

Psychosocial Challenges Experienced by Children Affected by HIV-Related Loss

Caroline Rukunga, Ph.D., Alice Munene, PsyD; & Paul Mbutu, Ph.D., Daystar University

Abstract

Children affected by HIV-related loss go through considerable levels of physical and psychosocial challenges which may result in psychological disorders such as depression, anxiety and Post-Traumatic Stress Disorders (PTSD), among others. This study sought to establish the psychosocial challenges faced by children of between ages 8 and 12 who had lost a parent to AIDS or were living with a relative suffering from HIV-related illnesses. The study population was comprised of 210 children from two non-institutionalized children's organizations in Nairobi County, Kenya. All the selected participants signed the assent forms while their guardians signed the consent forms. The participants, both girls and boys with a mean age of 11 years, were purposively sampled. Data was collected using a socio-demographic questionnaire to gather data on socio-demographic characteristics of the participants and the psychosocial challenges that they encountered in life. Frequency analysis of the psychosocial challenges revealed that 63.8% of the 210 participants had fear of losing another person; 62.9% had fear of being infected by HIV; 45.2% had experienced a change of life status; 41.0% were faced with multiple losses and 40.5% were being blamed for the loss. Recommendations were made to the concerned organizations and stakeholders dealing with similar population to consider addressing both physical and psychosocial needs of HIV-affected children to ensure their overall well-being.

Key words: psychosocial challenges, HIV-affected, sibling separation, multiple losses

Introduction and Background

According to a report by the United Nations, little is known about children who have lost their parents through AIDS in terms of their psychological needs (Joint United Nations Programme on HIV/AIDS, 2010). Instead, much attention has been directed on their poverty, education, and health concerns, especially in sub-Saharan Africa. This could possibly be informed by the fact that poverty and disease as the child's survival concerns are highlighted among the United Nations Millennium Goals and physically observable (Joint United Nations Programme on HIV/AIDS, 2010). It could also be because funding agencies find it less involving when

addressing poverty and health issues than when dealing with complex and culturally sensitive psychosocial needs of bereaved children which are not only difficult to identify but also to address (Foster, 2007).

On the other hand, it is likely that the social and psychological issues of children with HIV-related loss are overlooked owing to their complexity in being identified and addressed accordingly. Another factor could be that some key people such as teachers and parents who spend most of their time with children may not possess adequate knowledge on their growth and development (Sengendo & Nambi, 1997). However, despite the above underlined challenges in identifying and dealing with children's psychosocial needs, if the affected children are not accorded enough security and love, there is danger that they might not have sufficient energy and motivation to care for themselves and others, as well as the confidence to learn and grow academically (Foster, 2007).

Reviewed literature has ascertained that orphans and particularly those resulting from AIDS experience more significant psychological distress than those orphaned through other means (Nyamukapa et al., 2010). For instance, Dowdney (2008) confirmed that death of a parent especially during childhood profoundly affects the child's psychosocial well-being, which could have a negative impact on their future. Such children are known to experience both social and psychological challenges, such as, stigmatization, the imminent or actual death of the surviving parent, interference with subsequent caregivers, sibling division, poor school attendance, potentiality of contracting HIV themselves and financial challenges (Belsey & Sherr, 2011; Li et al., 2008). It has also been established that the helplessness of the children caused by parental or close family members' death may intensify as deaths of more family members are likely to continue being experienced (Wood, Chase, & Aggleton, 2006).

It is obvious that with parents being the children's most significant guardians and partners in their key developmental milestones, losing one or both may be a very traumatic and disabling experience for a child (Chi & Li, 2013). Such an experience may result in aspects of grief such as denial, delusions of reunion with the deceased, the absence of overt expression, and persistent feelings of anger and blame, among others (Cluver & Gardner, 2006). In particular, the stigma

appended to the cause of the parent's illness and death has been found to inhibit children's expression of negative emotions, which, with time, may result in mental distress and high possibility of unresolved grief (Lin et al., 2014). This was verified through a study conducted by Nyamukapa et al. (2010) in Zimbabwe which found AIDS-orphaned children to have a higher chance of experiencing stigma than children from families free from HIV. The stigma could also be associated with the fact that HIV is mostly sexually transmitted making it possible for the disease and death clusters to run in families, thereby compromising caregiving and instilling feelings of shame.

Besides stigma, children affected by HIV and AIDS have been found to take up multiple caregiving tasks, such as taking care of themselves and their sick family members. They may also experience disruption of family routines, shifting of traditional family responsibilities and dropping out of school, among others (Zhang et al., 2009). It has further been established that apart from suffering psychological distress due to parental death, children may also suffer anticipatory grief following the long period of their parents' illness before they ultimately succumb to death (Rotheram-Borus, Stein, & Lester, 2006).

Specifically, Cluver, Orkin, Gardner, and Boyes (2012) associated traumatic life events among children affected by HIV and AIDS with pathologies such as PTSD, anxiety, and depression. They argued that such pathologies are caused by the kind of distress children go through, among which are lack of homes, relocation, discrimination in treatment, inadequate resources, stigma and several deaths of the family heads to AIDS. This compares closely with a recent research by Sherr et al. (2014) that found HIV infection as resulting in severe and long-lasting financial constraints including low family income, high health care expenses, and limited savings in families. As a result, the living conditions of children and their level of care especially in regard to food security, medical care, and availability of household heads is indirectly affected (Cluver et al., 2012; Delva et al., 2009; Nyamukapa et al., 2008). In essence, the above challenges are likely to hamper the grief process, exposing the children to a higher risk of long-lasting psychological and behavioural problems (Cluver & Gardner, 2006).

Informed by the above findings, this study sought to establish the various psychosocial

challenges that children who have lost their parents to AIDS or are living with guardians and relatives with HIV-related illnesses go through.

Methodology

This research was conducted in two children's organizations purposely selected due to their similarity in relation to demographic characteristics as they were both located in slums within Kawangware sub-County, Nairobi County, Kenya. A total of 210 participants of between ages 8-12 years were involved in the study out of which, 110 (52.4%) were boys and 100 (47.6%) were girls. The participants with a mean age of 10 years were purposively sampled. Data was collected using a socio-demographic questionnaire to gather data on socio-demographic characteristics of the participants and psychosocial challenges that they had encountered in life. A total of 18 psychosocial challenges were listed for the participants from which to select the ones they were facing. A frequency analysis was done that indicated the level at which the participants were affected by the listed challenges. Data was presented by use of a table. Codes were used instead of real names for all the participants' documents to ensure anonymity was maintained during the data collection process.

Results

The demographic characteristics of the participants are as shown in Table 1.

Table 1: Distribution of Socio-Demographic Characteristics of Participants by Study Groups at Baseline

Variables	Total(n=210)	%
Age		
8 & 9 years	61	(29.0%)
10, 11 & 12 years	149	(71.0%)
Gender		
Boy	110	(52.4%)
Girl	100	(47.6%)
Birth position		
First born	44	(21.0%)
Middle born	67	(31.9%)
Last born	83	(39.5%)
Only child	16	(7.6%)
Class		
Lower class (3-4)	106	(50.5%)
Upper class (5-7)	104	(49.5%)

The study sample comprised 210 participants from two selected organizations. A relatively high proportion of the participants (71.0%) were aged 10–12 years with the least (29.0%) falling between age 8-9 years. Regarding gender, the boys were slightly more (52.4%) than the girls (47.6%). In terms of class in school, those from lower class were slightly more (50.5%) compared to those who were in upper classes (49.5%). In relation to their birth positions, the majority of the participants were lastborns (39.5%), followed by middleborns (31.9%), then firstborns (21.0%) and the lowest birth position in terms of representation was the/an only child (7.6%). These showed that among the study participants, the lastborns were more highly represented than those who had no siblings.

Frequency analysis was used to identify the various psychosocial challenges that the 8-10-year-olds who were affected by HIV-related loss faced. According to the findings, the most prevalent included fear of losing another person (63.8%), fear of being infected by HIV (62.9%), change of life status (45.2%), multiple losses (41.0%), being blamed for the loss (40.5%), being bullied (29.0%), sibling separation (23.8%), and relocation from home (21.4%). Though the rest of the challenges reported by the participants were low in frequency, they too played a role in determining the psychological state of the affected individuals as established by various studies. The frequency analysis results are as shown on Table 2.

Table 2: Psychosocial Needs Experienced by Children Affected by HIV-Related Loss

Psychosocial needs (N=210)	Frequency (% , n)	
Fear of losing another person	63.8% (134)	Dis cus sio ns Th e abo ve fin din gs agr
Fear of being infected	62.9% (132)	
Changing life status	45.2% (95)	
Multiple losses	41.0% (86)	
Others blaming you	40.5% (85)	
Bullying	29.0% (61)	
Guilt	24.8% (52)	
Siblings separation	23.8% (50)	
Relocation from home	21.4% (45)	
Feeling shame	19.0% (40)	
Stigma	17.6% (37)	
Competition for love	17.1% (36)	
Inconsistent caregivers	12.9% (27)	
Discrimination in treatment/care	11.4% (24)	
Lack of good care	11.4% (24)	
Neglect and abuse	7.1% (15)	

ee with those from previous studies that, indeed, children going through HIV-related loss not only suffer physical loss due to lack of basic needs but also experience psychological distress at the loss of their attachment figures (Cluver, Gardner, & Operario, 2007; Harms, Jack, Ssebunnya, & Kizza, 2010). For instance, Cluver and Gardner (2006) established that besides grief, children who lose their parents through AIDS face other psychological and social problems that impact greatly on their general well-being, namely stigma and discrimination due to the nature of the death of their parents, uncertainty regarding the effectiveness and consistency of their subsequent caregivers or guardians, and unpredictable financial resources. Further, a study by Betancourt et al. (2010) found children going through HIV-related loss to be at a risk of developing depression and anxiety as a result of being separated from their attachment figures, loss of a home, failure to continue with education, stigma, discrimination and guilt as some imagine they may be the cause of their parents' deaths.

The above study findings appear to explain why in the present study, the majority of the participants reported fear of losing another family member as a major challenge they experienced. This finding demonstrates how HIV-affected children get psychologically tormented as they observe their parents agonize in pain during moments of prolonged sickness

before they become disabled and ultimately succumb to death, leaving them as orphans. Borrowing from Cluver and Gardener's (2006) earlier findings, the fear and anxiety by the affected children over the imminent or actual death of their surviving parent may be informed by the uncertainty regarding the efficiency and reliability of the subsequent caregivers, and especially where the sick family member is the present guardian.

The above discussions are also in keeping with the findings by Dowdney (2008) who asserted that AIDS-orphaned children are faced with the challenge of being placed under a different care that may result in a different life approach in relation to the age of the subsequent caregivers, their economic status and emotional disposition. Clearly, in a situation where the caregivers are elderly or affected by similar loss, or are financially challenged, such an experience is likely to greatly hinder smooth adjustment process for the affected child, both physically and emotionally. Considering that the current study was carried out within a slum setting, with the majority of the participants having relocated from their homes closer to the sponsoring organization, it is likely that just the thought of losing another key family members would lead to psychological distress for the children and result in their being placed under a different care.

Although Bowlby (1980) and Fraley and Shaver (1999) had argued that there is a possibility of the child adjusting easily in a situation where there is quality relationship between the bereaved child and the subsequent caregiver, this may not be the case for the participants of this study. With the majority of the current study participants living in a slum, the environment might not be safe enough to ensure optimal development and reasonable emotional regulation for the child. Bowlby (1988) therefore recommended that a good relationship between a child and at least one primary caregiver should be maintained to ensure the emotional survival of the child. In view of the above therefore, knowledge on attachment is crucial for the caregivers and therapists as it would help in dealing with bereaved children to facilitate their emotional growth as well as build their resilience.

Besides, 41% of the participants reported that they were psychologically disturbed by the fear of a death or multiple deaths in their families. The fact that HIV is majorly transmitted through sex could mean the possibility of the disease and death clusters running in the families, which could further compromise caregiving, and in consequence instill feelings of fear and anxiety in the

children. According to Bowlby (1989), such an experience exposes a child to a risk of particularly developing separation anxiety as their search for proximity with the caregiver could be halted. It is also worth noting that as Wood et al. (2006) explained, the feeling of helplessness in children caused by parental or close family members' deaths may intensify as deaths of more family members continue to occur, thus resulting in a high possibility of their exhibiting symptoms of depression and Post-Traumatic Stress Disorder.

Another challenge that came out strongly as affecting the psychosocial lives of the participants in this present study is the fear of being infected by HIV as indicated by an elevated score of 62.9% of the total population. It is imagined that children living for a prolonged time with parents or guardians who are sick of AIDS would be a threat to their psychological well-being. Though not many studies have established this as a common psychosocial need for this kind of population, Belsey and Sherr (2011) and Li et al. (2008) found the potentiality of children contracting HIV themselves and financial constrains as a major challenge for such children.

Change of life status also came out as profoundly affecting the psychosocial life of the participants in the current study at 45.2%. This finding is in agreement with a study done in Rwanda by Betancourt et al. (2010) that at some point children suffering from parental loss get psychologically affected when their living situations are negatively affected by death or prolonged illness of their parents or caregivers. This is especially when some have to move from high level status urban homes to low level rural homes of their relatives away from other siblings, while others have to stay alone in child-headed families.

The above discussion compares closely to a research by Sherr et al. (2014) that found HIV infection as resulting in severe and long-lasting financial constraints including low family income, high health-care expenses, and limited savings in the families. This consequently ends up affecting the children's living conditions and level of care, especially in regard to food security, medical care, and availability of household heads (Cluver et al., 2012; Delva et al., 2009; Nyamukapa et al., 2008).

Sibling separation and relocation from home of origin are other psychosocial challenges faced by participants in this study. It is common practice that once parents die or are rendered disabled by

poor health, children may be taken by extended family members who may be living far from the children's homes of origin. Sometimes where children are more than one, they may even be placed under different caregivers resulting in both sibling separation and relocation from home. Such an experience to a child is quite stressful and may be the reason the majority of the current study participants ended up exhibiting high levels of anxiety and depression symptoms. It is therefore necessary that the needs of children affected by HIV and AIDS be looked into beyond the physical needs, such as education, food and shelter. Failure to address the above psychological needs in good time might lead to psychological disorders such as depression and anxiety, as this study has found out.

Research work done on the same population in other counties in Kenya may have different results. therefore, a similar research can be done with adolescents faced with HIV-related loss for comparison. In addition, a comparative study between children affected by HIV-related loss and those affected by loss not associated with HIV would be crucial.

Conclusions

Generally, the above discussions illustrate that just as it happens with adults in the face of loss, children are not exempted, hence the reason they may require psychosocial support to help them appropriately resolve their grief challenges as well. Otherwise, it is the failure to notice and address the above vulnerable children's challenges that may consequently lead to the development of disorders such as depression and anxiety in such children.

References

- Belsey, M. A., & Sherr, L. (2011). The definition of true orphan prevalence: Trends, contexts and implications for policies and programmes. *Vulnerable Children and Youth Studies*, 6(3), 185-200. doi: 10.1080/17450128.2011.587552.
- Bowlby, J. (1980). *Loss: Sadness and depression*. New York, NY: Basic Books.
- Bowlby, J. (1988). *A secure base: Parent-child attachment and healthy human development*. New York, NY: Basic Books.
- Bowlby, J. (1989). The role of attachment in personality development and psychopathology. In S. I. Greenspan & G. H. Pollock (Eds.), *The course of life, Vol. 1: Infancy* (pp. 229-270). Madison, CT: International Universities.
- Chi, P., & Li, X. (2013). Impact of parental HIV/AIDS on children's psychological well-being: A systematic review of global literature. *AIDS and Behavior*, 17(7), 2554-2574. doi: 10.1007/s10461-012-0290-2.
- Cluver, L., & Gardner, F. (2006). The psychological well-being of children orphaned by AIDS in Cape Town, South Africa. *Annals of General Psychiatry*, 5(8), 423-434.
- Cluver, L., Gardner, F., & Operario, D. (2007). Psychological distress amongst AIDS orphaned children in urban South Africa. *Journal of Child Psychology and Psychiatry*, 48(8), 755-763.
- Cluver, L., Orkin, M., Gardner, F., & Boyes, M. E. (2012). Persisting mental health problems among AIDS-orphaned children in South Africa. *Journal of Child Psychology and Psychiatry*, 53(4), 363-370.
- Delva, W., Vercoutere, A., Loua, C., Lamah, J., Vansteelandt, S., De Koker, P., ... Annemans, L. (2009). Psychological well-being and socio-economic hardship among AIDS orphans and other vulnerable children in Guinea. *AIDS Care*, 21(12), 1490-1498. doi: 10.1080/09540120902887235.
- Dowdney, L. (2008). Children bereaved by parent or sibling death. *Psychiatry*, 7(6), 270-275. doi: 10.1016/j.mppsy.2008.04.007.
- Betancourt, T. S., Rubin-Smith, J. E., Beardslee, W. R., Stulac, S. N., Fayida, I., & Safren, S. (2010). Understanding locally, culturally, and contextually relevant mental health problems among Rwandan children and adolescents affected by HIV/ AIDS. *AIDS Care*, 23(4), 401-412. doi: 10.1080/09540121.2010.516333.
- Foster, G. (2007). Beyond education and food: Psychosocial well-being of orphans in Africa. *Acta Paediatrica*, 91(5), 502-504.

- Fraley, R. C., & Shaver, P. R. (1999). Loss and bereavement: Attachment theory and recent controversies concerning "grief work" and the nature of detachment. In J. Cassidy & P. R. Shaver (Eds.), *Handbook of attachment: Theory, research, and clinical applications* (pp. 735-759). New York, NY: Guilford.
- Harms, S., Jack, S., Ssebunnya, J., & Kizza, R. (2010). The orphaning experience: Descriptions from Ugandan youth who have lost parents to HIV/AIDS. *Child and Adolescent Psychiatry and Mental Health, 4*(1). doi: 10.1186/1753-2000-4-6
- Joint United Nations Programme on HIV/AIDS. (2010). *Global report: UNAIDS report on the global AIDS epidemic 2010*. Geneva, Switzerland: Author.
- Li, X., Naar-King, S., Barnett, D., Stanton, B., Fang, X., & Thurston, C. (2008). A developmental psychopathology framework of the psychosocial needs of children orphaned by HIV. *Journal of the Association of Nurses in AIDS Care, 19*(2), 147-157. doi: 10.1016/j.jana.2007.08.004.
- Lin, X., Fang, X., Chi, P., Li, X., Chen, W., & Heath, M. A. (2014). Grief-processing-based psychological intervention for children orphaned by AIDS in central China: A pilot study. *School Psychology International, 35*(6), 609-626.
- Nyamukapa, C. A., Gregson, S., Lopman, B., Saito, S., Watts, H. J., Monasch, R., & Jukes, M. C. (2008). HIV-Associated orphanhood and children's psychological distress: Theoretical framework tested with data from Zimbabwe. *American Journal of Public Health, 98*(1), 133-141.
- Nyamukapa, C. A., Gregson, S., Wambe, M., Mushore, P., Lopman, B., Mupambireyi, Z., ... Jukes, M. C. H. (2010). Causes and consequences of psychological distress among orphans in Eastern Zimbabwe. *AIDS Care, 22*(8), 988-996.
- Rotheram-Borus, M. J., Stein, J. A., & Lester, P. (2006). Adolescent adjustment over six years in HIV affected families. *Journal of Adolescents Health, 39*(2), 174-182.
- Sengendo, J., & Nambi, J. (1997). The psychological effect of orphan hood: A study of orphans in Rakai district. *Health Transition Review, 7*, 105-124.
- Sherr, L., Cluver, L. D., Betancourt, T. S., Kellerman, S. E., Richter, L. M., & Desmond, C. (2014). Evidence of impact: Health, psychological and social effects of adult HIV on children. *Aids, 28*, S251-S259.
- Wood, K., Chase, E., & Aggleton, P. (2006). 'Telling the truth is the best thing': Teenage orphans' experiences of parental AIDS-related illness and bereavement in Zimbabwe. *Social Science & Medicine, 63*(7), 1923-1933.
- Zhang, J., Zhao, G., Li, X., Hong, Y., Fang, X., Barnett, D., ... Zhang, L. (2009). Positive future orientation as a mediator between traumatic events and mental health among children

affected by HIV/AIDS in rural China. *AIDS Care*, 21(12), 1508-1516.