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Research Article

Perception of Care from Primary Caregivers, External Support and Psychosocial State of AIDS Orphans in High HIV Prevalence Regions of Ghana

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Abstract

Background: Extended families of Africa in the past easily absorbed orphans, however, because of the increased numbers of orphans due to AIDS, and dwindling support from other sources, the extended family finds it difficult to cope with the AIDS orphan crisis. Empirical evidence indicates an elevated risk of psychosocial distress among AIDS orphans compared to non-orphans. The aim of the study was to determine adequacy of external support, to assess the psychosocial state of orphans, and to find out from orphans how they perceive and rate the care received from primary caregivers.

Methods: Two hundred and ninety-two AIDS orphans were purposively selected, and mixed-method of data collection was used. The quantitative data consisted of responses from orphans with interview questionnaires, whilst the qualitative data consisted of responses from in-depth interviews with 20 orphans.

Results: The majority of orphans-69.7% and 76.4% rated the support receive they from extended family and external sources respectively as poor. Only about21% rated care from primary caregiver as excellent. Although about 88% of orphans stay close to caregivers, almost 40% were unhappy or depressed.

Conclusion: We recommend that orphan care management policies and interventions should look into the relationship of orphans with their primary caregivers and the extended family support systems, and draw up programmes to improve these relationships and foster sense of belongingness for orphans.

Keywords: Orphans; External support; Psychosocial state; Care perception

Introduction

Where HIV prevalence rates have been high since the discovery of the virus in the early 1980s, children and adolescents have borne the brunt of the impact of AIDS. These children are faced with the problem of caring for their ill parents as well as fend for themselves and their younger siblings. Defining those children under age 18 years who have lost one or both parents to AIDS as AIDS orphans [1], most of them tend to live with grandparents and other family members of the extended family. These orphans usually find themselves in households that are faced with financial hardships, and high dependency ratio relative to their non-orphan counterparts [2-6]. Thus, they are confronted with material hardships, stigma and discrimination, socio-economic difficulties as well as psychological trauma.

African extended families in the past, absorbed orphans with little or no problem [7], however, because of the increasing numbers of orphans due to AIDS, and decreasing support from governments, Non-Governmental Organizations (NGOs) and others, the extended family can no longer cope with the problem of orphans [8]. Thus, increasing numbers of orphans are falling away from the extended family protection system, resulting in child headed households, street children and child labour. Other researchers have also indicated that although the traditional extended family system finds it difficult to manage with the increasing numbers of orphans, the system in itself is not disintegrating, however, the wider society plays a critical role in its effectiveness in caring for orphans [9].

Although HIV prevalence is relatively low in Ghana compared to most parts of sub-Saharan Africa, there are areas within the country where HIV prevalence rates have risen above the threshold of 5% for some time and have experienced deaths from AIDS. These areas therefore have a sizeable population of orphans [10]. These orphans are disadvantaged compared to non-orphans in terms of the numerous problems that they are confronted with [2]. In spite of the increasing availability of programmes for prevention of HIV transmission and AIDS management interventions to reduce new infections, the impact of the previous HIV situation in these areas of Ghana will linger for decades because of its consequences on the present generation of orphans. Thus, it still demands that much attention is given to the situation of orphans in the country so that effective interventions can be drawn and implemented for the betterment of society.

Various research findings have indicated increased risk of psychosocial distress among children orphaned by AIDS compared to non-orphans with symptoms ranging from anger, anxiety,

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depression, post-traumatic stress, delinquency, conduct and peer relationship problems to suicidal tendencies [11-15]. Although governments, orphan care agencies and children's organizations have taken cognisance of the psychosocial and emotional needs of orphans, and are struggling to incorporate psychosocial and emotional support into their intervention programming activities, there is the need for the specific areas of focus of psychosocial distress to be addressed, and this formed the basis for this study. The study was therefore carried out to determine whether Ghanaian orphans receive adequate external support of any kind, to assess the psychosocial state of these orphans, and to find out directly from orphans how they perceive and rate the care they receive from their primary caregivers.

Methods

The research was carried out between 2008 and 2011 in the Ashanti and Eastern Regions of Ghana. These Regions were purposively selected because of their high HIV prevalence rates over a long period of time since the discovery of HIV in the country in 1981 [16]. Consequently these two regions have seen relatively high numbers of children orphaned by AIDS, as a result, identification of AIDS orphans and access to information are easier relative to other regions of the country.

Two hundred and ninety-two (292) orphans between the ages of 5–17 years were selected purposively for the study. They consisted of one hundred and forty one (141) orphans from the Ashanti Region and one hundred and fifty-one (151) orphans from the Eastern Region. They were made up of single orphans- those who have lost either parent to AIDS and double orphans- those who have lost both parents to AIDS.

The research protocol met the guideline for research involving human subjects of the Ghana Health Service (GHS), with identification number GHS-ERC-13/3/08. Written and verbal assent were obtained from all literate and illiterate primary caregivers respectively on behalf of all orphans, additionally, consent was sought from all orphans before they were recruited into the study. Research procedures and purpose were explained carefully and thoroughly to allay the fears of all participants and confidentiality was assured and maintained for all participants throughout the study.

Mixed-method of data collection was used. Thus, all orphans aged 10 – 17 years answered interview questionnaires that sought information on their demographic characteristics, and emotional/psychosocial state. They were also asked to rate the financial and material support they receive from sources other than their primary caregiver, and the care they receive from their primary caregiver. Primary caregivers assisted orphans aged 5 – 9 years (who formed only about 2% (6/292) of study orphans), to respond to the questionnaires, but these orphans rated their primary caregiver care independently. Relevant portions of the questionnaires from the Children's Needs Assessment Tool Kit (CNA Toolkit, version 3, March, 2002) which is aimed at assisting organizations in assessing the needs of children in areas that are heavily impacted by HIV and AIDS were adapted in line with the objectives of the study and used. The qualitative data consisted of responses from in-depth interviews with 20 orphans aged 10 – 17 years pulled from the study participants: 10 from each of the two regions, using an interview guide.

Table 1: Socio-Demographic and Socio-Economic Characteristics of Orphans.

	EASTERN		ASHANTI		ALL	
AGE OF ORPHANS						
AGE	Freq.	Percent	Freq.	Percent	Freq.	Percent
5-9	23	15.2	38	27	61	20.9
10-14	82	54.3	70	49.6	152	52.1
15 -17	46	30.5	33	23.4	79	27.1
N	151	100	141	100	292	100
SEX OF ORPHAN						
Male	66	46.8	75	49.7	141	48.3
Female	75	53.2	76	50.3	151	51.7
Total	141	100	151	100	292	100
ORPHAN STATUS						
Single: Maternal	49	32.5	45	31.9	94	32.2
Single: Paternal	63	41.7	56	39.7	119	40.8
Double	39	25.8	40	28.4	79	27.0
Total	151	100	141	100	292	100
SCHOOL STATUS						
In-school	129	85.4	128	90.8	257	88
Out of school	22	14.6	13	9.2	35	12
Total	151	100	141	100	292	100
RELIGION OF ORPHAN						
Christian	151	100.0	135	95.7	286	97.9
Muslim			6	4.3	6	2.1
Total	151	100	241	100	292	100

Source: Field Data

The quantitative data were analysed with SPSS version 18.0, and descriptive statistics were used to interpret the results. In-depth interview responses were recorded with MP3 recorder, transcribed, and analysed on the basis of the emerging themes and sub-themes alongside the study objectives. Some of the results were triangulated.

Results

Socio-Demographic characteristics of orphans

The ages of study orphans ranged from 5 to 17 years with an average age of 12.2 years, 151 (51.7%) were females and 141 (48.3%) were males. Seventy three percent (73%) were single orphans and the remaining 27% double orphans. The majority257 (88%) were in-school, whilst 35 (12%) were out-of school. Thirty one percent (31%) of orphans were living with their maternal or paternal uncles and aunties, 28.8% were with their grandparents, 34.6% were living with either parent and 5.1% were with their siblings (Table 1). During the in-depth interviews with orphans, it was however realized that some caregivers were friends of the deceased parent or friends of the family of the orphans. This information was not captured by the interview questionnaires.

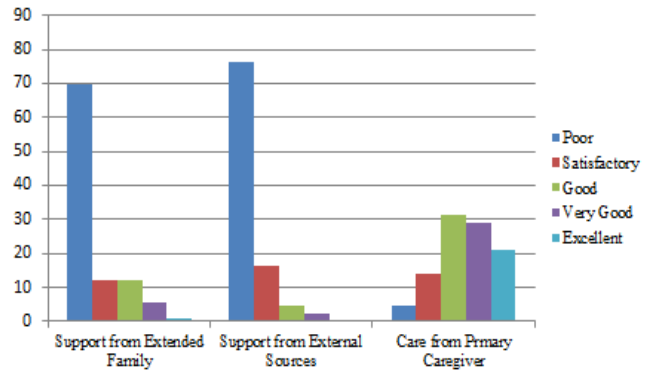

Figure 1: Rating of Support from Extended Family, External Sources, and Rating of Care from Primary Caregiver by Orphans.

Support from external sources other than primary caregiver

The majority of orphans rated the support they receive from both their extended family and external sources as poor, that is 203 (69.5%) and 223 (76.4%) orphans respectively. Only 2 (0.7%) orphans from the Eastern felt that the support they receive from their extended family was excellent, 51 (20.9%) orphans rated their extended family support as either very good or good whilst 36 (12.3%) rated it as satisfactory. Again only 1 (0.3%), orphan from the Ashanti Region rated support from external sources as excellent, 20 (6.9%) rated it as either very good or good, and 48 (16.4%) orphans rated support from external sources as satisfactory (Figure 1).

Thirteen (65%) out of the 20 orphans involved in-depth interviews indicated that they do not receive any external support of any kind. The remaining 7 (35%) receive support directly from some extended family members and some AIDS support groups through their primary care givers. The support from external sources consisted mainly of food items and in some few cases clothing items.

Rating of care received from primary caregivers

About 21% (61) of orphans indicated the care they receive from their primary caregiver as excellent, out of this, 93.4% (57) are orphans from the Eastern Region. One hundred and seventy six (60.3%) orphans rated primary caregiver care as very good or good and the remaining 4.8% (14) of orphans rated the care they receive from their primary caregiver as satisfactory (Figure 2).

However, 11 (55%) out of 20 orphans involved in in-depth interviews felt unloved by their primary caregivers, whilst the remaining 9 (44%) were of the view that the way and manner their caregivers take care and relate to them is satisfactory, though they felt that more could be done for them by their caregivers. The responses from the orphans included the following:

"My caregiver does not like me because she insults and beats me a lot; she also gives me little food. I am not being taken care of well at all. I don't feel loved by her, so I also don't like her". (Orphan, Female, 15, Eastern Region).

"My sister should stop beating me, stop insulting my dead father, and treat me with a little respect, then will I know that she is my sister". (Orphan, Male, 13, Eastern Region).

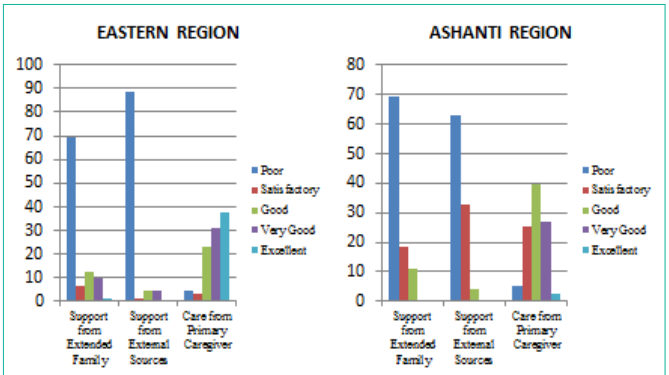

Figure 2: Rating of Support from Extended Family, External Sources, and Rating of Care from Primary Caregiver by Orphans.

"The care we receive from grandmother is not enough, she must try and provide us with all we need and make sure that I have continuous education". (Orphan, Male, 12, Eastern Region).

"My aunt does not take good care of me; she did not take me to school, and does not give me enough food." (Orphan, Female, 14, Ashanti Region).

"I know I'm not loved by my aunt, and that is why she does not take good care of me. I see my cousins happy, because their mother attends to their needs, but as for me I still use floor sack to cover myself when I'm sleeping." (Orphan, Female, 13, Ashanti Region).

"If my caregiver likes me, she wouldn't let me work for long hours before I'm given something to eat. I'm still living with her because I don't have anybody to assist me. All I'm waiting for is the day I can be independent and can have some happiness, I'll be very grateful to God." (Orphan, Male, 14, Ashanti Region).

Psychosocial state of orphans

In assessing the Psycho-social state of orphans, they were asked to indicate how often they stay close to their primary caregiver; whether they perceive themselves to be withdrawn; unhappy, sad, or depressed most of the time, whether they are too fearful or anxious, or whether or not they have trouble sleeping. The responses are indicated in table 2. The results indicated that the majority, 256 (87.6%) of orphans stay close to their caregivers when they are at home, and the remaining 36 (12.4%) do not stay at home or rarely stay close to their caregivers. About 21% indicated that they prefer to be alone most of the time; 40.4% were unhappy or depressed most of the time; 38% were too fearful or anxious; and 16.4% could not sleep as well as they should. In all cases the majority of orphans were alright psycho-socially.

Discussion

The economic and social effects of HIV and AIDS on children have taken precedence over the worry about the psychological impact that HIV and AIDS have on children [17]. Thus where basic needs like food, clothing and shelter are not met, families, governments and child-focus organizations tend to focus on these unmet needs rather than addressing obvious psychological needs that are considered less immediate [18-21]. This is understandable because such phenomena have been explained by Abraham Maslow in his hierarchy of needs way back in the early 1940s.

Children go through traumatic periods over the death of a parent, but for AIDS orphans, many factors aggravate their experience of bereavement [12,20,22]. Various stressors in the experience of morbidity and mortality by children affected by HIV and AIDS have been unraveled in addition to stigma. These include living with a parent with a terminal illness, witnessing HIV and AIDS-related death, psycho-social effects of death; and multiple losses [23]. There is usually reversal of parent-child roles when a parent becomes ill, with the child assuming care responsibilities for the household and sick parent, and this is most often accompanied by an elevated feeling of loneliness on the part of the child [23]. Also, when children witness and nurse parents through the debilitating terminal stages of AIDS, they are affected in all aspects of their lives that can dwindle school performance and family relationships [19]. The death of a parent may generate fear, sense of insecurity and hopelessness for the orphan psychologically and this may intensify and complicate the grieving process for the orphan. Moreover, children who lose one parent to AIDS may suffer multiple losses because they stand the risk of subsequently losing the other parent, other caregivers, and younger siblings or loved ones. When this happens, orphans are left at the mercy of caregivers who may or may not be their family members. Their care then becomes dependent on a vast range of socio-cultural factors that compete with care of the orphans with limited finance and time [24].

The stress and trauma of orphans are usually heightened due to stigma and discrimination, increased workload, dropping out of school, changed friends and social isolation resulting from parental death [17]. In an attempt to assess the psychosocial state of the study orphans, the results showed that about 2 out of 5 (40%) orphans were unhappy, sad, or depressed most of the time; about 38% reported being too fearful or anxious; and about 21% were withdrawn. Some of the orphans rarely stay close to their caregivers or do not stay home at all (12.4%); whilst about 16% of the orphans had problems with sleep (Table 2). These results indicate that many of the orphans were not psychosocially sound and this may be the result of the stigma and poverty situation in which they find themselves. Studies in Uganda have reiterated the fact that orphans are about six times more at risk of higher levels of anxiety, and depression than non-orphans. Also, orphans are about five times more at risk of being angry than non-orphans, and that the elevated levels of psychological distress found in AIDS orphans suggest that material support alone is not sufficient for these children [11]. Thus it is time for orphan care and support agencies including governments of AIDS-affected countries to take action with regards to psychosocial needs amidst limited resources for basic physiological needs.

The source of stigma and discrimination may come from the extended family as was indicated by some of the orphans in the study. This may throw light on the reason why support from the extended family is poor. The extended family in some cases may regard support to orphans in the family as a philanthropic duty, and not a responsibility. Thus, although the in-depth interviews indicated that the main support for orphans is the extended family, some relatives exploit and abuse orphans, and fail to meet their basic needs for food, clothing, and education. The study findings also indicate that support from external sources which are in the form of basic physiological needs is also poor, and this may be due to the fact that there are no

Table 2: Psycho-Social State of Orphans.

	EASTERN		ASHANTI		ALL	
	Freq.	**Percent**	**Freq.**	**Percent**	**Freq.**	**Percent**
Staying close to caregiver when at home						
Very often	78	51.7	52	36.9	130	44.4
Quite often	51	33.8	75	53.2	126	43.2
Rarely	16	10.6	9	6.4	25	8.6
Don't stay at home	6	4.0	5	3.5	11	3.8
Total	151	100.0	141	100.0	292	100.0
Being withdrawn/Preferring to be alone						
Yes	35	23.2	27	19.1	62	21.2
No	116	76.8	114	80.9	230	78.8
Total	151	100.0	141	100.0	292	100.0
Unhappy,sad/depressed most of the time						
Yes	58	38.4	60	42.6	118	40.4
No	93	61.6	81	57.4	174	59.6
Total	151	100.0	141	100.0	292	100.0
Being too fearful or anxious						
Yes	52	34.4	59	41.8	111	38.0
No	99	65.6	82	58.2	181	62.0
Total	151	100.0	141	100.0	292	100.0
Trouble sleeping						
Yes	14	9.3	34	24.1	48	16.4
No	137	90.7	107	75.9	244	83.6
Total	151	100.0	141	100.0	292	100.0

Source: Field Data

structured financial and physical systems in place for the government and for the few non-governmental orphan care agencies to directly reach out to orphans in the country. Hence, AIDS orphan care support is often channeled through adult AIDS support groups which may or may not reach the orphans.

A study in Uganda has indicated that most orphans especially those between the ages of 10 – 14 years are depressed and are doubtful of bright and successful future [25]. It has also been reported in South Africa that, when socio-demographic factors like age, gender, age at orphan-hood, and formal or informal dwelling are controlled, AIDS orphaned children are more likely to report symptoms of depression, have post-traumatic stress, have peer relationship problems, delinquency and conduct problems, show behaviour problems and report suicidal tendencies than both children orphaned by other causes and non-orphans [23]. The researchers further pointed out that South African children orphaned by AIDS exhibited higher levels of internalizing problems and delinquency, but lower levels of conduct problems compared to Western norms. The authors however found no differences in the anxiety levels exhibited by the three groups of children [23]. There have been similar findings in the measurement of psychosocial effect of orphan-hood in a sub-Saharan African population which evaluated a new frame work for understanding the causes and consequences of psychosocial distress among orphans and other vulnerable children [26]. The authors found that for

both genders, paternal, maternal, and double orphans exhibited more severe distress than non-orphaned, non-vulnerable children. After controlling for differences in more-proximate determinants, the author's realized that orphan-hood remained associated with psychosocial distress [14].

Poverty is acknowledged as a primary psychosocial stressor for children affected by AIDS in addition to orphan-hood [23]. The effects of poverty as found in the present study were expressed through in-depth interviews with orphans in terms of their pressing needs comprising food, clothing, items for school, and shelter. These effects were expressed in terms of material needs, thus, the emotional and psychosocial effects are likely to be ignored. However, child developmental outcomes are likely to be influenced significantly by enduring conditions of deprivation [20,27], thus, poverty, leading to malnutrition and low educational levels is associated with common mental disorders. Hence, factors like hopelessness, insecurity, poor physical health, and limited opportunities arising from less education may trigger the risk of mental disorders in affected individuals [28].

The factors expressed by some of the study orphan swhich may have some psychosocial outcomes for them include stigma and discrimination, hunger, humiliation, anxiety, and loneliness. There will however, be hope for these orphans, if support is made available to the mand family process variables play important role in predicting their adjustment than parental illness or death [29]. It is therefore critical that orphans have access to support networks that are functional, to enable them develop a sense of inclusion to help them cope better with psychosocial problems.

Some researchers have asserted that not all emotional and psychological experiences of orphans yield negative psychosocial outcomes, thus, some orphans display resilience from negative childhood experiences [30]. However, just as the many dimensions of vulnerability in the household may affect psychosocial outcomes, the type of risk or adversity the child or orphan is exposed to, how severe or chronic it is, may also be important, and hence, resilient outcomes should be determined in terms of exposure to particular adverse conditions [31].

The physical and emotional relationships that orphans have with their caregivers may be equally important in determining the psychosocial state and outcome of this vulnerable group of children. Findings of the study indicate that whilst the majority of orphans (about 81%) perceived the care they receive from their primary caregiver as excellent, very good or good, some (about 19%) perceived the care they receive as either satisfactory or poor. The data portray that more orphans from the Eastern Region receive better care than their counter parts from the Ashanti Region (Figure 2). This may account for the differences in the nutritional status of orphans from these two regions in the country [32]. Eleven out of the twenty orphans (55%) involved in the in-depth interviews indicated that the care provided by their primary caregivers was either satisfactory or poor and that they felt unloved by their caregivers. A study in Sagamu, Ogun State in Nigeria, has indicated that orphans and other vulnerable children who demonstrated a higher satisfaction of life are those who had three meals per day, those who felt that their community treated them equally as any other children, and those who had good relationship with their caregivers [33]. These findings throw light on the perception of the study orphans in terms of their level of satisfaction with the care given to them. Some of the orphans whilst admitting that the care provided by their caregivers in terms of provision of basic needs such as food, clothing and school gadget were inadequate, they also felt that their caregivers did not have the financial strength to provide them with all their basic needs. This highlights the importance of monetary input in the care of orphans.

Conclusion

Children orphaned by AIDS in high HIV prevalence regions of Ghana experience substantial psychosocial stress. The stress is made more profound by the orphan-hood itself as well as the stigma and discrimination associated with AIDS. This may find expression in the form of anxiety, withdrawal, depression and a fearful state. Even though the majority of orphans reported satisfactory to excellent care by primary caregivers, in a few instances, they constitute a form of stress. Support from the extended family system is weak; in addition, financial inadequacy contributes to psychosocial stress. It is therefore recommended that orphan care management policies and interventions should look into the relationship between orphans and their primary caregivers, as well as the extended family support systems and draw up programmes that would improve these relationships in order to foster a sense of belongingness for orphans. Policies and interventions should also include structured, regular and periodic counselling and increased interaction with peers for children orphaned by AIDS to allay their fears and anxiety, to assure them of their safety and security, and to promote their psychosocial well-being.

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