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CAREGIVERS' EXPERIENCES IN CARING FOR HIV POSITIVE CHILDREN: A QUALITATIVE STUDY AT A COMPREHENSIVE CARE CENTRE IN KENYA

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Abstract

Purpose: Caring for HIV positive children poses various challenges and uncertainties depending on the disclosure of their status. To explore the caregivers' experiences in caring for HIV positive children before, during and after disclosure of their HIV positive status.

Methodology: A qualitative study was conducted at a Comprehensive Care Centre in a national referral Hospital in Kenya. The study population included parents/guardians of HIV positive children with complete disclosure of their HIV status. Data was collected through in-depth interviews. The socio-demographic characteristics of the respondents were analysed using descriptive statistics. The qualitative data is analysed by use of content analysis and presented in themes and narratives.

Results: The results revealed that caring for these children was more challenging before disclosure than after disclosure. The main challenge was in responding to the children's questions in regards to their health status. The questions asked by the children before disclosures include the reason for treatment, clinic follow up and when treatment will stop among others. The study further established that the parents/guardians expressed diverse fears of how the children might react during disclosure; however, the children mostly did not display the feared reactions at the moment of disclosure. Finally, the findings of this study established that care after disclosure becomes easier and that the children become more engaged in their own care.

Conclusion: The study found that caring for HIV positive children is less challenging after disclosure of their HIV status. Further, fears by caregivers are unfounded and there are minimal negative reactions by the children upon disclosure. In order to become actively engaged in their own care, children as early as 11 years old need to be informed about their positive HIV status.

Unique contribution to practice, theory and policy: The healthcare providers should ensure early preparation of the caregivers for disclosure to the children of their HIV status. Further, community members and school teachers need to be educated about the beneficial effects of disclosure of an HIV diagnosis to a child or adolescent. Research is needed on the development and implementation of caregiver support groups similar to that of children living with HIV.

Keywords: *Caregivers' Experiences, Caring, HIV, Positive Children*

INTRODUCTION

Since the diagnosis of the first case of Human Immunodeficiency Virus (HIV), advances have been made in its diagnosis and management. Before the advent of Antiretroviral Therapy (ART) and the adoption of Prevention of Mother to Child Transmission (PMTCT), the rate of mother to child transmission was high leading to increase in the number of children exposed to HIV. With the introduction of widespread HIV counselling, testing and PMTCT there is a dramatic drop in the rate of perinatal transmission. Further, many HIV-infected children who were not expected to survive childhood are entering adolescence and young adulthood. With increased survival, one of the greatest psychosocial challenges that parents and caregivers of perinatally HIV-infected children face is disclosure of HIV sero-status to their infected children (Wiener, Mellins, & Marhefka, 2007)

According to the World Health Organization (WHO, 2014) an estimated 3.2 million children were living with HIV at the end of 2013, mostly in sub-Saharan Africa. The report further indicates that the number of children (younger than 15 years) receiving ART in low- and middle-income countries more than doubled from 2009 to 2013, from 355 000 to 740 000. According to the Kenya Aids Indicator Survey (KAIS, 2012), the prevalence of HIV among children aged 18 months to 14 years was 0.9%. The United Nations Children's Fund (UNICEF, 2015) estimates infant exposure to HIV in Kenya at 70,000 to 100,000 infants every year and a transmission rate of approximately 10 per cent resulting to 7,000 – 10,000 newly infected children annually.

The prevalence disclosure to children of their HIV status is documented to be low in the less industrialized countries as compared to the industrialized countries. A study conducted in Congo by Vaz (2010) among 259 HIV positive children established that only eight (3%) of them had been informed of their HIV status. Another study in Ethiopia established a disclosure rate of 17.4% (Biadgilign, Deribew, et al, 2011). A similar study in Western Kenya established that out of twenty HIV positive children participating in the study only two had been disclosed to their HIV status (Vreeman, et al. 2010). Further, a study on the prevalence, perceptions and correlates of pediatric HIV disclosure in an HIV treatment program in Kenya established a prevalence rate of disclosure to children of their HIV positive status of 19% (John-Stewart, et al., 2013). The low rates of disclosure are associated to a number of barriers including local norms that deter parents from communicating to their children about sexuality, fear of HIV stigma and underlying presumption that children and adolescents cannot understand the consequences of HIV diagnosis in their lives and relationships (Vreeman, et al. 2010 & Mburu, et al. 2014).

Caring for HIV positive children before disclosure of their HIV status poses various challenges and uncertainties. Fear of stigma or discrimination, not knowing how to tell the child, fear of the child disclosing to others and believing that a child is too young, are among the strongest motivator not to tell the child (Vreeman, Nyandiko, Ayaya, Walumbe & Marrero, 2010; Clifford, Craig, McCourt, & Barrow, 2013 & Mburu, Hodgson, Kalibala, Haamujompa, Cataldo, Lowenthal & Rose 2014).

Studies conducted among parents/guardians and health care providers of HIV positive children, reveal that children ask various questions before the disclosure of their status is revealed to them. Some of these questions include the type of sickness they have, why they are constantly ill, and why they have to continually take medications (Vreeman et al, 2010)

and Vaz, 2013). Vreeman et al (2010) established that parents in Western Kenya give diverse reasons to these questions like; stopping the child from being sick again, the child has a chest problem and the child has a stomach problem. However, the parents/guardians feel guilty for lying to the children (Vreeman et al., 2010).

Caregivers discourage communication between the child and the healthcare providers. A study in Congo showed that parents deter children from talking with healthcare providers as a way of safeguarding them from getting to know their HIV status. The study further established that the children who get to interact with the healthcare providers were given diverse responses to their questions including general information on chronic illness, recommended, actions to avoid contaminating others, and advising them not to worry (Vaz, 2013).

A study in Zambia established that both parents and healthcare providers of children living with HIV experience difficulties in determining when to reveal their HIV positive status. The time and circumstances pose a challenge amid the willingness. One of the motivations for disclosure is the child's inquisitiveness. The moment of disclosure occurs at an opportune time like during discussions about antiretroviral therapy (ART), HIV transmission or by the parents/guardians revealing their HIV status first (Mburu et al., 2014). Studies reveal mixed reactions by the children immediately upon disclosure. Such reactions include anger, sadness, disbelief, asking questions or not showing any reaction at all (Vreeman et al., 2010; Linda, 2013; Mburu, et al., 2014)

Studies by the WHO indicate that disclosure to children of their own HIV status has more health benefits and little psychological or emotional harm. Despite the benefits, the rate of disclosure in developing countries are much lower than in the developed countries (John-Stewart, Wariua, Beima-Sofie, Richardso, Farquhar, Maleche-Obimbo, Mbori-Ngacha & Wamalwa, 2013). Further, a systemic review by Vreeman et al (2013) on the disclosure of HIV status to children in resource limited settings revealed minimal documentation on the impact of disclosure to children and lack of documentation on the evaluation of the pre and post disclosure impact to children. Most studies have concentrated on the impact of disclosure to children of their HIV status on adherence to ART and the child's social life (Linda, 2013). These studies recommend further research to determine the impact of full disclosure on the child-caregiver relationship. This study was designed to explore the effect of disclosure on the caring experience.

1. To describe the parents'/guardians' experiences in caring for the HIV positive children before disclosure
2. To explore the parents'/guardians' perceptions of the children's reaction to the disclosure of their HIV positive status
3. To gain an understanding of the parents'/guardians' experiences in caring for the HIV positive children after disclosure

LITERATURE REVIEW

Prevalence of HIV in Children and Adolescents

The World Health Organization (WHO, 2014) estimated that 3.2 million children were living with HIV at the end of 2013, mostly in sub-Saharan Africa. The report further indicates that the number of children (younger than 15 years) receiving ART in low- and middle-income

countries more than doubled from 2009 to 2013, from 355 000 to 740 000. According to the Kenya Aids Indicator Survey (KAIS, 2012), (Kenya Aids Indicator Survey, 2012) the prevalence of HIV among children aged 18 months to 14 years was 0.9%. The United Nations Children's Fund (UNICEF, 2015) estimates infant exposure to HIV in Kenya at 70,000 to 100,000 infants every year and a transmission rate of approximately 10 per cent resulting to 7,000 – 10,000 newly infected children annually.

Models of HIV Disclosure

A study by Moyer et al, 2013 on the duty to disclose in Kenyan facilities established the existence of three models of disclosure to an individual of their HIV positive status. These models include: Voluntary whereby the disclosure is consented; Involuntary in which the disclosure is non-consensual and may be intentional or accidental and Obligatory disclosure which is forced disclosure so as to access health services. The immediate outcome of disclosure is dependent on the model. Studies have revealed that the how of communication to children about their HIV positive status determines the outcome of the disclosure (Vreeman, 2010).

Pre-disclosure Caring Experiences

Caring for HIV positive children before disclosure to them of their HIV status poses various challenges and uncertainties. Fear is documented as one of the underlying factors in disclosure to children of their HIV status. The main fears expressed include fear of stigma or discrimination, not knowing how to tell the child, fear of the child disclosing to others and believing that a child is too young (Clifford et al, 2013).

Studies conducted among the parents/guardians and health care providers of HIV positive children, reveal that these children ask various questions before the disclosure of their status is explained to them. Some of these questions include the type of sickness they have, why they are constantly ill and why they have to continually take medications (Vreeman et al, 2010 and Vaz, 2013). Vreeman et al (2010) in their study on the perceived impact of disclosure in Western Kenya established that parents give diverse reasons like; stopping the child from being sick again, the child has a chest problem and the child has a stomach problem. Vreeman further established that the parents/guardians live with guilty for lying to the child and on the other hand ART adherence problems set in as the children grow older. A similar study in Congo established that parents deter children from directly communicating with the healthcare providers as a way of safeguarding them from being disclosed to their status. The study further established that the children who get to interact with the health care providers are given diverse responses to their questions including general information on chronic illness, recommended actions to avoid contaminating others and advising them not to worry (Vaz, 2013).

Moment of Disclosure

A study by Mburu et al (2014) in Zambia established that both parents and health care providers of children living with HIV experience difficulty in determining when to reveal to them their HIV positive status. The time and circumstances pose a challenge amid the willingness. One of the motivations for disclosure is the child's inquisitiveness. The moment of disclosure occurs at an opportune time like during discussions about ART, HIV transmission or by the parents/guardians revealing their HIV status first.

Studies reveal a mixed mode of reaction by the children immediately upon disclosure. Such reactions include anger, sadness, disbelief, asking questions or some children not showing any reaction at all (Vreeman et, 2010, Linda, 2013 and Mburu, et al, 2104)

Post Disclosure Experiences

Disclosure to children of their HIV positive status has both positive and negative outcomes. One of the positive outcomes as documented by Heoakan (2009) and John-Stewart, et al., (2013)) is that those who know their HIV status play an important role in their treatment by taking their own medicines when they know how to do so or remind the care givers when it is time to take the medicines. Disclosure is further indicated to foster positive benefits on the parent – child relationship (Clifford, et al, 2013). These positives however, are not experienced immediately at disclosure but after the child has undergone through a process of denial to acceptance. Upon disclosure the children develop anxiety, depression, withdrawal, and blame on themselves (Vaz, et al 2010).

Communication between the children and care givers changes after disclosure. According to Vaz et al, 2010, the caregivers adopt one-way communication whereby they give advice, and ignore HIV discussions because of discomfort. This form of communication is necessitated by the nature of questions and clarifications sought by the children. These includes the source of their infection, confirming the diagnosis, whether they were get better or cured and AIDS being fatal, taking medications for life and whether they were able to finish school.

Research gap

Most studies have concentrated on the impact of disclosure to children of their HIV status on adherence to ART and the child's social life (Linda, 2013). These studies recommend further research to determine the impact of full disclosure on the child parent/caregiver relationship. No study has been conducted at the KNH Comprehensive Care Clinic (CCC) on the impact of disclosure on the child-parent/guardian relationship while comparing their previous relationship. In this regard therefore the findings of these study bring to the fore the caring experiences before and after disclosure. The determination of the effect was based on the caregiver's descriptions of their encounters in caring for the HIV positive children before and after disclosure.

METHODS

This was a qualitative study carried out at a Comprehensive Care Clinic (CCC) between in a national referral hospital in Kenya. The study population comprised caregivers of HIV positive children who have had complete disclosure of their HIV status and are attending the CCC. There are a total of 468 active HIV positive children in this cohort that attend the CCC. According to the data of the clinic, out of these children, (N=142) had completed the process of disclosure. Therefore, the target population was 142 parents/guardians of the children. To be included in the study, the caregiver must have been actively involved in the care of the child for at least one year before and after disclosure.

Study Procedures

Sampling, Recruitment and Consenting Procedures

Purposive non-probability sampling was used in selecting the study participants. Being a qualitative study, data was collected until saturation. The point of saturation was determined

when there was no new information from three subsequent respondents since the last respondent with similar responses.

Data Collection Tools

Data was collected by use of an in-depth interview guide. The interview guide was developed based on the review of literature. The following questions were answered in the process:

- i. What are your experiences in caring for HIV positive children before disclosure?
- ii. What aspects pose challenges in the caring process?
- iii. How does the disclosure process affect the caregiving?
- iv. What is the difference in caring for the HIV positive children in the pre and post disclosure period?
- v. How does caring for HIV positive children differ from the care of the HIV negative children

Data Management

All socio-demographic information data sheets were checked for completeness and stored securely. Upon completion of the data collection, the data was entered, code and analyzed using descriptive statistics using the “Statistical Package for Social Science Programme (SPSS)”. The recorded interview data were transcribed verbatim. The field notes were used as a backup to the recorded data. The data were coded in themes and sub-themes. After the coding was complete the data were interpreted and correlated with the verbatim responses.

RESULTS

Socio-Demographic Characteristics of the Study Participants

The parents/guardians who participated in the in-depth interviews were aged between 20 and 60 years with a mean age of 41 years. Their education level varied from having had no formal education to university education. Eight of them were the children’s biological parents comprising six mothers and two fathers; one was a grandmother and one a cousin.

Children’s Socio-Demographic Characteristics

The children whose parents/caregivers participated in the study were aged between 11 and 18 years with a mean of 14 years. Their age at initiation of disclosure ranged between 8 and 15 years with a mean and a median of 11 years. The age of completion of disclosure ranged 9 to 15 years with a median of 11 years. Six of the children were males and four were females. Five lived with both parents, for two both parents were diseased and the remaining had one parent alive.

Caring Experiences

The study aimed at understanding the caring experiences of HIV positive children before and after disclosure. Respondents were asked to narrate their story in providing care for these children before disclosure, during disclosure and after disclosure. The themes emanating from the narrations are discussed in the following sections.

Parents’/Guardians’ responses to children’s questions before disclosure

The caregivers expressed having responded to various questions and concerns raised by the HIV positive children. The concerns raised before, during and after disclosure are not similar.

Further, the children are more inquisitive before disclosure than after. The common questions from all the children before disclosure as explained by the caregivers and their responses are outlined in Table 1 below.

Table 1: Children's Questions and Responses Given by the Caregivers

Children's questions	Parent's/Guardian's responses
Why am I taking these drugs?	<ul style="list-style-type: none"> • For treatment of TB, Pneumonia, chest problem, leg problem • You are sick • To become a doctor • Everyone in the world is sick
For how long will I take the drugs?	The doctor will say
Why do I keep going/coming to the clinic?	The doctor said you have to go
How come others take the medicines for a short time and stop but I am not stopping?	Encourages the child to continue taking
My sickness is healed, why am I still taking the drugs?	Just encourages the child to continue taking the medication
Is somebody who is HIV positive one that takes a lot of drugs never ending?	Switches discussion to another topic or assumes has not heard the question

Experiences with the children at the moment of disclosure

The study explored the caregiver's perceptions of the children's reactions to disclosure of their HIV status. The caregivers explained that the children's reactions depended on prior knowledge of HIV/AIDS, mode of disclosure whether planned, self or accidental and source of infection. The main reactions include silence, crying, casting blame on the parents and violence.

"This child is usually very quiet; she does not talk most of the time. You ask her whether she has any question, she says no. At the point of disclosure, I asked what they have discussed with the counsellor, she said she is also shocked of the result. (Huyu the problem ile ako nayo ni haongeangi ukimuuliza uko na swali hasemi anajibu tu hakuna yeye ni wa kunyamaza. Hajauliza nilimuuliza umeongea na huyo mtu, ati eeh, amekuambiaje, ati ata yeye anashangaa)." CG9

Concerning the child's prior knowledge, the respondents explained that most of the children obtain the information about HIV from the media and school curriculum. The nature of information the children have influences how they react to disclosure. The study established that the caregivers have had to deal with the negative pictures portrayed of HIV while being taught in school. They explained that the children generally know that if they are HIV positive then they are going to die.

"When the child was in standard four, they were taught that HIV kills, so explaining him otherwise was difficult because they trust what they have been told by their teachers. They were informed that if one gets infected by HIV, they lose weight and die. (Wakati akiwa class 4 wakafundishwa wakaambiwa HIV inauwa sasa kumwelezea mambo ya HIV haiwi ilikuwa ngumu juu mwalimu aliwasomesha akatwambia ukishikwa na HIV utakonda alafu ufe)" CG5

According to the caregivers, the children's reactions at the moment of disclosure are usually contrary to their expectations. The children mainly ask why they were being cheated in

response to questions listed in Table 1 and about the source of infection. To the caregivers the question on the source of infection is the most distressing as it entails revealing their own status to the child. Further, it results in the need to disclose the actual relationship between the child and the caregiver for the children who are under the care of guardians who was either a stepmother or an aunt and they have all along known as their biological mother.

"I told him, you see me taking medicines, I am also HIV positive but you should not reveal to people that we usually go to the hospital for follow up. (Nilimwambia si unaona pia mimi nakunywa, kwa hivyo hata mimi niko hivyo wewe unakunywa dawa lakini maneno ya kwenda ukisema tunaenda hospitali usiseme)."CG5

Experiences with the children after disclosure

The main sub-themes from the parents'/ guardians' narratives on experiences after disclosure include children's concerns, responsibility for adherence and maintaining secrecy.

Children's concerns after disclosure

After disclosure, the number of questions asked reduces significantly. The most common concern as pointed out by almost all the caregivers during the in-depth interviews is in regard to probability of having a family and children in the future or stop taking the medicines. The caregivers' response was to encourage and give a message of hope.

"For now she doesn't have many questions though at times she asks whether there is a time she will stop taking the medicines. I encourage her to just continue taking them for now but it is possible that a remedy may be found." CG1

Responsibility for adherence

Responsibility for adherence focuses on clinic attendance and taking of medicines. The study established that responsibility for adherence before disclosure rests on the caregivers whereas after disclosure the children take up the responsibility. This is not only on adherence but also in educating and guiding others including their own siblings and parents. This was explained by one of the caregivers as follows:

"Disclosure relieves you worries, when he is away you are sure he is able to take care of himself when he is doing something he knows at the back of his mind I have to protect everybody around me because when he is injured he always tells me please don't handle me without gloves it becomes easy for him to protect himself and to protect others."CG2

The study further revealed that the issue of taking responsibility was a key motivator for the caregivers' acceptance to disclose to the children their HIV positive status. In affirming this, one of the respondents expressed the following:

"Kwa sababu ningemfundisha mapema sasa unajua mimi ndio baba ndio mama na mara nyingi naenda kumtafutia so ajifundishe kutumia ile dawa (I trained her early because of that I am the only parent I go to search for jobs to fend for her so that she can learn to take her medicines)."CG 5

Maintaining Secrecy

Maintaining the secrecy of the child's status is one of the causes of parental fear of disclosure to children. Most of the caregivers explained that the child's condition is known either by the child and the parents only whereas others have disclosed to the child's grandparents, aunts or siblings. To maintain the secrecy upon disclosure, the caregiver explains to the child that it is

a personal or a family affair and should not be shared with anybody. The main reason for ensuring secrecy is to avoid stigmatization of the child or the family. Out of the ten caregivers who participated in the study, only one had informed the child's class teacher about their status.

DISCUSSION

The findings of this study have revealed that the parents/guardians of the HIV positive children face different experiences before, during and after disclosure. The most common distressful experience is in responding to the questions from the children in regards to the condition they are being managed for. This finding is similar to those documented by Vreeman et al (2010) and Vaz (2013). Based on the responses given to the children's questions by the caregivers, it is evident that the children's concerns are not fully addressed. Further, tossing the responsibility for disclosure to the children from the caregivers to the healthcare providers and vice versa was a source of distress and anxiety for the child. These findings imply that there is need to counsel and guide the parents on what to expect as the children grow and how to respond to questions that are causing undue stress.

The children's caregivers especially the biological parents express fear for disclosure to children of their HIV status. This concurs with the finding by Clifford et al (2013). The concerns raised can be averted by networking between the parents so that they can share and support each other. The respondents suggested linking the parents who have not disclosed to their children with the ones who have already disclosed in a way for enhancing disclosure as the advantages of disclosure. Therefore, there is need for early and adequate preparation of the parents from the time the child is told that it is living with HIV.

The study established that during the moment of disclosure children exhibit mixed reactions. Some of the children reacted with anger and asked many questions thus confirming the parent's fears whereas others just were silent. These findings concur with those established by Vreeman et al, 2010, Linda 2013 and Mburu et al 2014. However, it is worth noting that the negative reactions by children do not last long if they undergo post disclosure counselling. Hence their relationship with the caregivers is not hindered but rather they become the best of friends. Further, the study established that the children under the care of guardians undergo two types of disclosure that is their HIV positive status and their actual relationship with the guardian. This would be a source of increased stress for the child, hence posing the need for early disclosure of the actual relationship before disclosing the HIV status.

The moment of disclosure to children of their HIV status is an opportune time for the parents to disclose their HIV status as well. The finding on revelation of parental HIV status concurs with that established by Mburu et al (2014). According to the findings disclosure of the caregiver's HIV status necessitated the disclosure to the child of their actual relationship with the child. This was particularly so, where the child acquired the infection through mother to child transmission and yet the caregiver whom the child knows as the mother is negative. Hence there need for emphasis to the caregivers on the importance of early disclosure of their actual relationship with the child to avoid subjecting the child to multiple stressors.

Contrary to the caregivers' fears about the likely reactions of the children upon disclosure of their HIV status, the study established that most of the children do not show any negative reactions. Further the study revealed that disclosure does not compromise the child – caregiver relationship. The immediate reactions include anger, disbelief, sadness, silence and

asking questions. This findings are similar those documented by Vreeman et al, (2010), Linda (2013) and Mburu et al (2014).

Similar to findings by WHO (2011), the caregivers expressed that disclosure has more advantages than disadvantages. The main advantages are that the child is able take responsibility for their health management and the communication is free and open. Based on these advantages, there is need to put in place strategies for enhancing disclosure particularly for the caregivers who are reluctant. Such strategies include networking the caregivers and establishment of caregiver support groups.

Conclusion

Based on the data from the interviews the study concluded that caring for the HIV positive children more challenging before disclosure than after for both the healthcare providers and the caregivers. These challenges occur mainly in communication, attending to children's concerns and questions and ensuring adherence. Further, children exhibit mixed reactions at the moment of disclosure of their HIV status depending on the mode of disclosure, the source of infection and their actual relationship with the caregiver with children not previously aware of their relationship with the caregiver are exposed to more stress. However, disclosure to children of their HIV status does not adversely affect their mode of interaction with the caregivers. Despite initial reaction, with continued counselling their interaction is more free and focused. Further the children take on responsibility for taking their medications and clinic follow up.

Recommendations

The study recommends that:

1. There is need for the establishment of caregiver support groups as a way of sharing experiences and encouraging those with fears to disclosure.
2. There is need for timely disclosure counselling for caregivers to avoid delayed disclosures.
3. There is need for policies and guidelines with clear stipulations on timelines for disclosure to children of their HIV status
4. A study be conducted to explore the children's experiences before, during and after disclosure.

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