic attendance in Nakivale refugee settlement in Uganda: a qualitative study. AIDS Behav. 2021 Jun;25(6):1729-36. doi: 10.1007/s10461-020-03102-x. PMID: 33263892; PMCID: PMC8081685.
30. Mellins CA, Ehrhardt AA. Families affected by pediatric acquired immunodeficiency syndrome: sources of stress and coping. J Dev Behav Pediatr. 1994 Jun;15(3 Suppl):S54-60. PMID: 8063921.
31. Hughes CB, Caliandro G. Effects of social support, stress, and level of illness on caregiving of children with AIDS. J Pediatr Nurs. 1996 Dec;11(6):347-58. doi: 10.1016/S0882-5963(96)80079-0. PMID: 8991335.
32. Fair C, Allen H, Trexler C, D'Angelo LJ. Experiences of young parents with perinatally acquired HIV. AIDS Patient Care STDS. 2017 Nov;31(11):479-85. doi: 10.1089/apc.2017.0141. PMID: 29087743.
33. Grubman S, Gross E, Lerner-Weiss N, Hernandez M, McSherry GD, Hoyt LG, et al. Older children and adolescents living with perinatally acquired human immunodeficiency virus infection. Pediatrics. 1995 May;95(5):657-63. PMID: 7724299.
34. Behboodi-Moghadam Z, Khalajinia Z, Nasrabadi AN, Mohraz M, Gharacheh M. Pregnancy through the lens of Iranian women with HIV: a qualitative study. J Int Assoc Provid AIDS Care. 2016 Mar-Apr;15(2):148-52. doi: 10.1177/2325957415593636. PMID: 26156585.
35. Corey G. Dialectical Therapy. Theory and Practice of Counseling and Psychotherapy, 8th ed. USA: Thomson Brooks/Cole Corporation, Cengage Learning. 2009. p. 207
36. Persson A, Smith AK, Wallace J, Valentine K, Bryant J, Hamilton M, et al. Understanding 'risk' in families living with mixed blood-borne viral infection status: The doing and undoing of 'difference'. Health (London). 2022 May;26(3):284-301. doi: 10.1177/1363459320946469. PMID: 32744122.
37. Skeen S, Sherr L, Tomlinson M, Croome N, Ghandi N, Roberts JK, et al. Interventions to improve psychosocial well-being for children affected by HIV and AIDS: a systematic review. Vulnerable Child Youth Stud. 2017;12(2):91-116. doi: 10.1080/17450128.2016.1276656. PMID: 29085436; PMCID: PMC5659734.
38. Assefa Y, Hill P, Van Damme W, Dean J, Gilks CF. Leaving no one behind: lessons from implementation of policies for universal HIV treatment to universal health coverage. Global Health. 2020 Feb 24;16(1):17. doi: 10.1186/s12992-020-00549-4. PMID: 32093771; PMCID: PMC7038514.
39. Norman T, Bourne A, Lyons A, Rule J, Power J. Antiretroviral therapy use, viral detectability and fear of onward transmission among people Living with HIV in Australia: changes between 1997 and 2018. AIDS Behav. 2023 Feb;27(2):591-9. doi: 10.1007/s10461-022-03795-2. PMID: 35838861; PMCID: PMC9908629.