A phenomenal of 'Social Loathing': Psychosocial Experience of Double Orphans before and after the Death of their Parents from HIV

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Abstract

The rate of new HIV infection is declining in Ethiopia. However, reduction in registered prevalence alone is not sufficient as the psychosocial impacts of the disease are still persistent. Little is known how family members experience stressors from the progressive illness and death of parents, how did they experience with changes in different care services? Hence, the purpose of this study was to explore and understand psychosocial experiences of HIV orphaned children. Fifteen double orphaned children, five care givers and five community leaders were identified by purposive and snowball samplings for interview. Focused group discussions were also conducted. Data were analyzed on progressive levels from pre-death to post-death experiences. Findings indicated that double orphans were vulnerable in many ways, and their vulnerability was more serious when they became the head of the family. The existing practices of care and support were focused on meeting their daily physical needs and were not meeting their psychosocial needs. The study illustrates that HIV/AIDS has impacted negatively on the psychosocial experiences of children including: abuse, fear, grief, loss of self-esteem, stigma and discrimination and social isolation. Children's experience can, therefore, be considered as a phenomenon of social loathing. These findings can be used as preliminary data supporting more researches to profoundly explore the psychosocial impact of parental loss on children and appropriately indicate the need for interventions.

Keywords: Double orphan, Parental loss, HIV orphan

1. Problem Statement

Of all life stresses a child might experience the death of a parent seems most devastating, the least reparable, and holding the greatest potential for harmful psychosocial consequences (Altshuler & Poertner, 2002; UNAIDS, 2004; UNICEF, 2002). Children's lack of continuous relationship with their mother and father are subject to maternal and paternal deprivations and may be implicated in the development of immediate, intermediate, and long-term psychiatric morbidity (Anthony, 2001; Case, 2003; Bowlby, 2001). Children's adversity following parental death (such as stigma, abuse, displacement, dropping out of school) may also eliminate contact with self-esteem-supporting caregivers and peers and reduce opportunities for self-esteem-enhancing activities (e.g. social activities) (Wolchik et al., 2006).

Of all children who have lost their parents, the largest group has lost their parents from HIV/AIDS more than any other causes of death (Bishani, 2005). Since HIV can spread sexually between father and mother, once AIDS has claimed the mother or the father, children are far more likely to lose the remaining parent (Altshuler & Poertner, 2002; UNICEF, 2002; UNAIDS, 2004) and experience the emotional trauma that results (Bradshaw et al., 2002).

The vulnerability of AIDS orphans starts with their parents' distress and progressive illness well before the death of parents (Brown, 2000; Giliborn, 2002). Children living with the dying parents experience many negative changes in their lives and start to suffer neglect, including emotional neglect even before the death of their parents (Levine & Foster, 2000). They often find themselves taking the role of a mother or father or both (Gust, 2001) doing the housework, looking after siblings (Ntozi et al., 2001), and carrying for ill or dying parents (Giliborn, 2002). They then have to adjust to a new situation, with minimum or no support and may suffer exploitation and abuse (MOH, 2002; MOLSA, 2003).

Children grieving for dying or dead parents are often stigmatized by society probably through association with HIV/AIDS (Tsegaye, 2001). The distress and social isolation experienced by these children is strongly exacerbated by the shame, fear and rejection (UNAIDS, 2002a) that often surround people affected by HIV/AIDS. Because of this stigma and often-irrational fear (ibid) surrounding AIDS, children may be denied access to schooling and health care. Often children who have lost their parents to AIDS are assumed to be infected with HIV themselves. This further stigmatizes the children and reduces their opportunities in the future.

More research is needed to better understand the psychosocial impact of HIV/AIDS on double orphans and appropriately indicate the need for interventions. This study takes the first step toward understanding the psychosocial experiences of double orphans. The study explores the psychosocial problems experienced by these children including emotional problems, interpersonal relationships, and stigma and discrimination. Understanding such orphans may help social workers and/ or other professionals to design services to meet their multifaceted needs. The objective of this study was, therefore, to examine and understand the psychosocial problems experienced by HIV double orphans in different care services. Hence, the study examined the following major research question:

What are the psychosocial experiences of HIV orphaned children before and after the death of parents with in different care services?

2. Literature Review

In sub-Saharan Africa there were 43 million orphans, representing more than 12% of all children (UNAIDS, 2004). Ethiopia is one of the countries in sub-Sahara Africa with the highest prevalence rate of HIV infection and AIDS-induced death. Children, as many as 3 million, are estimated to be orphaned because of the death of parents infected by the virus. About 539,000 children in Ethiopia have lost one or both parents in 2003 alone (Disease Prevention and Control Department of Ministry of

Health, 2005). According to research commissioned by the Nelson Mandela Children's Fund (Thompson, 2001), these children were found, among others, to suffer as a result of deprivation of parental guidance, emotional trauma as a result of the loss, and the problem of having to cope with adult responsibilities prematurely. In view of all these and other related findings, one would argue that AIDS orphans are more vulnerable than other children, for example, children affected by war (Belay, 2005). In a study conducted on resilience and coping of war and HIV/AIDS affected children in four African countries, including Ethiopia, it was found that the HIV/AIDS affected group was less resilient and less likely to be restored to effective coping skills.

According to Fourier and Schonteich (2004), HIV ultimately makes people ill but it runs unpredictably. There are typically months or years of stress, suffering or depression before a patient dies. It is said that the psychological impact on a child who witnesses his parent suffering one time, seemingly recovering another time for an extended period, and inevitably dying of AIDS can be more intense than for children whose parents died from a more sudden cause. Under such conditions, recovering from parental bereavement is so lengthy and severe that it may sometimes be seriously compromised (Korcza, 2005). Although they face loss and grief like any other orphan, their loss is exacerbated by prejudice and social exclusion because HIV/AIDS is an illness of social stigma (USAIDS, 2004; UNICEF, 2002; UNAIDS, 2002b). The shame, fear and rejection often surrounding people affected by HIV/AIDS can create additional stress on and isolation of children both before and after the death of their parents (Fourier & Schonteich, 2004). They are ostracized by their communities and exploited financially (Thompson 2001). Moreover, the death of parents with AIDS often leads to expulsion from their parental residence (MOLSA, 2003) and /or loss of parental homes (FHI, 2002) for the majority of AIDS orphans. Many studies indicate that AIDS orphans (Fourier & Schonteich, 2004) are the first to be denied education when extended families cannot afford to educate all the children of the household. They were abused, raped and drawn into prostitution rings (ibid) particularly by neighbors and relatives (Thompson, 2001).

As an aftermath, many young orphans come now under the care of overtaxed elderly grandparents, or of older siblings in child-headed households who have little knowledge about the needs of children (Korcza, 2005), low income and educational backgrounds and, hence are unable to provide for the physical, educational and health needs of the child (MOLSA, 2003). Studies indicate that AIDS orphans live below the absolute poverty line (Fourier & Schonteich, 2004), thus running a greater risk of being malnourished and hence, growth stunted (Korcza, 2005). Orphaned households often have more children, larger family sizes, and hence less favorable dependency ratios (Fourier & Schonteich, 2004).

Compared to other children, AIDS orphans are likely to be more vulnerable mainly because of the nature of HIV/AIDS. Their care and support was characterized by four patterns: provision of no support (or indifference), provision of support in a wrong way, provision of negative support (eg, stigma, discrimination, abuse), and/or reversed provision of support in which children care for others rather than being cared for by adults (Belay, 2005).

3. Method

The study collected qualitative data using semi-structured interview and focus group discussion. The life experiences of double orphans before, during and after the death of their parents in different care settings: in the home together with the dying parents; living with relatives/extended families after the death of parents and finally in the children's village institution were examined.

3.1. Study Participants

Community ("Idir") leaders were approached to participate in the study. They should be able to provide information on (1) the HIV/AIDS epidemic situation in the community, (2) living situation and experiences of double orphans, and (3) perceptions on the psychosocial needs of

children whose parents were affected by HIV/AIDS. Five interviews were held with key community informants. Caregivers were selected based on their (1) stay of the institution, (2) institutional position, and (3) level of education. Finally, to recruit double orphans inclusive criteria were used. The following steps were employed:

- 1. The institution called Children's Village was selected based on prior experience to the institution.
- 2. Lists of children registered as a member (beneficiary) of the institution, whom they considered as orphans due to HIV (one or two parents), were obtained.
- 3. Orphans who lost both parents were selected from the list.
- 4. Orphans whose age was greater or equal to 13 who could readily narrate their stories were selected.
- 5. Those who were willing to participate and discuss issues openly were selected.
- 6. Finally with the support of institutional documents and principals in the institution 15 double orphans were selected as the main informants of this study.

Institutional ethics approval to conduct the study was obtained from Children's Village. The interviewer talked to the participants about the aim of the study and started the informed consent process. Informed consent was obtained before interview directly from caregivers and key community informants. For children, caregivers provided consent. Informed consent contained information about the purpose of the study, voluntary participation, potential risks and benefits of participation, and confidentiality.

3.2. The Interviews

The interview questionnaire was prepared and revised with the help of academic colleagues. The time and place of interviews were decided through mutual agreement. The duration of each interview ranged from 30 min to 1.5 hours. All interviews were recorded. During the interview sessions the relationship was simply open, friendly and attractive that we, the researcher and respondents enjoyed, except in some cases where children had painful memories in telling their stories.

3.3. Data Analysis

In collaboration with the principals of the Children's Village, the researcher used the identified orphans to select the respondents. Fifteen double orphans ranging in age between 13-15 years of age were selected and interviewed. Each interview was tape recorded and an independent transcription was made immediately after the interview. To keep the trustworthiness of the data, the recorded Amharic version was given to a language instructor for transcription. The researcher's transcription was compared with a language instructor's interpretation which resulted in insignificant differences. To analyze the data the researcher started reading the transcribed data and notes recorded during the interview were read. For confidentiality, the informant names were changed. transcripts were coded and analyzed by the researcher. After careful and repeated examination of the transcripts, categories and subcategories of analysis were developed. Constant comparative method was employed to facilitate theme development. In the categorizing data step, groups were created for children, caregivers and community informants. In the comparing data step, similarities and differences within and between groups were compared to detect patterns, variations, or concepts. The categories of themes evolved during the analysis, as more patterns, variations and concepts were identified. Analysis was further accomplished by identifying the themes that emerge most frequently across the transcripts. Valuable individual experiences were also narrated.

Efforts were made to collect in-depth data from the informants. In the researcher's opinion the very fact that the respondents consider themselves and are externally designed as beneficiary had a deceptive implication. The data are retrospective and therefore dependent on the memory of the respondents.

4. Findings

4.1. Experience of parental death

The respondents' stories depict that parents didn't take important measures to direct children on how to manage their life without them that may eventually support on children's coping adaptation and resilience. The majority of children had no information as to whom to contact when they needed support. Children themselves were the primary source of support for their sick parents, which was a challenging experience for them. Parents did not openly discuss with members of the family, though some of the respondents realized that, their parents were living with HIV. This made life difficult for them and their siblings. Some parents gave them hope by telling them that they were getting better and would recover. The reality was the reverse, their health was deteriorating and that made it even more difficult to accept the loss of their parents. Some remarked their experience:

My mother had been on bed for a long time. I did not know what was happening to her. She had never communicated (a girl, P 12). I was so scared that she may die. She did not say anything (A boy, P7).

While parents are in the dying process, some children reported that they did not witness what was happening. But as some reported seeing parents dying, they shouted, cried, shocked and fainted. During the burial process some were deliberately kept away from witnessing and participating in the burial ritual for beliefs that they may be disturbed by observing what was happening in the process. After the burial, all of the family members were expected to pass through a lengthy process of grieving. A number of rituals were successively observed for days and months in remembrance of, and to blessing the soul of the deceased (For example, intensive mourning days – expressing condolence).

No doubt, loss of parents brings a number of changes in the life of children including a change in the care taker, a redefinition of a role (Urassa et al., 2001) a change in daily routines, and a change in lifestyle. The majority reported sadness and tears when talking about their lost parents. Two orphans did not mention such feelings because they were very young when their parents died. Two children were held from knowing the truth about their parents' death. In some cases, children choose to deny the truth of parental illness or death, and avoid thinking about anything unhappy. One girl stated "I just do not want to think about my parents' death I just want to live a happy life".

Though many Ethiopians habitually are involved in working for a living even with the presence of parents, children reported that the type and amount of working roles considerably changed with the death of parents. They began working to substitute their parents without required, abilities, skills and strengths, which obviously meant over- work followed by irregular class attendance consequently resulting in dropout from school.

Children experienced constrictions in their social life after the death of their parents. Friends and relatives of parents who used to visit their homes during parental presence were seen vanishing away after parental death. Although neighbors offered them some material provisions occasionally, they reported lesser connection with neighbors after their parents' death. For example, calling each other for coffee and other social occasions, borrowing and lending items, barely occurred after the death of parents.

There are many children who take over the responsibility of the family headship with the death of parents. Responsibilities like managing the family and siblings, working for income, and caring for siblings. Children felt unhappy because of what was happening to their siblings: being unable to satisfy their basic needs, difficulty in paying siblings' school fees and holiday needs, difficulty in finding jobs, etc. Meeting the material needs of siblings, handling younger siblings' demands for lost parents, settling conflicts with neighbors, and dealing with feelings of parental loss are amongst the major problems reported by respondents.

Some children felt they grew more mature from the painful change in family situation. One boy spoke about his increased responsibility for his family members, "I am the only male in the household I think it is my duty to take care of my sisters and help them with housework."

4.2. Children's Experience under Grandparents Care

Like children, it appears that HIV/AIDS has brought a role reversal among the elderly. Usually grandparents accept these responsibilities. But the major challenge is that it is occurring at the time of aging. It appears that the loss of parents is the source of challenge and distress for grandparents and to the orphans as well, the children reported. On the one hand, they are unable to meet the basic needs of their children, and on the other hand, they are highly worried about the future of their grandchildren. Grandparents are also vulnerable to different illnesses as well. Children reported such conditions forced them to consider institutional care as the best solution. One boy reported his experience: "I am really worried about my grandparent. He has been sick in bed since my dad died." The loss often worsened the life condition of grandparents which is already delicate. Despite the challenges, most orphans reported better care by grandparents: less abuse, replacing parents, their commitment gave high morale and others.

4.3. Children's Experience in Institution

Once children were institutionalized, they possibly face psychological and social problems as they are outside a commonly understood home environment. Some respondents mentioned that there were times when food may not be provided sufficiently. And coming to the institution was followed by separation from their younger siblings and other relatives, and it was simply the beginning of a new life. Other services provided by the institution were almost non-existent. Poor dressing, lack of stationary items made some of the orphans stop going to school or get involved in fights and also perform poorly academically because they felt inferior to others. From their perspective the focus of the principals in the institution was to meet their basic physical needs.

Caregivers, during the interviews, reported experiences of stigma and discrimination against the orphan children. Orphans were stigmatized by their peers because their parents had HIV/AIDS or died of AIDS. For these children, the feeling of stigma was often attributed to ignorance about their claims and strongly correlated with rejection. A community leader added his experience "one day when I was on my way home, I met a girl age 15 weeping. I asked her, and told me she was abused by her classmates in saving, 'your dad has that disease [AIDS]; you shouldn't be in the same class with us". One girl talked about her feeling, "I do not know how they [the classmates] knew that [my dad died of AIDS] I am so embarrassed that sometimes I even do not want to go to school anymore." Caregivers were concerned that due to lack of friendships, these children might turn to others in the community and get involved in risky behaviors/ activities. The deaths of parents make them feel guilty in front of others. Some may become introverted and rarely communicate with others; some children got involved with a bad crowd. They learnt to smoke, drink, and even use drugs. Children were also able to find ways to express their feelings and make themselves feel better. A community leader talked about one orphan: "One day he came to my house and told me that he wanted to work and live his own independent life than living in the institution. He wanted the work because he believed it could make him feel better. That event helped me think of the situation of orphans in the institution".

Community leaders reported non-discrimination in the community. The people are not afraid of HIV/AIDS. May be some people will look down on them and keep away from them, but most people are definitely willing to help. Leaders also reported the change of attitude toward people living with HIV/AIDS in the community. We have launched lots of educational campaigns focusing on the prevention of HIV/AIDS. Now the attitude towards people living with HIV/AIDS has changed a lot. Many of us spontaneously act out to help those children with their basic material needs and other things. The double orphans seemed to be holding on to unresolved life crises, ranging from a lack of or occasional trust to role and identity confusion. In some instances they succeeded in resolving their life crises, yet in most cases they suffered identity diffusion, a lack

of stability and feelings of being threatened by life encounters that were ruled by both rational and irrational childhood experiences.

5. Discussion

This finding indicated that orphans living in HIV/AIDS affected families were suffering from a number of psychosocial problems, which is in line with previous studies (Atwine et al., 2005; Makame & Grantham-Mcgregor, 2002; Nyambedha et al., 2003). The dimension of psychosocial problems varies among children of different orphan status. For those who had lost both parents, sadness and grief were the most common feelings. Our findings seemed to suggest that children could clearly remember the scene when their parents died years ago. Older children tended to silently bear the grief of loss and do not tell their caregivers. This is in line with findings of another study (Woodring et al., 2005). As a result, adults might ignore the real feelings of children and fail to provide proper emotional support for them (Foster, 2002). This suggests that it is necessary to increase caregivers' capacities to monitor and deal with children's psychosocial problems in intervention programs.

They were found to have many problems, concerns, needs and worries. Respondents indicated experiencing a number of changes in life patterns (including a change in the care taker, a redefinition of roles, and change in daily routines) and also receiving different types of care and support before, during and after parental loss. Although they worked for a living, they hardly managed their and their young siblings' basic needs. They seriously struggled with meeting their daily material needs including food, clothing and more importantly to their younger siblings, the need for educational materials.

These same struggles tended to cast shadows on the perception of their future life because, asked to describe their feelings, they have serious concerns about the future. Expenses needed for observing at least major holidays of the year were another source of concern that usually made them and younger siblings remember their parents. More importantly paying school fees and buying educational materials were also repeatedly mentioned. In fact, some caregivers have reported that they are trying

their best to save the soul at least on an individual basis providing support that ranges from buying educational materials to counseling and advising.

In addition to unmet basic needs respondents' also indicated problems of a psychosocial nature: a sense of missing parental love and care, a decline in self-confidence, loneliness, poor social interaction, inappropriate help-seeking behavior and feeling unprotected and vulnerable. These concerns show that respondents and their younger siblings need not only material but also psychosocial support. Although respondents were appreciative of different persons for giving a hand in this regard, they felt the support obtained from relatives, institutions and others has not met the growing material needs. It is, however, encouraging to note that with all these problems, respondents also manage to maintain a vision for their lives. Most of them have hope to continue their education, get good marks, and complete their education.

One respondent described his experience saying, "I remember the lost parents whenever issues related to parents are raised." He was depressed and weeping seeing the photographs of his parents. Going back to before the parents died, one can reiterate that there are a number of pre-parental loss experiences that contribute to coping mechanisms to deal with the loss. Once respondents were engaged in nursing sick parents, it seems as if helping helps. That is despite the problems encountered nursing for their sick parents; many assumed the responsibility by themselves. They described that it was a good thing that they cared for their sick parents. In fact, training how to care could be important because as indicated by respondents, they did not even recognize the very need for taking protective measures against HIV while caring for their sick parents in the first place, not to talk of taking precautions.

Because of cognitive immaturity and lack of proper information, young children were unable to properly understand the loss and in some cases held on to the expectation that parents would come back again. On the contrary, respondents indicated that they were able to properly understand the loss which in a way has helped them to accept the inevitable. One respondent described the condition as "to adjust the

feeling of loss, I sometimes try to convince myself and accept the situation." Some older children participated in the burial process, performing all the rituals like adults, which eventually could enhance their coping. Such helpful experiences were also reported by respondents. They indicated following the death of their parents, they changed their dressing (full black color) and physical appearances as appropriate for grieving.

The number of AIDS orphans was increasing in their communities, and the support provided to these children was as yet traditional (institutionalized, uncoordinated, on the spot, less sustainable and less visionary). Respondents felt institutional responses were slower to come (most joined the institution after leaving grandparents' care). The structural and legal frameworks with which these institutions are operating are still monolithic and hence often ineffective for meeting the needs of AIDS orphans. Although HIV/AIDS is an illness involving social stigma and discrimination, leading to many psychosocial problems for orphans, the existing meager services are as yet geared to material provisions. The lack of attention to psychosocial needs could be more distressing for AIDS- orphaned children.

6. Conclusion

These findings examine the problems of HIV orphans in different care settings. Based on the findings, one can say that orphaned children were indeed vulnerable in many ways. The existing practice is focused on fulfilling daily physical needs which is uncoordinated and not sustainable. Rather the focus should be on empowering them which might pave the way to independence. Some children serving as a household head feel bad about themselves that no matter what they did to help their family members become happier, they were preoccupied with the loss of their parents, and hence unhappy in most cases.

In fact, there are some emerging trends in the practice of care and support like emergence of child and grandparent guardianship, and a growing awareness of the problems of AIDS orphaned children. There are some signs of change influencing future directions in the care of AIDS orphans. The establishment of different offices, and committees to take care of HIV/AIDS-related issues, the initiative taken by some *Idirs* to redefine their rules to allow children membership instead of their parents, and the awareness of the children that they themselves can be the agents of change to better their life if empowered. What is needed is to encourage, empower and strengthen such beginnings. But at the moment, we have ambivalent attitude, practice and provisions of care and support.

7. Limitations and potential application

The study has several potential limitations. First, the participation of orphans was limited to double orphans. As a result the study may be more generalizable to double orphans. An additional limitation is that the children were accompanied by their caregivers to our interviews. Although they were interviewed separately, children might have still been hesitant to discuss particular issues in depth, knowing their caregivers were nearby. Finally, the study was conducted in children's village, with different kinds of orphans living together. It is likely that the psychosocial issues and experiences of the participants may differ from those children who lost their parents for other than HIV. Despite the disparities, these findings still apply to most of the double orphans and can inform the development of interventions that promote care and support for children orphaned by HIV/AIDS.

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