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UNDERSTANDING DIFFERENCES IN EMOTIONAL EXPERIENCES AMONG CAREGIVERS IN CARING FOR CHILDREN UNDER FIVE EXPOSED TO HIV

Happy Hayati[1], Dessie Wanda[1], Nani Nurhaeni[1], Nuraidah[2]
[1]Faculty of Nursing, Universitas Indonesia, Jl. Prof. DR. Sudjono D. Pusponegoro, Pondok Cina, Beji, Depok, Jawa Barat 16424, Indonesia
[2]RSPI Sulianti Saroso, DKI Jakarta, Jl. Sunter Permai Raya No.2, RT.2/RW.12, Papanggo, Jakarta Utara, Jakarta 14340 Indonesia
*happy@ui.ac.id

ABSTRACT
An increase in HIV cases in housewives is at risk of increasing the population of children exposed to HIV. Caregivers of children exposed to HIV are at risk of having problems caring for children exposed to HIV. The difficulties experienced by caregivers can be affected by the condition of the child, who may or may not be infected with HIV. This study aims to get an n overview of the emotional experience of caregivers in caring for children underfive who are exposed to HIV. Methods: The research design uses a qualitative method with a phenomenology approach. Data collection was carried out using snowball sampling techniques and obtained from ten participants domiciled in Jakarta and its surroundings. The participants recruited in this study are caregiver of HIV-exposed children. Data collection was carried out using in-depth interview techniques. Data analysis uses thematic analysis using the Colaizzi method. This study obtained ten participants consisting of seven biological mothers, two children's relatives and one foster parent. There were seven children with HIV-negative and five children with HIV-positive. Two caregivers in this study cared for more than one child exposed to HIV, namely one child with HIV-positive and one child with HIV-negative. The study found three themes: easy versus complex; grace and entrustment; and love and pity. This study concluded the that there are differences in emotional experiences among caregivers in caring for children underfive exposed to HIV influenced by the child's HIV status. Positive affirmations and emotional support from health professionals adjusted to the values and socio-cultural condition of caregivers will benefit caregivers in providing adequate care for children.

Keywords: caregivers; children exposed to HIV; emotional experiences

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INTRODUCTION

The increase in HIV cases among housewives risks an increase in the population of children exposed to HIV. An HIV-exposed child is a child born to a mother with HIV, where the child is at risk of contracting HIV infection during pregnancy or after childbirth. Based on the report on the development of HIV AIDS and sexually transmitted diseases in Indonesia (Ministry of Health of the Republic of Indonesia, 2022), the number of HIV-positive pregnant women is 2.133 people. The highest number of AIDS by occupation/status are non-professional workers (employees) (25.119), housewives (20.785), self-employed/self-employed (19.470), manual laborers (7.259), and farmers/breeders/fishermen (7.130). AIDS cases in housewives rank second highest after the group of non-professional workers (employees). Without intervention or treatment, children born to HIV-positive mothers are at risk of contracting the virus during pregnancy, childbirth, and breastfeeding. According to the

same report, the number of babies born to HIV-positive mothers is 134 people. The number of babies who were tested for HIV early diagnosis was 451 babies, and the number of babies (<18 months) who were diagnosed with HIV positive was 28 babies. Based on data in Africa, in 2017, it was estimated that there were 14.8 million (uncertainty limit of 10.7-19.2 million) children who were exposed but not infected, of which 90% lived in sub-Saharan Africa. The number of children not infected with HIV in South Africa increased from one million in 2002 to more than three million in 2017. This increase is primarily due to the success of public health programs in preventing perinatal and postpartum vertical transmission of HIV (Ramokolo, Goga, Slogrove, & Powis, 2019).

Based on the results of the study, children exposed to HIV have a risk of disturbances in their growth and development. Wedderburn et al. (2022) found that HIV-exposed children who were not infected with HIV had a risk of impairments in expressive language and gross motor development at the age of two years. Compared to children not exposed to HIV, HIV-exposed children who are not infected with HIV have a small deficit in early growth due to the universal maternal ART policy and breastfeeding. Most HIV-exposed and non-HIV-exposed children are overweight by 12 months of age, suggesting a great risk for early onset of obesity among children in South Africa (le Roux et al., 2019). The results of the study on HIV-exposed children show the challenges that caregivers may face in caring for HIV-exposed children.

A caregiver is a person who provides direct care (such as to children, the elderly, or people with chronic diseases) (Merriam-Webster dictionary). Caregivers of HIV-exposed children are people who provide direct care to children born to HIV-positive mothers. Childcare in Indonesia generally involves biological parents and other family members such as grandparents or relatives. This caring for the child is influenced by the extended family culture still developing in Indonesia, namely the nuclear family and other blood-related family members. If the parents/relatives are absent or unable to care for the child, then the child is cared for by a guardian or foster parent.

A study on the experience of caregivers caring for HIV-exposed children by Alvarenga and Dupas (2014) obtained four categories: caregivers experiencing loneliness in administering children's antiretroviral therapy, mainly due to lack of information or incomplete information; caregivers paying attention to necessary care, such as the use of prophylaxis for pneumonia, vaccines, and other practices that are limited to mother-child interaction; and the desire to eliminate HIV because they are afraid of prejudice and fear of disease, as well as considering prospects. Another study found that caregivers were burdened with insufficient food supplies and difficulty accessing health services. Caregivers survive such pressures by managing relationships, sharing the burden with care recipients, social networks, and instrumental spirituality (Osafo, Knizek, Mugisha, & Kinyanda, 2017). Regarding caregiver burden, Khairunnisa and Hartini (2022) found that caregiver burden has a negative relationship with subjective well-being. The more the burden caregivers face increases, the lower the caregivers' subjective well-being level.

Some of the studies described above illustrate the challenges that caregivers face in caring for children exposed to HIV. Generally, the challenges faced are related to the condition of HIV-exposed children infected with HIV, where children need continuous treatment and health monitoring. Various challenges that exist may affect the emotional status of caregivers of HIV-exposed children. Studies related to the emotional experiences of caregivers caring for HIV-exposed children, both infected and non-HIV-infected, have not been widely conducted,

especially in Indonesia. The limitations of the study are the background for this study. This study aims to get an overview of the emotional experience of caregivers in caring for children under five who are exposed to HIV. The results of this study will provide helpful information for health services in planning programs that can support the welfare of caregivers and children exposed to HIV.

METHOD

The research design uses qualitative methods with a descriptive phenomenological approach. Descriptive phenomenology involves the direct exploration, analysis, and description of a particular phenomenon that is as accessible as possible from unexamined preconceptions, aiming for maximum intuitive presentation (Streubert & Carpenter, 2011). This study was conducted in 2021-2022 in Indonesia, especially in the Jakarta area and its surroundings. The selection of participants began by establishing communication with people living with HIV companions as the informant who connected researchers with caregivers of HIV-exposed children. Furthermore, the researcher used snowball sampling to recruit the next participant. The participants involved in this study are ten people with inclusion criteria, namely parents or caregivers of children exposed to HIV aged less than five years, who have at least one year of experience in care. The recruited caregivers are seven parents (biological mothers of children), two relatives, and one foster parent. Data was collected through in-depth interviews online and recorded using the Zoom meeting application concerning the regulation of social distancing during the COVID-19 pandemic. The duration of the interview lasts for 45-60 minutes. After completing the interview with the informant, the researcher transcribed the interview results. Data analysis uses phenomenological analysis, following the analysis stage according to Colaizzi (Colaizzi, 1978). The analysis stage, according to Colaizzi, is reading all the transcripts of the interview results, analyzing each transcript and extracting meaningful statements; deciphering the meaning of each meaningful statement (formulating the meaning); organizing the meanings that have been formulated into thematic clusters; integrate the results into a complete description of the research phenomenon; formulate a thorough description of the phenomenon being studied in the identification of the statement as clearly as possible; Ask participants about the research findings as a final validation step.

Ethical Consideration

Before starting data collection, the researcher conducted a research ethics test. The research design has been reviewed and approved by the research ethics committee of the Faculty of Nursing, Universitas Indonesia, with a certificate of passing ethics number Ket-217 / UN2. F12. D1.2.1/PPM.00.02/2021. Data was collected after obtaining an ethics pass letter from the research ethics committee. The researcher gave informed consent to prospective participants, namely explaining the objectives, benefits, and methods of the research and allowing participants to decide whether to be involved in the research voluntarily and without coercion. Participant consent to engage in the study is expressed online using the Google form application. The researcher guarantees the confidentiality of participant data by applying anonymity, namely using pseudonyms in presenting the research results. The researcher seeks to avoid losses by agreeing on a time for the interview according to the participant's free time to not interfere with the participant's activities and comfort. The researcher also applies the principle of justice by giving the same reward to each participant as an appreciation for the participant's willingness to be involved in the research.

Rigor Credibility is an important aspect in the validity of qualitative research data. Credibility is a belief in the value of the truth of the data and the interpretation of research results (Polit & Beck, 2014). To ensure the validity of the data, the researcher conducted a peer audit with

members of the research team to identify the accuracy of the theme resulting from the interview results. The researcher also conducted validation in the form of member checking for all participants involved in the research. Participants validated the resulting theme according to the participants' experiences in caring for HIV-exposed children under five. The researcher also described the participants' characteristics according to the variations found so that the study results could be applied to individuals or groups with similar characteristics or backgrounds.

RESULTS

This study obtained ten participants: seven biological mothers, two children's relatives, and one foster parent. There were seven children with negative HIV and five children with HIV positive. Two caregivers in this study cared for more than one child exposed to HIV, namely one child with HIV-negative and one child with HIV-positive. The study found different emotional experiences among caregivers of HIV-exposed children. The theme summarizes these differences: easy versus complex, grace and entrustment, love and pity. Participant characteristics can be seen in Table 1.

Table 1.
Participant Characteristics

Name	Age	Gender	Relationship with children	Status HIV	Children's HIV Status
Rose	36	Woman	Mother	Positive	Negative
Jasmine	34	Woman	Mother	Positive	Negative
Tulip	42	Woman	Mother	Positive	Negative
Rafflesia	34	Woman	Mother	Positive	Positive (1) and negative (1)
Orchid	32	Woman	Mother	Positive	Negative
Edelweiss	39	Man	Foster father	Unknown	Positive
Lilly	38	Woman	Will	Negative	Positive
Daisy	32	Woman	Mother	Positive	Positive (1) and negative (1)
Amaryllis	32	Woman	Many	Negative	Negative
Lavender	23	Woman	Mother	Positive	Negative

Easy versus complex

Five participants revealed they found it easy to care for their children. Children can grow and develop like any other child. Participants who revealed this were mother participants who cared for HIV-exposed children without being infected with HIV. Some of the participants' expressions are as follows:

"*Alhamdulillah, from the time my child was born until now, my child has never experienced sickness that is so severe; maybe if a cold cough is a normal thing, when she has a fever, there may be abilities such as she wants to grow teeth, wants to be able to walk. Alhamdulillah, until now, there have been no obstacles*." (Jasmine)

"*Alhamdulillah, my child never gets sick... Yesterday, she was immunized with the diphtheria pertussis tetanus vaccine; she got warm, it was warm because of the injection, but the next day, she was okay*." (Tulip)

Participants Tulip and Jasmine revealed that they found it easy to take care of their children because children rarely get sick. When there are complaints of pain, it is only a mild pain and does not last long. Children grow and develop well like other children who are not exposed to HIV. Meanwhile, a different thing was felt by participants who cared for HIV-infected children who were infected with HIV. Some participants experienced difficult or complex conditions in caring for children under the age of five, and the child's HIV status was not

known. Some of the participants' expressions are as follows:
"*Oh, it is hard to express. From 6 months onwards, since eating, given the porridge, then starting to cough, the cough does not go away continuously. Yes, it is the cough that is frequent; the cough is the point. My child recovered for two weeks and then got sick again, like that. My child got well for three weeks, then got sick again; he did not want to eat anymore, that is it."* (Rafflesia).

"*When he was ten months old, he began to look wilted and tangled. ... That is why his body is getting smaller. From the weight at that time of five kilos, just four kilos, she can go down and down until one year, which weighs only three points and four."* (Edelweiss)
"I do not understand A; suddenly, A is getting thinner and thinner. She got diarrhea. I was thinking, why did the child defecate frequently; why did the defecation continue like this? I see that. When I took the child to Budi Asih hospital, she weighed only four kilos, four kilos at the age of more than a year, and her eyes were like this: she had looked up ... she was unconscious, she was pinched but did not give a response. However, A could pass the critical period at that time. At that time, she was severely dehydrated, malnourished too; there was also HIV." (Lily)
"*From a young age, the first child, ... from the age of six months, his ears are leaking fluid. We took him to the ENT, the doctor said: it turned out to be a hole, whether it was affected by HIV or not, I do not know."* (Daisy)
"*At least twice a month. At most, three times, sometimes every week he gets sick*." (Amaryllis)

Five participants who treated children with HIV revealed that the children were often sick, had recurrent sickness, and had difficulty recovering. The longer they are sick, the worse their condition. Two children in this study were in critical condition and threatened with death, but the children managed to survive through the critical period.

Grace and entrustment
Seven participants who are biological parents of children generally reveal that the children they are cared for are a grace in the family. One of the expressions related to the theme of the award is as follows:
"When I was positive for pregnancy, I immediately consulted with the specialist whom I had planned to get pregnant. My doctor asked for a booster, and I asked for help once; whether it was a boy or a girl baby, I accepted. Alhamdulillah, his father M does not have a daughter; he loves baby girl, and his fortune is the last." (Tulip)
Caregivers feel that the child being cared for is a grace to the caregiver of the mother and her husband. She believes that children are a necessary thing in a marriage. The presence of a child brings happiness to the mother and family, especially when the gender of the child is to the expectations of the mother and spouse.

Some participants, Edelweiss, Lily, and Amaryllis, felt that caring for the child was an entrustment. The following is the expression of the caregiver that the child being cared for is a trust:
"*Yes, I took that this is entrusted to me; I have to take care of it as much as possible, whatever I am, what will happen later*." (Edelweiss)
"*Hopefully, A will be healthier, and later, when his father comes home, my thoughts are that if his father comes home, if his father takes it, yes, please, because it is my limit, I am just watching. It is the right of parents."* (Lilly)
"*Yes, she is also one of my mother's trustees. The late Mama said R should not be wasted if Mama is no longer there. Keep taking care of R; that is it. Yes, I remember that; it made me*

care for R." (Amaryllis).
Participants Edelweiss, Lilly, and Amaryllis, who are not the child's biological parents, revealed that they feel that the child they are caring for is an entrustment that must be kept. Participants felt that they did not have full rights to their children. They are ready if one day the child will be taken by the child's parents, relatives, or extended family. Children who were cared for by not the biological mother in this study were cared for by relatives and foster parents because some of the child's parents had died, and some were in terminal condition. Others had no news about the condition or whereabouts of their parents.

Love and pity
Almost all of the mother's participants conveyed expressions that described her affection for the cared child. Some of the participants' expressions related to affection are as follows:
"*It is a pity I cannot breastfeed my child. However, I returned and said I wanted to save my child. I do not want to decide for it (-breastfeeding-) because I want my child to be healthy*." (Rose)
"*Yes, actually, the doctor already knows, with my condition, that the CD4 is good, the viral load is good; I was told to take it (-breastfeed-); it is just that I do not want to take the risk. Let the risk be for me; let my child get formula milk. (-if I breastfeed-), my child should take ARV drugs; I do not want it; it is enough for me to take the medicine."* (Tulip)
"*Encouraged by the doctor, do not stop taking medication; that is the point. I follow the doctor's advice for the sake of my child who is conceived. Yes, it is finally until now; Alhamdulillah, my son is negative*." (Lavender)

The expressions of the participants above describe the affection of the caregiver shown by the caregiver making efforts so that the child does not contract HIV. Caregivers do not want their children to suffer from the same diseases suffered by caregivers (parents) and do not want their children to have to take ARV drugs. Because of this desire, the mother's caregiver in this study takes medication regularly and does not breastfeed the baby.

It is somewhat different from the affection expressed by participants other than parents who care for children with HIV positive. There is a feeling of pity in the participants' expressions as follows:
"*she rebelled when given medicine. Sometimes I am sad too. How do you have to do it (-taking the medicine-), forever, the term is a lifetime of using the drug."* (Edelweiss)
"If you feel heavy, it is just a pity for this child. Why the child is different from others, he is just sick. I said, my children do not have anything (-any health problems-) like this. I wonder if it may be because my nephew got formula milk (not breast milk). I do not know. Yes, as soon as I found out (positive for HIV), I was more sorry. The baby bears the sin of his parents. There is no intention of this; after I know his illness, I even pity." (Amaryllis)
Edelweiss, the participant who cared for HIV-infected children felt sad because he had to give medication. Sometimes the child refuses when given medication. Edelweiss also felt pity because the child had to take medicine forever. Other participants (Amaryllis) felt pity because the child's health condition was different from other children's. After learning about the child's HIV status, Amaryllis felt pity because the child seemed to bear the sins of the parents.

DISCUSSION
Easy versus complex
The results of this study found that caregivers felt easy to care for toddlers exposed to HIV. This experience was expressed by caregivers who care for HIV-exposed toddlers who are not

infected with HIV. Caregivers revealed that children in care rarely get sick, grow, and develop with age, like other children who are not exposed to HIV. The results of this study provide a different picture from previous studies that found that HIV-exposed children who are not infected with HIV are not only more likely to be born prematurely and have a small pregnancy but also tend to have poorer growth and development compared to children who are not exposed to HIV (Evans, Jones, & Prendergast, 2016). In addition, another study found that HIV-exposed children born to mothers who received optimal treatment had similar growth characteristics and immune profiles compared to children who were not exposed and not infected with HIV. HIV-exposed children who are not infected with HIV may reduce the risk of malaria and respiratory disease, which may have a secondary effect of prophylactic cotrimoxazole (Ray et al., 2024) . The progress may influence the difference in the results of the previous studies in the treatment program of children exposed to HIV, such as the administration of prophylactic ARVs, prophylaxis of opportunistic infections, immunization, and nutrition (Muhammad & Binuko, 2022). However, in this study, the picture of children's growth and development was only obtained based on the caregiver's perception, which needs further study with an objective examination to ensure the child's condition.

A different experience is felt by caregivers who care for HIV-infected toddlers. Caregivers revealed that they often face difficult or complex situations when caring for HIV-infected toddlers. In this study, there were 5 out of 12 children who were diagnosed positive for HIV. It is a difficult experience for caregivers when the child's HIV status is not known. Children are often sick, treated, healed for a while, then recurred from the pain. Children are often taken in and out of the hospital. In this study, two children had experienced critical conditions and were threatened with death due to very poor health conditions. Some of the symptoms of the disease expressed by caregivers are cough (pneumonia), diarrhea, white patches in the mouth (oral candidiasis), ear problems (otitis media), tuberculosis, and difficulty gaining weight (malnutrition). Five caregivers revealed that the child showed growth and decreased condition at the age of 6 months and above or under the age of one year. Research by Andini, Kurniati, and Tamin (2015), found that most children are diagnosed with HIV at the age of over 18 months. The description of the symptoms of the child's disease revealed by the caregiver is in line with the results of a study on 191 children at Yogyakarta Hospital, Central Java, Indonesia, where the nutritional status of HIV pediatric patients at the beginning of diagnosis was dominated by underweight and stunted. The most common clinical picture of diseases when children are diagnosed early is lymphadenopathy, oral thrush, pneumonia, and persistent or chronic diarrhea (Indrawanti, Arguni, Laksanawati, Puspitasari, & Husada, 2021).

After undergoing treatment in the hospital and knowing the child's HIV status, then the child's condition slowly improved and stabilized after receiving ARV therapy. Caregivers should not stop giving ARV therapy to children, so they need to regularly visit clinics or hospitals to get medication and monitor the health status of children. One of the children in the study also experienced developmental delays, so caregivers need to take the child regularly to health services, participating in a physiotherapy program in the medical rehabilitation unit. This illustrates the complex experiences experienced by caregivers, especially those caring for children infected with HIV when the child is less than five years old. About the complex experiences experienced by caregivers, one study on psychosocial challenges in caregivers of children with HIV found that parenting is affected by inadequate financial resources and single-headed households where most grandparents act as primary caregivers for children with HIV. HIV remains a stigmatizing disease that weakens support networks, as well as timely and free access to health care. This has a negative impact on the mental health of

caregivers, with the majority of women in the study showing symptoms of depression (Lentoor, 2017). Another study related to the psychosocial challenges experienced by caregivers was also found in a different case, namely caregivers caring for stroke patients. The complexity of the challenges faced by caregivers caring for stroke patients includes psychological impacts such as anxiety, depression, and workload, as well as related factors that affect caregiver well-being (Upami, Handayani, & Johan, 2024).

Grace and entrustment

The presence of children in the family is generally felt as a gift for married couples. This is generally experienced by new couples or couples who have long missed the presence of children in their home life. Some of the children exposed to HIV in this study are children of new couples, where the couple wants a baby born from a new relationship. The five caregivers in this study were HIV-positive mothers who contracted HIV from their husbands, and their husbands had died. A study by Hasanah and Sulistiadi (2019) on HIV/AIDS infection among housewives in Asia found that The most important risk factors for HIV/AIDS transmission in housewives are caused by the poor sexual behavior of a husband and the lack of knowledge of the wife about HIV/AIDS.

The mother who survived after being diagnosed with HIV, then married a new partner. One of the values embraced by the people in Indonesia is that if you are married, you should then have children from marriage. This value makes couples feel less complete in their family if they do not have children from marriage with a new partner, even though they have children from the previous partner. For a mother, having a child increases self-esteem because she can play the role of a mother, and for some families, the presence of a child can affect satisfaction and happiness. Hairunisa (2021) in her research obtained the influence of the presence of children and the number of children depends on the socioeconomic conditions of the spouse or parent. Sometimes there had been many children can increase welfare, satisfaction, and happiness for parents if the socioeconomic conditions are good. The large number of children greatly affects the conditions of satisfaction, happiness, and well-being for women compared to men. The number of children and the presence of children for parents are also influenced by religious aspects, where there are some beliefs as well as religions that are pronate or support birth.

A different experience is felt by caregivers who are not biological mothers of HIV-exposed children. The caregiver feels that the child he is caring for is a trust. Caregivers who are relatives and foster parents of children, reveal that they do not have full rights to the child, only take good care of them, then the caregiver declares that he is ready if one day the parents/extended family will take over the care of the child. The care provided seems to be temporary. In this regard, Diaz (2017) explained that it is understood that being a foster parent to one child is a temporary arrangement. The ultimate goal is permanent placement with the biological family. Foster families struggle with uncertainties surrounding the unknowns of how long a foster child will be with them. Participants in the previous study reported that they were motivated to continue fostering by a sense of religious mission and also noted that their faith gave them support throughout their foster experience (Diaz, 2017). The caregivers in this study also believe that the children they care for are entrusted by God, so they need to be cared for properly.

Love and pity

Affection is a feeling that generally exists between parents to their children. Affection can arise by itself, especially if the child being cared for is the baby whose presence is expected.

The existence of feelings of affection is a motivator for parents to take whatever action the child needs, and that can protect the child from danger. The expression of affection is drawn from the caregiver, who is the child's biological mother. Seven mothers revealed that they did not want their children to contract HIV, did not want their children to take ARVs, and did not want their children to be ostracized by others because of HIV. So, the mother's caregiver decided not to breastfeed, even though there was a feeling of sadness because of it. This result is in line with previous studies that found that mothers' caregivers are worried about the transmission of the virus from mother to child; mothers do not want their children to suffer from the same disease as mothers, so mothers give breast milk substitutes to their babies (Hayati, Nurhaeni, Wanda, & Nuraidah, 2023).

Caregivers other than mothers in this study have compassion for the children being cared for. The feelings of compassion expressed by the three caregivers were related to the child often suffering from recurrent illnesses, the child having to take medication regularly for life, and the child did not receive adequate care from his biological parents. Three children exposed to HIV in this study were not cared for by their biological parents because one of the child's biological mothers was seriously ill related to AIDS, one of the child's biological mothers had died, and the other child was not known to the news and whereabouts of their parents. The difficult conditions experienced by children arouse sympathy from caregivers. In this regard, Rushton and Ballard (2011) found that caring for seriously ill and dying children demands empathy, sympathy, and compassion, three closely related responses. Empathy, the ability to feel and relate to the suffering of the other, invites mutual vulnerability and connection. Schulz et al. (2007) explain that caregivers' perception or knowledge of the patient's suffering generates varying degrees of compassion. Feelings of love and concern for the patient, distress, and strong motivation to reduce patient suffering characterize a high level of compassion.

One of the caregivers in this study felt compassion for the child because he thought that the child seemed to bear the sin due to the bad deeds that his parents might have committed. Caregivers' perceptions illustrate the stigma that exists in society against individuals with HIV. Stigma originates in the mind of an individual or society, believing that AIDS is the result of immoral behavior that is unacceptable to society. Many people think that people infected with HIV/AIDS deserve punishment for their actions (Nasution & Ritonga, 2022). Other study presents the perspective and view of healthcare providers that HIV stigma and discrimination against people living with HIV/AIDS (PLWHA) still occur in families, communities, and healthcare environments. This is reflected in negative labelling, separation of personal belongings, avoidance, refusal of treatment and rejection of PLWHA by healthcare providers, families and community members. Some healthcare providers report that they have personally stigmatized and discriminated against PLWHA. Lack of knowledge about HIV, fear of contracting HIV, personal values, religious thoughts and sociocultural values and norms are reported as the driving force or facilitators behind this HIV-related stigma and discrimination (Fauk, Ward, Hawke, & Mwanri, 2021). The result of this study describes the experience of caregivers in Indonesia, where the results obtained are influenced by the characteristics and values, beliefs, and culture embraced by caregivers. The existence of stigma and discrimination in society is a challenge for caregivers in caring for children exposed to HIV.

Strength and limitations

This study has succeeded in revealing the experience of caregivers caring for HIV-exposed children, both HIV-positive and HIV-negative. The results of the study also describe the

condition of the child in care, although only based on the perception and observation results of the caregiver. This result is the basis for the need for further studies to ensure the health status of children objectively. The experiences and feelings of the participants revealed in the study are greatly influenced by the beliefs and socio-cultural conditions of the Indonesian people, which needs to be further reviewed for its application in regions with different socio-cultural conditions.

CONCLUSION

The results of the study showed that there were differences in the emotional experiences of caregivers of toddlers exposed to HIV, namely easy versus complex, grace and entrustment, and love and pity. Differences in caregiver experience are influenced by the child's HIV status, which affects the child's health condition and the care that needs to be provided. The results of this study are beneficial information that needs to be known by health professionals involved in HIV services to be able to provide services with the appropriate approach to the values, beliefs, and socio-cultural conditions of caregivers.

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