

ORPHAN AIDS CAREGIVING NEEDS IN COMMUNITY: THE CASE WORKERS PERSPECTIVE

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Abstract

Deaths among adults due to HIV/AIDS have left their children as AIDS orphans. UNAIDS defines AIDS orphans as children who have lost both parents and one of them due to HIV / AIDS. The shift of responsibilities of AIDS orphans to extended families or informal caregivers such as grandparents, relatives, and foster families causes a change in the pattern of family dynamics. However, there is still a lack of studies that explore the family dynamics of caregiving of AIDS orphans in particular caregiving needs. This study was conducted to explore the needs of AIDS orphans living in the community from the perspective of caseworkers. The study has applied qualitative methods (case study). A total of five HIV-positive child caseworkers were selected as informants using purposive sampling. Data collection was conducted through face-to-face interviews and thematic analysis was applied during the data analysis process. The result has shown there is four caring needs have been identified i) economic stability, ii) health status, iii) psychosocial support, and iv) knowledge and skills. An understanding of caregiving needs is essential to ensure the social functioning of individuals such as caregivers, AIDS orphans, and family members are secured and the family system can function properly. Apart from that, the exploration of this study can also be a guide for caseworkers to plan a family-community-based intervention outline for AIDS orphans.

Keywords

Orphans AIDS, informal caregiver, caregiving needs, caseworkers

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Introduction

Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) are dangerous and taboo infectious diseases in the community. People living with HIV and AIDS often receive discrimination and rejection. The latest data from UNAIDS (2020) shows that a total of 38 million individuals were diagnosed as HIV seropositive, 1.7 million individuals were new cases of infection, and 690 thousand individuals died of AIDS opportunistic infection-related diseases worldwide year of 2019.

The summary of HIV/ AIDS infection statistics in Malaysia shows that from the first cases detected in 1986 until 2014, a total of 105,189 individuals were infected with HIV, 21 384 AIDS cases, and 17 096 HIV/AIDS-related deaths were reported. Therefore, the reported number of people living with HIV /AIDS at the end of 2014 was 88,093, covering all age groups. The trend of infection is through needle-sharing activities, heterosexuals, sex workers, transmission from mother to child during pregnancy, infection through sexual intercourse between married couples, and blood transfusions (Ministry of Health of Malaysia, 2015). However, reports of HIV infection and AIDS cases in Malaysia are still manageable due to the government's strategy to curb HIV infection and AIDS in the community. Apart from that, the statistics released by Malaysia AIDS Council (2018) also explain that as of December 2017 a total of 115,263 HIV infections and 42,864 deaths have been reported. The number of people living with HIV is 72,399 people.

Since people living with HIV/AIDS are individuals who are at a productive age and head of the family, their deaths inevitably leave children orphaned and neglected. Malaysia also did not escape the phenomenon of AIDS orphans. Deaths among adults due to AIDS directly prove the level of dependence of AIDS orphans on others to continue survival is high. This statement carries the broader meaning that parental deaths due to AIDS lead to an increase in the number of AIDS orphans under the age of need of adult care. The changes in our healthcare system have created two terms of care: formal and informal. Formal care refers to caregivers or individuals who are professionals in institutions such as nursing homes and are considered substitute families for AIDS orphans. Typically formal caregivers involve individuals who are paid salaries and wages by the institution (Mohd Suhaimi et al., 2017) and do not have any family relationship with AIDS orphans. Formal care, particularly in the form of institutional care, is performed by individuals who are trained and have skills in carrying out caring responsibilities. The placement of AIDS orphans in institutions can be considered one of the solutions to ensure that AIDS orphans receive good support services after dealing with the death of their parents.

However, policy changes undertaken by the government have encouraged the process of destitution by transferring the caregiving role to their extended or foster families in the community. Applications are taken from the concept of Home-Based

Community Care or Community Home-Based Care (CHBC). The care process is known as informal care. The Carers consist of members of the biological family, extended family, or adoptive families in the community. Informal caregivers are classified as individuals who carry out care activities without receiving remuneration and are performed by those who are untrained and do not have specific caregiving needed skills such as in institutions. Even routine care activities are performed within the environment space and clusters of their family systems (Fatimah, 2009; Fatimah et al, 2011).

According to the Family Caregiver Alliance (2017), after parental death, informal caregivers for AIDS orphans are more composed of extended family members such as grandparents, aunts, uncles, relatives, and foster families. Furthermore, informal care refers to in-home care that involves members in a social system at home (Siti Fatimah & Mohd Suhaimi, 2016). The caregiving duties include personal, practical, and psychosocial support activities. Caregivers in the community also play dual roles to other family members who live in the same household such as parents or spouses displaced by chronic illnesses. McNamara and Rosenwax (2010) stated the responsibility as caregivers automatically shifted to uncles or aunts or other extended family members in their family system.

In addition, uncles and aunts can be considered as a group with high potential to become official caregivers or guardians of AIDS orphans due to their proactive and productive age suitability. They are individual adults who have a strong identity, as well as a mature relationship with the environment, and are more stable in terms of financial acquisition. Meanwhile, Twigg and Swan (2007) stated that adoptive families are also categorized as caregivers of AIDS orphans in many countries. The absence of caregivers among extended family members who are qualified to presume caregiving responsibilities leads to the handing over of custodial powers to adoptive families. Adoptive families involve individuals other than extended family members and usually do not have blood-related relationships with AIDS orphans (Abebe & Aase, 2007).

The family is the unit responsible for developing the potential of micro-individuals and providing a conducive environment to children orphaned from AIDS emotionally, physically, mentally, and socially. According to Rika Fatimah and Abdul Aziz (2015), family life is considered the heart of the stability of a society, plus an important entity in ensuring the development of individual and community personality. Each needs help and support from their family systems, including the AIDS orphans who have lost their parents to AIDS. In addition, the family institution also plays an important role in individuals' development such as self-personality, and has a close relationship to social functioning, behavioral issues, mental stress-related problems, and the children's well-being in general. Due to these matters, the caregiving need issues among the informal orphan AIDS caregivers justified the importance of receiving pre-in-home care skills at the beginning shift stage in AIDS orphan care.

A study by Tan and Kamiah (2015) found that interactions, relationships, and activities between members of the family system influence the level of psychosocial development of adolescents. This includes the psychosocial development of AIDS orphans who live with informal caregivers after experiencing a phase of parental loss. Caregivers who take over the responsibility of care must be prepared and able to provide a positive atmosphere for their children. Family functionality not only refers to the flexibility of the family organizational systems to accept additions and dynamic changes but encompasses patterns of interaction, transactions, and role changes towards individual and family life survival as a whole at the same time. Plus, the role of a caregiver to seropositive HIV patients could also bring negative perceptions, fears, and stigmatization not only to the PLHIV children but also to their family system.

Therefore, the shifted responsibility as orphans of AIDS requires caregivers to be well prepared in all aspects such as physiological, mental, emotional, psychological, skills, and knowledge. Community Home-Based Care (CHBC) for People Living with HIV/AIDS (OHDHA) is an intervention that involves collaboration between the community, healthcare workers, and especially important actors, which is the family itself. In addition, Qalinge (2011) also emphasizes the community concept as an important entity in offering support services and treatment in society. CHBC intervention itself can be seen as holistic in nature which is aimed at improving the quality of life of ODHA and their families. Therefore, to ensure the caregiving needs of AIDS orphans are met, caregivers should prepare themselves and understand their roles as AIDS orphans holistically. Based on the previous literature studies, several important aspects of caregiving needs should be highlighted, such as the physiological, psychological, social, and emotional development care of AIDS orphans after living with an informal caregiver.

Study Objective

There is a lack of studies that take into account the perspectives of social workers on the real needs of family members who accept the responsibility of caring for AIDS orphans in a community setting. Many studies focused on formal care by child protection institutions or shelter homes such as the study conducted by Ezarina, Nur Saadah and Wan Nornazmiera (2018). Therefore this exploration is surely important in ensuring the needs of orphans' AIDS remain preserved while life in the home-based care setting, the study has explored and addressed the orphans' AIDS caregiving needs under the care of informal caregivers (under home-based care) based on Case Workers' perspectives.

Methodology

Research on orphan AIDS caregiving needs in the community has fully applied a qualitative approach (case study). The case study design was used as seen to fit the requirement of the study objective and data primer obtained directly from the one-to-one in-depth interview sessions. Apart from that, the purposive sampling method was applied to select research informants. A total of five caseworkers were selected to be involved as informants to obtain information on orphan AIDS caregiving needs in the community. The sample selection process is an important stage in this research, to ensure that sufficient information can be obtained from the selected sample (Ryan et., 2002). The research uses purposive sampling to select a sample from a population according to certain criteria in line with the purpose of the study (Calmorin & Calmorin, 2008). According to Sabitha (2005), researchers need to use their judgment to select the most appropriate informants and suit them accordingly to the purpose of the study.

Interview guidelines were constructed based on literature analysis that coincided with the scope of the study and was consistent with the formation of the objectives of this study. So two main sections of the interview questions were formed. Part A section discusses on informant profile, while part B refers to the informant's experience in managing orphan AIDS cases in NGOs and also in the community. Part B has produced data to answer the question of exploring the caregiving needs in the community from the informant's perspective in more depth. To ensure the comfort of the informants, informal and unstructured forms of interviews were used so they can answer all questions and be more open in sharing personal experiences.

The data analysis method is the process of organizing, structuring, and interpreting the collected data. The obtained data were analyzed using thematic analysis methods. This method of analysis was designed to find the themes (specific and general) from the collected data. The similarities and differences between the themes were grouped for further analysis. The analysis includes single-case analysis and cross-case analysis.

Result

Orphan AIDS caregiving in the community by the informal caregiver is nothing new in society nowadays. Responsibilities shifted after the death of orphan AIDS parents to extended families, adoptive families, or single-parent families have long been documented by previous researchers. The finding of this study reported the caregiving needs among caregivers who live in the community through the perspective of Case Workers. The selected informants in this study are professionals who work in non - governmental organizations (NGOs), and directly with informal orphan AIDS caregivers. All informants strongly emphasized the importance of exploring and discussing

caregiving needs aspects in more depth and widely to ensure that the psychosocial functioning of caregivers can be met and the development of AIDS orphans in care is also better. A brief profile of all informants involved in this study is shown in Table 1.

Table 1: Informants Profile

Case Worker	Age	Education	Position	Service Period (Year)	Family Caregiving Needs
CW 1	38	Master	Case Manager	10	Economy stability, knowledge, and skills, good health
CW 2	35	Degree	Case Manager	10	Economy stability, psychosocial supports.
CW 3	29	Diploma	Case Manager	2	Knowledge and skills, good health and nutrition, economic stability.
CW 4	32	Degree	Case Manager	3	Psychosocial supports, and economic stability.
CW 5	38	Degree	Case Manager	3	Good health and nutrition, knowledge and skills, and economic stability.

Through the thematic analysis conducted, these are four main orphan AIDS caregiving needs in the community. The four most important needs that informal caregivers need to emphasize are i) economic stability, ii) level of health and nutrition, iii) psychosocial support, as well as iv) knowledge and skills.

The stability in the family economy

Based on the interviews conducted, the researcher found all informants shared the same point of view about the importance of the issue of economic stability in the family during the orphan AIDS caregiving period. This can be identified through statements;

".....in my opinion, the most important caregiving needs before the caregiver takes over and transition responsibility happens in the upbringing of an HIV-positive child whose is lost their parents because of AIDS is economic stability. This is because most of the orphan AIDS caregivers live in urban areas, so the household expenses are high. Even those living in the suburbs also experience poverty..." (CW 1, 38 years old)

".....I think the economy greatly influences caregiving needs while nurturing individuals with HIV positive. As caregivers, they need to have a fixed and sufficient income to take care of new members of the family. If you want to take over the responsibilities of nurturing people living with HIV and AIDS, you need a relatively high budget. Seropositive children need good nutrients and nutrition to maintain antibodies, then if they started consuming HIV drugs for second-tier medication, the medicine is expensive, and it feels like they can't afford to buy if the economy is not sturdy. This second-tier medication is not free..." (CW 4, 32 years old)

".....in order to carry out the responsibilities as an orphan AIDS caregiver, the caregiver should be prepared from various aspects, especially the financial aspect. If you want to know, babies born with HIV need high treatment expenses, they can not consume normal milk because of allergies, and low antibodies level also cause the baby more susceptible to other diseases. So I think it's most important for grandparents, and other family members to have strong financial resources before they can take over the responsibilities for children with special needs like this...." (CW 5, 38 years old)

Economic stability is an important factor to ensure the caregiving needs of AIDS orphans in the community can be met. Apart from that, they also acknowledged urban poverty as

one of the challenges faced by AIDS orphan caregivers that directly affect the social functioning of their families.

Priority to caregivers with good health status

The analysis results showed that three out of five informants stated that the health status of primer caregivers is one of the important caregiving needs that we should emphasize together with time duration in the orphan AIDS care process. The first informant said;

".....here in this NGO, I can say that most of the orphan AIDS main caregivers are also those who are HIV positive, relatively older such as grandparents, and suffer from other chronic diseases such as diabetes, high blood pressure, and heart disease. So in my opinion, I would like to emphasize the need for orphan AIDS caregivers from a young, productive, and healthy group. But I did not mean, those who are sick are not qualified to be caregivers, they absolutely can take over the responsibility in nurture orphans, but first, they need to make sure they are healthy enough to carry out this heavy kind of responsibility. As we all know, caregiving needs covered treatment activities (monitoring medication time), caring, monitoring, and having to provide adequate basic needs. If the caretaker is sick, who will earn money for living....." (CW 1, 38 years old)

Further analysis found the health status of caregivers is important because the role of an orphans AIDS caregiver living in the community requires good physical as well as emotional fitness. The care of a seropositive child can cause an emotional burden due to stigma which certainly adds to the physical burden of the existing physical health status.

".....To me, if you want to take on orphans' AIDS upbringing responsibility, the caregiver must be healthy and free from any disease. That is one of the most important needs in families with AIDS orphans. If they are already sick before taking care of the child how can they provide good care at home? The opposite situation might happen, they become more stressed and experience more severe complications that affect their daily functioning....." (CW 3, 29 years old)

".....moreover, I think the other caregiving need in the community is an emphasis on the health status of caregivers. To be an orphan AIDS caregiver I think the health status screening should be done among the caregivers before the child is moved into a new home, so caregivers' psychosocial burden and emotional can be avoided. But we also have to understand, that some of these caregivers belong to the category of single mothers, widows, and no other qualified relatives are eligible

to take over the responsibilities after the death of orphan AIDS parents. So the unhealthy caregiver had to take care of and increased the burden of responsibility. Therefore, as the Case Manager, I am responsible for monitoring the caregiver at all times, just to ensure the unhealthy caregiver is also able to carry out social functions well to fulfill the children's welfare..” (CW 5, 38 years old)

Psychosocial supports

To make sure, the orphan AIDS caregiving needs can be fulfilled the researcher also suggested Case Workers monitor less fit caregivers while providing care, which is the informants also agreed on the importance of having enough psychosocial support throughout the process. Psychosocial support care is a necessity that should be emphasized in-depth.

“.....orphan AIDS caregivers live in the community it's not only dependent on financial help and food supplies alone. They also need help in psychosocial support from the family system, friends, and NGOs like us. Throughout the orphan AIDS upbringing period, caregivers are at high risk for experiencing depression. For example, there is a caregiver or client of this agency who is a single mother who is HIV positive, responsible as a single caregiver for orphan AIDS, and also a former victim of domestic violence. So she needs help in various aspects such as psychological due to her trauma, emotional help because of her loneliness and no one to speak on their worries, financial assistance for the insufficient monthly salary, and much more. Its shows that, responsibility as orphan AIDS informal caregivers is not easy. They should consider many things beforehand.....” (CW 2, 35 years old)

“.....and usually, the informal caregivers need extra psychosocial supports, they faced poverty issues and sometimes experience overly stress and a sense of fatigue. They tend to do 2-3 different jobs at a time just to meet their family members' and household needs. They are also highly exposed to stigma and discrimination and experience social isolation from the neighborhood once their status is noticed. To ensure their functionality is not disrupted and the responsibility of care can be carried out properly. I think the psychosocial support from various parties is important in helping AIDS orphans and families live in the community....” (CW 4, 32 years old)

Caregivers who take over the responsibility of care need to be prepared and able to provide a positive atmosphere to their children. At the same time, the need for psychosocial support for caregivers should also not be denied.

Knowledge and skills in managing AIDS orphan medicine routines

The analysis of interview data conducted found, the majority of informants stated that AIDS orphans need certain knowledge and skills.

".....knowledge and skills on HIV infection and managing orphan AIDS at home are important aspects throughout the nurturing process. Information on how to be infected, and how to take medication is important to all people living with HIV, including caregivers of HIV-positive children. The caregivers should be informative enough and know how HIV count works on the PLHIV body, they are responsible to ensure patient CD-4 counts are controllable and avoiding HIV infection in the family. Plus, I also agreed with that. The impact of skills is important for caregivers, especially in wound-handling situations. As a Case Worker at this NGO, I emphasize the updated information distribution and knowledge about HIV for home-based clients are compulsory..." (CW 1, 38 years old)

".....in my opinion, the need to acquire knowledge and care skills is one of the mandatory aspects we should emphasize for orphan AIDS families living in the community. The accurate information and methods in handling treatment at home must be memorized by the caregiver ..." (CW 5, 38 years old)

Uncertainty information about HIV / AIDS is mostly driven by stigma and discrimination. Since then, the misunderstanding of information about HIV/AIDS directly has left negative impressions, and affected and disrupted PLHIV and their family's social well-being holistically. Despite these fear being general, the family system itself is not exempt from experiencing and suffering the after-effects of this fear. Feelings of uncertainty and fear can be reduced when they, especially primary caregivers are provided with actual knowledge and skills about the medium of infection as well as the need to routinely monitor medications for AIDS orphans in their care.

Discussion

Case Workers are one of the vital professions in the social work field that provided direct services to individuals and families. Caseworkers are responsible for developing and maintaining interaction relationships between clients, and social systems so that efficient aid delivery and intervention can run effectively. Caseworkers' involvement in managing

and caring for AIDS orphans is seen to be increasingly widespread and important. Caseworkers is a profession that helps individuals solve personal, family, group, and community problems satisfactorily through social work practices (Sinikki, 2011; Farley, 2016). Thus, caseworkers have a role to help affected individuals recover, develop and maximize their ability to help themselves.

The research was conducted to understand the orphan AIDS caregiving needs for families living in the community from the perspective of caseworkers. Thus, the results of the study found there are several aspects of caregiving that need to be emphasized by informal caregivers while carrying out the nurturing responsibility for AIDS orphans after the death of their parents. From the perspective of the caseworkers involved in this study, the increase and change of roles as caregivers of AIDS orphans have had an impact on the economic stability of the family. Urban poverty and the hardships ensuing economically forced caregivers to do two to three jobs at a time, which indirectly affects their psychosocial well-being and daily life as a whole. The study by Deventer and Wright (2017) argues that economic burdens or strains and difficulty of getting on with life due to poverty cause caregivers to face psychosocial challenges thus affecting their function and role as caregivers to AIDS orphans.

The family's economic stability is important while carrying out the responsibility of nurturing orphans with AIDS. The economic stability status correlates with the emotional and psychological well-being of caregivers. Urban poverty issues faced by caregivers lead to unattainable fulfill the orphan AIDS caregiving needs who live in the community. A study by Rahmah and Norlinda (2015) found that the allocation of rental expenses and utility payments in urban areas is higher. Caregivers have already faced less stable financial conditions with existing family members. The transition and increase in responsibilities after the death of orphans with AIDS directly would affect their household system because the number needs to be supported also enlarged. However, inadequate income and elevated household expenses cause caregivers inability to carry out their nurturing responsibilities for orphans with AIDS properly.

In addition, the orphan AIDS caregiving needs also involve aspects of strengthening knowledge and skills. Informal caregivers should be provided with knowledge of HIV/AIDS infection as well as treatment and medication needs for AIDS orphans. The results from the study show informal caregivers have been provided with knowledge and skills, although case workers still provide guidance and always ensure their in-home care knowledge and skills are updated from time to time. Accurate knowledge and skill about HIV/AIDS infection will lower caregivers' emotional and psychosocial stress rates. Plus, it also helps to strengthen emotional relationships such as love and strengthen family dynamic patterns, while reducing stigma and uncertainty about illness and risk of death (Thampanichawat, 2008).

The caregiving need in the community should also emphasize the importance of health status and nutritional intake, especially for caregivers who are also HIV seropositive. The impact of HIV infection and old age factors not only cause caregivers to face difficulties in carrying out daily activities such as work but also in orphans with AIDS upbringing who are on average 4 to 18 years old because individuals at this age need tighter attention and control. So, caregivers' physical inability due to affected health factors can lead to the formation of a sense of lethargy, deadlock in problem-solving, and other negative emotional reactions. Family interactions, relationships, and activities in microsystems can influence caregivers' psychosocial development level.

Thus, self-formation such as aspects of behavior, attitudes, children's ways of thinking, and adolescents are influenced by family background. If the caregivers and family system of AIDS orphans suffer from emotional and psychological disabilities, then there is a high probability for AIDS orphans to also be affected by the negative environment. Therefore, orphan AIDS caregiving should also emphasize efforts to provide psychosocial support for informal caregivers living in the community. Psychosocial support should involve the interests in all aspects of life such as the interests of psychosocial, emotional, economic, medical, and dissemination of information.

Conclusion

In conclusion, to ensure the orphan AIDS caregiving needs in the community can be met and effective, more social support sources and assistance are needed especially involving aspects of home care or In-Home Care. Even though statistics show a decline in the number of death and percentage due to HIV/AIDS in recent years, the need for AIDS orphan care at home still needs to examine in depth. This is because HIV-positive children have the opportunity to live longer with the help of medical treatment as well as the balance of their psychosocial needs increases in youth and adulthood. The debate on the need for orphan AIDS care in the community should not involve knowledge and caring skills alone other aspects should be considered also. Aspects of economic stability, the health status of caregivers, and other psychosocial support sources need to be emphasized so the social functioning of the family system is not affected. At the same time, also increase confidence in Malaysia's health services and reduces stigma in the community towards the families of AIDS orphans. Furthermore, this study also indicated limitations in the sample sizes, due to the unclear statistic provided by the authority. This study faces difficulty in mapping out the informants in the research area (Kuala Lumpur and Selangor). Therefore, an upgraded sample size (the additional number of informants) is needed to make sure the results will be able to be generalized.

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