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Surviving Overwhelming Challenges: Family Caregivers' Lived Experience of Caring for a Child Diagnosed with HIV and Enrolled in Antiretroviral Treatment in Ethiopia

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Key words: Child, HIV, antiretroviral treatment, family caregivers, experience, Ethiopia.

Abstract

Background: Family caregivers play a critical role in caring for children living with HIV; however there is little knowledge about their experiences. The aim of this study was to illuminate the family caregivers' lived experiences of caring for a child when he or she has been diagnosed with HIV and enrolled to antiretroviral treatment.

Method and design: Qualitative interviews with 21 family caregivers of 21 children diagnosed with HIV were analysed using an inductive design with a hermeneutic phenomenological approach.

Results: The caregivers' experience were articulated in five subthemes under the main theme of "Surviving overwhelming challenges": "*Committed care-giving*", "*Breaking the family life*", "*Caring burdens*", "*Confronting conflicts*", and "*Living with worry*". Despite the difficult situation the family caregivers experienced with extensive worry, caring burdens and disrupted family and social networks, they were committed caregivers. They were empowered by their belief in God but also by their strong belief in the child's treatment and support from healthcare workers.

Conclusion: The healthcare system needs to consider possible ways to support the family caregivers during child's HIV diagnosis and treatment initiation as part of a continuum of care.

Surviving overwhelming challenges - Family caregivers' lived experience of caring for a child diagnosed with HIV in Ethiopia

Human immunodeficiency virus (HIV) continues to be a major developmental challenge and cause of death worldwide, particularly in low- income countries. Globally, 35 million people are estimated to live with HIV by the end of 2013, with estimated 24.7 million of these being in Sub-Saharan Africa. Ethiopia belongs to the top ten countries in terms of the total number of people living with HIV/AIDS. About 3.2 million of the global totals are children under 15 years of age, and of which about 2.9 million are estimated to live in Sub-Saharan Africa (UNAIDS, 2014). In Ethiopia, about 200, 000 children live with HIV in 2013 of which only 9.5% received anti-retroviral therapy (ART) (Federal HIV/AIDS Prevention and Control Office [FHAPCO], 2014). This means a significant proportion of HIV infected children remain at risk of death or of disease progression. Since ART is a lifelong therapy its effectiveness requires support from a multidisciplinary team of professionals as well as family caregivers.

In addition to the child's disease-stricken state and risk of mortality, HIV poses considerable challenges to the family caregivers (Antle et al., 2001; Potterton, 2007). A family caregiver can be defined as anyone who is an unpaid family member, a parent, sibling extended family member or recognized guardian involved in providing any type of physical and/or emotional care for an ill or disabled individual at home (Family Care Giver Alliance [FCA], 2012). Some of the observed challenges include the caregivers' need of spending more time with the child in their daily routine, as well as accompanying the child to the ART clinic (Mathambo & Gibbs, 2009). This means that the caregivers are more frequently absent from their work place and in most cases take leave without pay. Eventually, there is a risk for the caregivers to be out of work. The burden of caring for a child diagnosed with HIV is

found to be higher for already poor families as related to social, economic and health consequences (Mathambo & Gibbs, 2009).

Several concerns for the caregivers include feelings of helplessness, guilt and their poor socio-economic status even if their stress decreases when the child's health improves due to their treatment (Antle et al., 2001; Potterton, 2007; Bejane, 2013). Another important fact which exacerbates the level of stress for the child's biological parents is, in the majority of cases, the biological parents also are diagnosed with HIV and are dealing with their own treatment. Furthermore, widely distributed stigma and discrimination in the community contributes to frustrations in the family (Hamra et al., 2005; Surkan, 2010; Charles & Washington, 2013) and may lead to psychosocial catastrophes (Surkan, 2010).

Therefore, unlike other childhood chronic diseases, caring for a child with HIV increases the level of stress for the entire family due to the aforementioned reasons (Potterton, 2007). There is limited knowledge in the area of family caregivers experiences of caring for a child with long-term illness and especially for caring a child diagnosed with HIV during their lifelong treatment (Cooper, 2006; Parker et al., 2006). The experience of family caregivers dealing with the care of a HIV infected child is not studied at all in Ethiopia. Our aim was therefore to illuminate the family caregivers' lived experiences of caring for a child when a child was diagnosed with HIV and enrolled to antiretroviral treatment.

Methods

Study design

An inductive qualitative design with a hermeneutic phenomenological approach was used. As part of a longitudinal study the experiences of 21 family caregivers to 21 children diagnosed with HIV and enrolled to ART treatment was explored through semi-structured qualitative interviews. All of the children were HIV positive based on our inclusion criteria but it is not

our criteria for family caregivers to be HIV positive. Purposive sampling was used to select the participants from the list of family caregivers enrolled in the longitudinal study.

The philosophy of hermeneutic phenomenology according to van Manen (1997) was applied. Hermeneutic phenomenology is rooted in philosophy, and attempts to gain insightful descriptions of the way the world is experienced pre-reflectively (van Manen, 1997). It seeks to go beyond descriptions in order to discover meanings that are not immediately apparent (Merleau-Ponty, 1996; van Manen, 1997; Kafle, 2011). According to van Manen (1997) a person's life world covers four existential dimensions; *lived body*, *lived time*, *lived space* and *lived human relations*. These existentials can be used as guidelines in life world research.

Study setting

The study was conducted in seven health facilities in both the Addis Ababa and Oromia regions of Ethiopia between January and September 2014. The health facilities were selected due to their high load of adult and paediatric patients enrolled in HIV treatment and follow ups. The total population of Addis Ababa is 3 million, accounting for 3.7% of the country's population, whereas Oromia has a total population of 27 million, accounting for 35 % of Ethiopia's population (Central Statistical Agency [CSA], 2007). In Oromia a total of 283 health facilities have ART clinics, and Addis Ababa has 58 health facilities (FHAPCO, 2012).

Most of the hospitals in Addis Ababa serve patients coming with referral slips from all over the country. The selected health facilities in Oromia also serve a high load of adult and paediatric patients coming from urban and rural peripheries.

Participants and procedure

A total of 21 family caregivers to 21 children consecutively enrolled to ART and who also got an appointment to start ART at one of the seven health facilities were purposively selected (Shenton, 2004) and approached through the ART focal person of the health facility. The inclusion criteria were: a family caregiver or responsible guardian older than 18 years to a

child between the age of three weeks and 14 years enrolled in ART during the last four weeks. Biographic data of the family caregivers are presented in Table 1.

Table 1. Biographic data of family care givers (n=21)

Characteristics	
Age caregivers	
Range (years)	19-75
Average age (years)	36
Biological mother (n)	13
Biological father (n)	4
Uncle (n)	1
Grand mother (n)	1
Other relatives (n)	2

All of the 17 biological parents were HIV positive. The age range of their enrolled child was three months to 14 years with a mean age of eight years.

Data collection

During the child's enrolment to treatment, the caregiver was informed about the study and that it included a conversational interview focusing on their experiences of caring for a child with HIV. Furthermore, that the interview was to be performed at earliest 15 days or more after the child was enrolled to treatment. Dates and places for the interviews were scheduled by the ART provider based on the participants' wishes during the child's treatment enrolment and follow up visits.

The first author conducted conversational semi-structured individual interviews (van Manen, 1997) using Amharic language with each family care taker. Two pilot interviews were performed to evaluate the flow of the interview, identify sensitive areas and to get further emerging ideas and direction. Accordingly, some questions based on the new insights were

added and the flow of the questions was slightly changed. The pilot interviews were not integrated in the analysis due to the modifications done. Before starting the interview, the interviewer spent some time chatting with the family caregiver in order to establish a good atmosphere. The caregivers were then asked to narrate, in their own words, their experiences of caring for a child living with HIV. The initial question was: Can we discuss what it means for you to care for a child living with HIV? Follow up questions such as; "Can you explain further?" and "Can you tell more about it?" were then posed.

All participants were interviewed in a private room at the ART clinic of the health facility to ensure confidentiality. The interviews lasted between 30 and 60 minutes with an average time of 40 minutes. The interviews were audio tape recorded unless the participant was not willing to be recorded. Two participants declined to be recorded and notes were taken manually by the interviewer. Furthermore, field notes in terms of emotions, silence, etc. were taken to complement the other information gained by the interviewer.

Data analysis

All interviews were first transcribed in the local language and then translated to English by the first author in collaboration with the third author (MM), who has extensive experience in qualitative research. Both authors are native Amharic speakers and fluent to speak English which prevented the risk of distortion in meaning. Each transcribed interview was read line by line by the four authors to come up with an overall picture of the interviews. Then the first author looked at every single sentence, asking what it revealed about the caretakers lived experience and key phrases from these were highlighted. Significant statements were organized and interpreted, based on their similarities and differences by all four authors. Preliminary sub themes and overall theme emerged during this organization, even before the writing process started (van Manen, 1997). Field notes were used to synergize information to

describe and reflect upon the participants' situation in combination with the transcripts. During the writing process there was a continuous back and forth process between the emerging themes and the individual transcribed interviews to ensure that the caregiver's lived experience was deeply embedded in the text (van Manen, 1997). The family caregivers lived experience was brought to light after a process of writing/ rewriting and discussions/reflections among the authors until agreement were reached.

Quotes from the interviews are used to elucidate the caregivers' lived experience. The letter and code number after the quotes are references to the participants; Mother (M), Father (F), and other relative (OR).

Pre-understanding

The authors all came into the study with a different pre-understanding, which was useful during the analysis. A special caution was taken in order not to reflect prematurely (van Manen, 1997; RYAN, 2011). The first author (MB) has a professional background of clinical nursing in the area of HIV/AIDS prevention, treatment care and support programs from both local and national levels in Ethiopia for over more than thirteen years. PL is a paediatric nurse with experience of family-focused care and is experienced in the use of the hermeneutic phenomenological method. MM is experienced in both qualitative research and HIV and human health development research. DJ is a medical doctor with extensive experience in clinical care and research with people living with HIV. IH is a professor in paediatric nursing with an extensive experience in involving children with long-term illness and their families in qualitative research. The authors' collective pre-understanding was discussed and reflected on before and during the data collection and analyses.

Ethical consideration

Formal ethical approval was obtained from the Swedish Regional Ethics Board (Ref. no. 2013/85) as well as from the Institutional Review Board of Addis Ababa University, two Regional Health Bureaus, and the National Research Ethical Review Committee in Ethiopia. The study strictly followed the international principles of research ethics outlined in the Declaration of Helsinki (World Medical Association [WMA], 2013) Written consent was obtained from all family caregivers. For those who could not read and write, the consent statement was read to the participant and their consent was given by their fingerprint. In addition, the ART clinic focal person was asked to put his/her signature as an impartial witness. Confidentiality was assured and explanation of the purpose and possible benefits and disadvantages of the study were provided to the participants, as well as the fact that they could withdraw from the study at any time without affecting the child's treatment.

Results

The essential theme of the caregivers' lived experience was described as "Surviving overwhelming challenges". Five subthemes were identified: "Committed care-giving", "Breaking the family life", "Caring burdens", "Confronting conflicts", and "Living with worry". Despite the difficult situation the family caregivers experienced, with extensive worry, caring burdens and disrupted family and social networks, they were committed caregivers. They were empowered by their belief in God but also by their strong belief in the child's treatment and support from healthcare workers.

Committed care-giving

Besides the multiple devastating challenges during the guardians' childcare process, it was important for the caregivers to provide the best support to their child. The love and concern

they felt for their child made their self-worth to be closely tied to their child's survival. The caregivers' commitment was linked not only to the child's physically mental care and to keep the child's treatment according to the prescription they were also committed in their daily life, living and sharing their experiences together.

"...I allocate significant amount of my time to follow his health conditions in a regular basis. I use alarms to ensure 100 % treatment adherence... my major attention will be on my HIV and my son and I believe that I have to live for the sake of him" (2001 F).

The family caregivers experienced a mental strength in their strong belief in God but also due to the benefits of the treatment. Having such belief empowered them to be committed to both the regular care for their child and also of their own care. They experienced that their commitment as well as their clear communication with the child helped the child to be empowered and able to take own responsibility for their medication.

"...After that day he is very careful for his treatment and takes carefully by himself with little support. I feel quite relieved now" (3007 M).

The caregivers themselves were empowered from the counselling and support by the health-workers in the health facility which strengthened them in their commitment to the child's care. They thought that they were able to cope over time and hoped for a future in which the treatment would help cure the child. This helped them also to believe in the child's future.

"I hope some time in the future she may be able to live her own life. At the time she was diagnosed with HIV, I thought she would die immediately. Through time, my thought has changed—thanks to the professionals' counselling" (2003 M).

Breaking the family life

When the child was diagnosed with HIV, the caregivers experienced that they faced a disaster; their entire family life became desperate and broken. At the same time they started to recognize restrictions in their family's daily life. They found themselves separated both physically and mentally from the rest of the community because of their fear of being stigmatized and discriminated against. The caregivers to children who had lost one or both parents to HIV felt that the disease was breaking apart their family life.

"Very bad feeling I had, I desperately cried when doctors told me that he is HIV positive. Doctors were even angry with me saying "are you trying to kill the child by stress"? ...I was totally out of my mind" (5001 OR).

The caregivers experienced that they were facing something evil attacking their family which exacerbated their frustration. For some female caregivers, the child's diagnosis ended with emotional and frustrating separations from their husbands, as he was the one who had concealed that he was HIV positive. Others felt helpless and depressed as they had been using prophylactics but got HIV nevertheless.

"... I previously had lost another child because I didn't know treatment was possible. I know several mothers including a friend of mine having healthy kids after having had proper prophylactics....but why is it different for me and my kid"? (3003 M).

When the caregivers were informed about the child's lifelong ART, the entire family life perspective was changed. They found their previous normal family life shifted towards a total focus on the sick child.

"Before we knew about his status we were not much worried about caring for him...but after we know about his status our attention and care is very serious and totally diverted towards him... With our capacity we ask him and try to fulfil everything he needs" (5001 OR).

Caring burdens

The caregivers experienced a strain when they were facing their child's many needs. They were well aware that the child's future health and survival was dependent on the HIV treatment, but they still found it difficult to manage. The family caregivers experienced their daily life to be overburdened and tied with the child's situation, regardless of whether they were at home or out of their home. They preferred to be close to their child all the time to guarantee the best care for the child.

"...Everything related to the child's treatment is very difficult. Worry about not to skip the time even the minutes of treatment has to be taken and which is great burden for me and my husband to think about it in our day to day life in addition to other conditions to be fulfilled to the family" (8007M).

The caregivers were aware of the HIV-related opportunistic diseases and were afraid that their child would fall ill from such diseases. The fear affected the family caregivers both physically and mentally as the situation demanded them to be nearby and observe the child closely. The situation became even worse when the child was critically ill and unable to eat.

"In the beginning before the treatment was initiated, my child was getting sick very frequently and sometimes to the extent of having difficulty breathing at night. I used to sit beside my child and cry the whole night" (8004 M).

Confronting conflicts

When the family caregivers were biological parents, their self-blame behaviour was quite frequent. Parents, especially mothers, felt as if they were criminals and that they themselves were the reason for the HIV transmission to the child. Fathers blamed themselves for being responsible for the HIV transmission to their partner. These experiences made the parents' world to be exacerbated, panicked and eventually they condemned themselves. They were

aware of that their decision of not having treatment themselves was wrong and it brought them to experience endless self-blame and existential questions.

“...If I were tested for HIV before marrying the second wife she would have been had better life expectancy. It is always in my mind and accepted that I am the one to be accused for her untimely death as well as this little child to be infected by HIV” (3001 F)

Reluctant feelings regarding their child's symptoms and seeking care rather late in the process made them blame themselves even more. Therefore the parents became sad because they thought that if their child had been taking treatment earlier it would have resulted in better health conditions for them.

“ ... I didn't allow my daughter to be tested but knew her status since I knew my status 7 years back. I feel sorrow and I think it was cruel of me because for the last 7 years my child has suffered from HIV without knowing her status” (5002 M).

Family caregivers felt embarrassed and blamed themselves for their past lack of knowledge surrounding HIV and its implications. The fear of losing their child was hard to withstand.

“Because of our ignorance we lost his mother (she died from HIV). She wouldn't have died if we were aware of her HIV status at the time. I was shocked when I thought that we were at the verge of losing this kid as well” (1002 OR).

After the child's treatment was begun, the child became curious about the treatment and wanted to know what the treatment was for, including how long it was supposed to take. This condition resulted in family caregivers' conflicts and confusion and they quite simply did not know what they would say to answer the child's tough question. Most of the caregivers believed that disclosure should happen when the child was mature, which was proposed to be at least at 12 years old or above. Due to the questions being raised by the child, some caregivers decided to disclose the child's status at an earlier age. They experienced that their

child was committed to their own treatment and that this resulted in fewer conflicts and less confusion.

“I fear that he may tell to his friends about his status and he may end up discriminated. On the other hand he is questioning the treatment he takes. He sometimes says “why do I take this treatment. I am not sick after all” (1003 OR.).

Living with worry

When healthcare workers told the caregivers that the child had to be on treatment, life became ambiguous and like a nightmare. It was difficult for the family caregivers to accept that their child had to start and continue a lifetime's worth of treatment. It made them feel that anything could happen to their child at any time.

“I was wondering like how someone can afford to take treatment from the childhood to the whole life time. I thought it is very tough to see my kid suffering the whole life” (2003 M).

The worry for their child's situation made the caregivers lose hope not only for their child but also for themselves. Most of the family caregivers preferred their child to receive treatment in a location far from their living environment. They did not want the child's status and treatment to be exposed to the neighbours or the child's friends. They felt if the child's friends knew about the illness, that they may disclose it, which would end up with bad implications for the child's mental wellbeing and future life.

“...The health service providers in the facility asked me where I would like my child to be referred for further treatment and follow up. I asked them to refer him to a facility that is a bit far from the village I am living—as I wanted to keep my child's status confidential” (2001 F).

Caregivers were worried that not only that their child's HIV status would be revealed to the child, but also to other members in the family, the village or the school. Worries especially arose in communities where people lived close together and were used to sharing their activities in their everyday life. Although it is very important for the family caregivers and

child to have good relationship and social network with the community where they live, caregivers already experienced society the beginnings of stigma and discrimination due to their own HIV status as well as their child's HIV status. If these facts were came to be revealed caused them much worry.

"I practically faced discrimination by my neighbours. My children were restricted not to be with other children to play together due to myself and my two children's HIV status have revealed. At a moment my daughter asked me why our friends saying that as if we are from HIV positive family and cannot be with them" (6003M).

Discussion

The overall lived experiences of the family caregivers of children newly diagnosed with HIV and starting ART was described as "surviving overwhelming challenges". The findings of the caregivers' experiences are reflected upon the four life world existential dimensions *lived body, lived time, lived space* and lived human relations (van Manen, 1997)

The *lived body* refers to that we are always physically present in our bodies while in the world (van Manen, 1997) and was illustrated by the emotions and physical burdens the family caregivers experienced when caring for their child with HIV as a life-time treatment. When the child was diagnosed with HIV, the family caregivers felt anxious and exhausted, and their worry increased. This affected their body and their health. They were crying, not sleeping well, and were unable to eat. This resulted in weight loss. Other studies have shown that the parents' stress increased and their physical and mental well-being worsened when they were caring for a child with HIV (Potterton, 2007; Bejane, 2013). This is also shown for parents when their child is diagnosed with other life threatening diagnoses such as cancer (Wong & Chan, 2006; Björk et al., 2009) or with treatment of a chronic disease e.g. diabetes (Wennick & Hallström, 2006; Jönsson et al., 2010;).

Family caregivers are shown to be physically and mentally overwhelmed in order to fulfil the comprehensive needs of their child with HIV (FHAPCO, 2007; Potterton, 2007; Punpanich et al., 2008) found that the stress of caregivers was related to their low socio-economic status. Increased physical burdens and additional economic needs are shown to exist for biological parents with children with long-term ailments due to the fact that their regular work activities are decreased or stopped when they need to take unpaid leave (Antle et al., 2001; Potterton, 2007; Rajaraman et al., 2008). Parents are also shown to neglect their own healthcare and their own needs (Nelms, 2005; Bejane, 2013).

Lived time refers to the subjective time as opposed to the objective time (van Manen, 1997) and was illuminated by the caregivers' feelings when their child was diagnosed with HIV. Parents felt as if their time stopped and seemed to end. After finding out that the child would need lifelong treatment, this was experienced as endless years of medication, struggle, as well as feelings of uncertainty and fear for the future. Understandably, this was overwhelming to them. Similar findings were spotted by Nelms (2005) who indicated that caregivers were uncertain about the child's future, the continuation of treatment and short and long-term effects of the treatment. However, as time went by, the family givers in the present study gained hope when they found that their child improved from recurrent infections and became healthier during the treatment period. Also Potterton (2007) and Björk (2008) indicated that when the child's health condition got better, the parents' level of stress lowered; they found hope and the whole family became empowered.

Lived human relation refers to the relations we share with others (van Manen, 1997) and was illuminated by the caregivers' relations with the child, other family members, the community and care professionals. After a child started life-long ART, the family caregivers experienced ambiguity in relation to others, including the sick child. Life patterns changed and boundaries were set up between the child with HIV and their siblings, even if siblings and

other family members were important for the child and the caregivers. The importance of a close and continuous contact with siblings and other family members when a child is diagnosed with a severe illness e.g. cancer is described earlier (Björk et al., 2005, 2009, 2011). For some mothers the child's status directly caused a break in their marriage, as the child's diagnosis made them realize that they themselves were HIV positive and that their husband had transmitted the disease to them. This resulted in an even worse position for the mothers as they found themselves to be not the only caregiver, but also the only one to give financial support to the family. This result is in line with Parikh (2007) which indicated that the husbands' extramarital sexual activities put their wives at risk of acquiring HIV as well as increased socio-economic burdens.

Family caregivers in the present study found themselves in conflicts when not revealing the child's diagnosis to the child, which caused tensions in their relations. This is also shown in other studies (e.g. Abebe & Teferra, 2012; Kyaddondo et al., 2013; Mengistu, 2013). Other researchers have emphasized that family caregivers should be empowered through detailed and continuous discussions to reveal the child's status and treatment in order to avoid confusion prior to a child's treatment initiation (Abebe & Teferra, 2012; Kyaddondo et al., 2013; Mumburi et al., 2014).

The caregivers experienced themselves to be empowered through the good relations with the healthcare providers. The healthcare providers' empathetic approach, advice, and support made them stronger and helped them to carry on. Also Potterton (2007) found that support from counsellors and social workers empowered caregivers.

Lived space van Manen (1997) refers to the "felt space" the family caregivers experienced in terms of frustration and stigmatization. When the child tested as HIV positive, the biological parents felt as if they were criminals. They felt panicked and condemned over the course of time. Other studies also indicate that biological parents experience high levels of

guilt when their child is found to be HIV positive (Bennetts et al., 1999; Kyaddondo et al., 2013). One unique condition of being a biological parent to child with HIV, is that the most common HIV transmission to the child is through mother (FHAPCO, 2007; WHO, 2013).

Caregivers were afraid of disclosing their child's diagnosis as they were afraid that the child would be discriminated against and excluded from society, especially at school. They chose to use care from health providers' located farther away so that neither they, nor their child's diagnosis would be revealed. They experienced that when other members in the society knew about the diagnosis, that they were stigmatized and discriminated against, which made their lives even harder to manage. Other studies have reported that family caregivers experience high levels of stigmatization and discrimination during their child's caring process for HIV (Orner, 2006). Stigma and discrimination is found to affect not only the sick child and the family psycho-socially but also it affects the process of healthcare service utilization at large (Surkan, 2010; Bejane, 2013; Washington, 2013).

In the present study, the caregivers were selected consecutively and differed in terms of gender, age and cultural, geographic and socio demographic factors. They all shared their experiences willingly and expressed their experience in a rich way. One of the limitations in this study is that the children's experiences were not illuminated. However, since the HIV status of children in Ethiopia seldom is disclosed (Brown et al., 2011; Mumburi et al., 2014), this was not possible. During the study we carefully avoided inadvertent disclosure of the child's status (Mumburi et al., 2014). Another limitation is that no other family members than the caregiver were interviewed. Earlier studies of children with long-term illness e.g. cancer (Björk et al., 2005, 2006, 2009, 2011) and diabetes (Wennick & Hallström, 2006, 2007, 2009) show that all family members' experiences are important. This would increase the understanding of the entire family's experience when caring for a child diagnosed with a long-term illness.

van Manen (1997) suggests that for a hermeneutic phenomenological study to be believable, the findings need to correspond with the reality. We conducted a pilot study to test the interview guide, to let the interviewer practice his interview skills, and to ensure that it was possible for the interviewee to be interviewed during a vulnerable and stressful time. All the family caregivers were approached by healthcare providers to receive information about the study. In order to create a comfortable atmosphere, a good relationship was built between participants and interviewer during informal chats that took place before the interview (Lincoln & Guba, 1985).

To ensure dependability, several researchers with different pre-understanding, competence and cultural background analysed the data in different steps. The findings were discussed at research seminars where senior and junior researchers gave feedback according to van Manens (1997) recommendations. To strengthen the conformability, the stages in the analysis process were clearly described and quotes were used to show that the findings were based on the informants' narrations (Lincoln & Guba, 1985; van Manen 1997). In order to affect the reader and to contribute to personal insights, the results are discussed according to the four life world existential dimensions - *lived body*, *lived time*, *lived human relations* and *lived space* (van Manen, 1997).

According to van Manen (1997) the only generalization that can be made from phenomenological studies is that they should never be generalized. However, regarding the transferability of the present study, it is likely that it may be transferable to other contexts with similar conditions (Krefting, 1991) due to the fact that the family caregivers' experiences were found to be very similar despite their age, sex and cultural differences. The results also may have a potential to develop further study hypotheses in the research area.

Conclusions

When a child is diagnosed with HIV in Ethiopia, caregivers find their situation intimidating and thus, their family life is destroyed in some sense. The unsecure future for the child and the risk of stigmatization fill the family caregivers' life with frustration and worry. Their relationship with healthcare workers' and the subsequent counselling empowered them and gave them hope for the future. The healthcare system in Ethiopia should continue the emphasis of empowering family caregivers through detailed and continuous family-centred discussions prior to the child's initial treatment. Intervention modalities and strategies need to be incorporated with the existing guidelines to support family caregivers during the child's HIV care. Also, the healthcare system may consider developing strategies for family-centred care (Smith et al., 2012) in planning and in practice to include the entire family in the care of the child with HIV (Shields, 2011). To reduce the experience of stigmatization in community and healthcare system, the society needs to find ways to support and empower affected individuals and family at large (Charles & Washington, 2013). Further studies are recommended to address family caregivers' needs at family, community and health facility levels.

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Declaration of Interest statement

The authors have no competing interests to declare.

References

- Abebe, W., & Teferra, S. (2012). "Disclosure of diagnosis by parents and caregivers to children infected with HIV: prevalence associated factors and perceived barriers in Addis Ababa, Ethiopia." *AIDS Care*24(9): 1097-1102.
- Antle, B. J., Wells, L. M., Goldie, R. S., DeMatteo, D., & King, S. M. (2001). "Challenges of parenting for families living with HIV/AIDS." *Soc Work*46(2): 159-169.
- Bejane, S. M. (2013). "PRIMARY CAREGIVERS' CHALLENGES RELATED TO CARING FOR CHILDREN LIVING WITH HIV IN A SEMI-RURAL AREA IN SOUTH AFRICA." *Africa Journal of Nursing and Midwifery* 15 (1) 2013 pp. 68–80.
- Bennetts, A., Shaffer, N., Manopaiboon, C., Chaikakul, P., Siriwasin, W., Mock, P.,... Clark, L. (1999). "Determinants of depression and HIV-related worry among HIV-positive women who have recently given birth, Bangkok, Thailand." *Soc Sci Med* 49(6): 737-749.
- Bjork, M., Nordstrom, B., & Hallstrom, I. (2006). "Needs of young children with cancer during their initial hospitalization: an observational study." *J Pediatr Oncol Nurs*23(4): 210-219.
- Bjork, M., Nordstrom, B., Wiebe, T., & Hallstrom, I. (2011). "Returning to a changed ordinary life--families' lived experience after completing a child's cancer treatment." *Eur J Cancer Care (Engl)*20(2): 163-169.
- Bjork, M., Wiebe, T., & Hallstrom, I. (2005). "Striving to survive: families' lived experiences when a child is diagnosed with cancer." *J Pediatr Oncol Nurs*22(5): 265-275.
- Bjork, M., Wiebe, T., & Hallstrom, I. (2009). "An everyday struggle-Swedish families' lived experiences during a child's cancer treatment." *J Pediatr Nurs*24(5): 423-432.
- Björk, M. (2008). "LIVING WITH CHILDHOOD CANCER. Family Members' Experiences and Needs." Lund University, Faculty of Medicine .Doctoral Dissertation Series 2008:60
- Brown, B. J., Oladokun, R. E., Osinusi, K., Ochigbo, S., Adewole, I. F., & Kanki, P. (2011). "Disclosure of HIV status to infected children in a Nigerian HIV Care Programme." *AIDS Care*23(9): 1053-1058.
- Charles H., & Washington, P. O. (2013). "Perceived and Experienced Stigma and Discrimination among Caregivers of Perinatally HIV-Infected Adolescents in Thailand." *Journal of Therapy and Management in HIV Infection*,1, No. 2.
- Cooper C. W. D., Woolfenden, S. R., Boss, T., & Piper S. (2006). "Specialist home-based nursing services for children with acute and chronic illnesses. *Cochrane Database Syst.Rev.* ." 4.
- CSA (2007). "population and Housing Census of Ethiopia." Central Statistical Agency of Ethiopia.
- FCA (2012). "Caregivers of Veterans: Serving on the Home Front " National Alliance for Caregiving and United Health Foundation. <https://caregiver.org/selected-caregiver-statistics> (accesses on 17 Dec, 2014)Fact sheet.
- FHAPCO (2007). "Guidelines for Paediatric HIV/AIDS Care and Treatment in Ethiopia." Etharc.
- FHAPCO (2012). "Multi-sectoral HIV/AIDS Response Monitoring & Evaluation Report."
- FHAPCO (2014). Country Progress Report on HIV/AIDS Response in Ethiopia.
- Hamra, M., Ross, M. W., Karuri, K., Orrs, M., & D'Agostino, A. (2005). "The relationship between expressed HIV/AIDS-related stigma and beliefs and knowledge about care and support of people living with AIDS in families caring for HIV-infected children in Kenya." *AIDS Care*17(7): 911-922.
- J Potterton, A. S., & Cooper, P. (2007). "Parenting stress of caregivers of young children who are HIV Positive." *Afr J Psychiatry*10:210-214.
- Jonsson, L., Hallstrom, I., & Lundqvist, A. (2010). "A multi-disciplinary education process related to the discharging of children from hospital when the child has been diagnosed with type 1 diabetes--a qualitative study." *BMC Pediatr*10: 36.
- Kafle, N. P. (2011). "Hermeneutic phenomenological research method simplified." An interdisciplinary.

- Krefting, L. (1991). "Rigor in Qualitative Research: The Assessment of Trustworthiness." *The American Journal of Occupational Therapy* 45.
- Kyaddondo, D., Wanyenze, R. K., Kinsman, J., & Hardon, A. (2013). "Disclosure of HIV status between parents and children in Uganda in the context of greater access to treatment." *Sahara j* 10 Suppl 1: S37-45.
- Lincoln & Guba (1985). "Naturalistic inquiry. Beverly Hills, CA: Sage."
- Mathambo, V., & Gibbs, A. (2009). "Extended family childcare arrangements in a context of AIDS: collapse or adaptation?" *AIDS Care* 21 Suppl 1: 22-27.
- Mengistu, A. D. (2013). "Disclosure of HIV diagnosis to children: a poorly addressed issue in pediatric HIV care." *Ethiop Med J* 51(4): 273-278.
- Merleau-Ponty, M. (1996). "Phenomenology of perception. C. Smith (Trans.). New York: Routledge. (First published 1962)."
- Mumburi, L. P., Hamel, B. C., Philemon, R. N., Kapanda, G. N., & Msuya, L. J. (2014). "Factors associated with HIV-status disclosure to HIV-infected children receiving care at Kilimanjaro Christian Medical Centre in Moshi, Tanzania." *Pan Afr Med J* 18: 50.
- Nelms, T. P. (2005). "Burden: the phenomenon of mothering with HIV." *J Assoc Nurses AIDS Care* 16(4): 3-13.
- Orner, P. (2006). "Psychosocial impacts on caregivers of people living with AIDS." *AIDS Care* 18(3): 236-240.
- Parikh, S. A. (2007). "The Political Economy of Marriage and HIV: The ABC Approach, "Safe" Infidelity, and Managing Moral Risk in Uganda." *American Journal of Public Health* 97(7): 1198-1208.
- Parker, G., Bhakta, P., Lovett, C., Olsen, R., Paisley, S., & Turner, D. (2006). "Paediatric home care: a systematic review of randomized trials on costs and effectiveness." *J Health Serv Res Policy* 11(2): 110-119.
- Punpanich, W., Detels, R., Gorbach, P. M., & Leowsrisook, P. (2008). "Understanding the psychosocial needs of HIV-infected children and families: a qualitative study." *J Med Assoc Thai* 91 Suppl 3: S76-84.
- Rajaraman, D., Earle, A., & Heymann, S. J. (2008). "Working HIV care-givers in Botswana: Spill-over effects on work and family well-being." *Community, Work & Family* 11(1): 1-17.
- RYAN, T. G. (2011). "The Teacher/ Researcher and the Role of Pre-understanding: A Personal Analysis." *New Zealand Journal of Teachers' Work* 8(2, 220-228).
- Shenton, A. K. (2004). "Strategies for ensuring trustworthiness in qualitative research projects." *Education for Information IOS press* 22, 63-7.
- Shields, L. (2011). "Family-Centred Care: Effective Care Delivery or Sacred Cow? ." *Forum on Public Policy*.
- Smith Fawzi, M. C., Eustache, E., Oswald, C., Louis, E., Surkan, P. J., Scanlan, F.,... Mukherjee, J. S. (2012). "Psychosocial support intervention for HIV-affected families in Haiti: implications for programs and policies for orphans and vulnerable children." *Soc Sci Med* 74(10): 1494-1503.
- Surkan PJ, M. J., & Williams DR, et al. (2010). "Perceived discrimination and stigma toward children affected by HIV/AIDS and their HIV-positive caregivers in central Haiti.." *AIDS Care* 22(7, 2010): 803-815.
- UNAIDS (2014). "Beginning of the end of the AIDS epidemic."
- van Manen, M. (1997). "Researching lived experience: human science for an action sensitive pedagogy. 2nd edition. Ontario: Althouse press, ."
- Wennick, A., & Hallstrom, I. (2006). "Swedish families' lived experience when a child is first diagnosed as having insulin-dependent diabetes mellitus: An ongoing learning process." *J Fam Nurs* 12(4): 368-389.
- Wennick, A., & Hallstrom, I. (2007). "Families' lived experience one year after a child was diagnosed with type 1 diabetes." *J Adv Nurs* 60(3): 299-307.

- Wennick, A., Lundqvist, A., & Hallstrom, I., (2009). "Everyday experience of families three years after diagnosis of type 1 diabetes in children: a research paper." *J Pediatr Nurs*24(3): 222-230.
- WHO (2013). "Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: recommendations for a public health approach." World Health Organization.
- WMA (2013). "World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects." *Jama*310(20): 2191-2194.
- Wong, M. Y. & Chan, S. W. (2006). "The qualitative experience of Chinese parents with children diagnosed of cancer." *J Clin Nurs*15(6): 710-717.