Overcoming Stigma and Discrimination among HIV/AIDS Orphaned Children: the Role of NGOs' In Kenya

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Abstract: This study investigated the efforts of NGOs on empowering HIV/AIDS orphaned children to deal with stigma and discrimination in Njoro Sub County. The effects of the HIV/AIDS epidemic pervade every aspect of children's lives, their emotional well-being, physical security, mental development, and overall health. To ensure these children enjoy their rights, NGOs have been involved in empowering them by mitigating the challenge of stigma. The study was informed by the Empowerment theory by Andrea Diane (1995). The study used descriptive research design. Purposive sampling was used to get a sample of 47 children respondents and 10 key informants comprising of 2 NGOs officials and 8 community volunteers. The study collected and analyzed both qualitative and quantitative data. The results obtained indicated that the NGOs have implemented programs to empower HIV/AIDS orphaned children on how to deal with stigma and discrimination e.g. by holding their self-esteem high. The study found that children respondents' lives have changed positively and they can freely play with their peers unlike before they were introduced to the programs. The study recommended that the NGOs should consider empowering the larger community on how to live with the children without stigmatizing or discriminating against them.
Keywords: Empowerment, Stigma, Discrimination, HIV/AIDS Orphaned Child.

INTRODUCTION

The Human Immunodeficiency Virus (HIV) and the subsequent Acquired Immunodeficiency Syndrome (AIDS), hereafter to be referred to collectively as HIV/AIDS, remains one of the most significant public health challenges in our lifetime, and certainly one of the major obstacles to socioeconomic development especially in developing countries. All nations across the world, particularly, low and middle income countries are significantly affected by HIV/AIDS and Kenya is no exception [1]. Worldwide, it is estimated that 17.8 million children under 18 years of age have been orphaned by AIDS and this is prospected to rise to 25 million by 2020 (World Health Organization, 2011).

In Kenya, 2.5 million children under the age of 18 years are orphans. Out of these 2.5 million children, 1.5 million are orphaned by HIV/AIDS. The emotional needs of HIV/AIDS orphaned children such as psycho-social support are critical given that these children have lost their parents who were the bread winners. Children are greatly affected for the rest of their lives when their parents die and leave them without someone to care for them. In addition, the society that is expected to take over the role of parenthood for these children turns against them through stigmatization.

Empowering HIV/AIDS orphaned children to deal with stigma and discrimination can play a crucial role in improving their prospects and securing their future. HIV/AIDS orphaned children are exposed to the risk of facing stigma and becoming victims of violence, child labor, discrimination and other abuses [2]. The scale of the orphan crisis is somewhat masked by the time lag between when parents become infected and when they die. As adults continue to die from AIDS-related illnesses over the next decade, an increasing number of children will grow up without parental care [3].Children orphaned by HIV/AIDS are stigmatized and as a result, they feel ostracized, devalued, rejected, scorned, bullied and shunned. This harms their self-esteem. To ensure these children enjoy their rights, NGOs have been involved in empowering them by mitigating the challenges of stigma and discrimination. However, little has been done on NGOs participation in empowering HIV/AIDS orphaned children in Njoro Sub County. It was on the back drop of the above reason that this study sought to find out the NGOs input in empowering HIV/AIDS orphaned children in the region.

LITERATURE REVIEW

HIV/AIDS related stigma comes about when HIV/AIDS orphaned children are blamed for their

parents' death and their own illness because they are viewed as immoral, unclean, and lazy [4]. Furthermore, it has been acknowledged that throughout history, stigma has imposed suffering on HIV/AIDS orphaned children and impaired efforts to thwart the progression of the disease. It is well acknowledged that stigma and discrimination contribute to increased HIV/AIDS epidemic. Compared to adults, children and adolescents affected by HIV/AIDS are disproportionally impacted by the HIV/AIDS epidemic and associated stigma and discrimination [5]. In HIV/AIDS, the detrimental role of stigma has become so clear that national and international health agendas explicitly identify stigma and discrimination as one of the major reasons limiting the access, care and treatment services, and is considered an overall major barrier to effective responses to the HIV/AIDS pandemic [6].

Children are particularly more vulnerable to stigma than adults, and are at a heightened vulnerability to discrimination because they are often not in control of their circumstances; and often do not know and/or are less likely to assert their rights. Moreover, stigma can affect children in multiple ways when it leads to active discrimination. It has also been reported that HIV/AIDS affected children find it difficult to access care and support due to negative attitudes by health care providers and other service and support workers [7]. Furthermore, the same study demonstrated that stigma and discrimination were poorly addressed in Kenya leading to a number of negative effects including isolation of HIV/AIDS orphaned children.

Addressing the needs of children affected by HIV/AIDS is particularly important in developing countries, not only because of the high proportion of young people infected by HIV/AIDS in these societies, but because young people are at a heightened risk of contracting HIV/AIDS as well. Stigma and discrimination can prevent proper access to education, well-being, treatment and care both directly through abuse, denial of care, forced child labour and loss of inheritance, and indirectly if children avoid potentially stigmatizing situations such as social interaction, healthcare and educational opportunities because they expect or internalize stigma [8]. There is variation in the extent, effects, and nature of stigma and discrimination across regional, cultural, socio-economic and gender contexts [9]. Stigma and discrimination can be affected by various epidemiological factors including stage of the epidemic, prevalence, distribution of HIV cases, political factors and so on [10]. While this variation does not always imply the need for different interventions to reduce stigma [11], it does suggest that research on children in other contexts may not be directly applicable in sub-Saharan Africa, and even within the region there may be significant differences in children's experiences [12]. In spite of ample anecdotal and descriptive evidence that HIV/AIDS-related stigma and discrimination are affecting children, not enough systematic research has been done to illustrate the nature and extent of the problem, and how it relates to other key sources of disadvantage for children in poor, high-prevalence areas.

METHODOLOGY

This study was undertaken in Njoro Sub County. Njoro Sub County is located in Nakuru County of Kenya. This region was suitable for this study because the region experiences ethnic clashes during general elections, which are held after every five years in Kenya [13]. These clashes render most residents homeless and poor. In return, women opt for commercial sex work to earn a living, which exposes them to HIV/AIDS infections. These women in return infect their spouses and eventually both parents die leaving behind HIV/AIDS orphaned children [14].

The highest number of HIV/AIDS orphaned children in Njoro Sub County are supported and empowered by Family Aids Initiative Response (FAIR), an NGO funded by a USAID project APHIA which is an overall project [15]. This NGO works in collaboration with other NGOs like Deliverance Centre, Jubilee Social Centre, Action against AIDS, Catholic Diocese of Nakuru and Action in Focus. All these NGOs are under the APHIA project, which is funded by USAID. This study used descriptive research design and Purposive sampling method was used to get the sample size because NGOs in Njoro Sub County have registered the HIV/AIDS orphaned children in the region. The unit of analysis for this study was the eldest child among the HIV/AIDS orphaned children in the selected households. This child had to be at least 15 years but below 18 years because they were old enough to give information [16]. The number of HIV/AIDS orphaned children in Njoro Sub County is 118 according to the registers in the NGOs. Out of the 118, only 40% of them are 15-17 years.

The study used 40% of 118 children (47 children) as the sample size. These 47 children came from different households. In case two or more of the 47 children came from the same household, the eldest child was interviewed. In addition, the researcher interviewed 2 NGO officials as key informants for this study. In addition, the study used Focus Group Discussion with 8 community volunteers as key informants to give data on this particular study. In-depth interviews and Focus Group Discussions were used to collect data. The study collected both qualitative and quantitative data. For qualitative data, the researcher sorted, coded and organized data into categories based on the themes to provide full description of empowerment and, life skills [17]. In addition, quantitative representation was required in some aspects. Ethical considerations were well thought out before conducting research. There was need to put more

measures which were applied directly to the children respondents. These measures prevented or minimized harm, which came up during the collection of data from the respondents.

RESULTS AND DISCUSSION

The key informants were asked to state if the NGOs they represented had programs and strategies meant to empower HIV/AIDS orphaned children to deal with stigma and discrimination and if so, what programs and strategies were in place. The results indicated that all key informants (100%) agreed that the NGOs represented in the study had programs and strategies used to empower HIV/AIDS orphaned children deal with stigma and discrimination. The Figure below depicts the programs/strategies that NGOs use to empower HIV/AIDS orphaned children in dealing with stigma and discrimination.
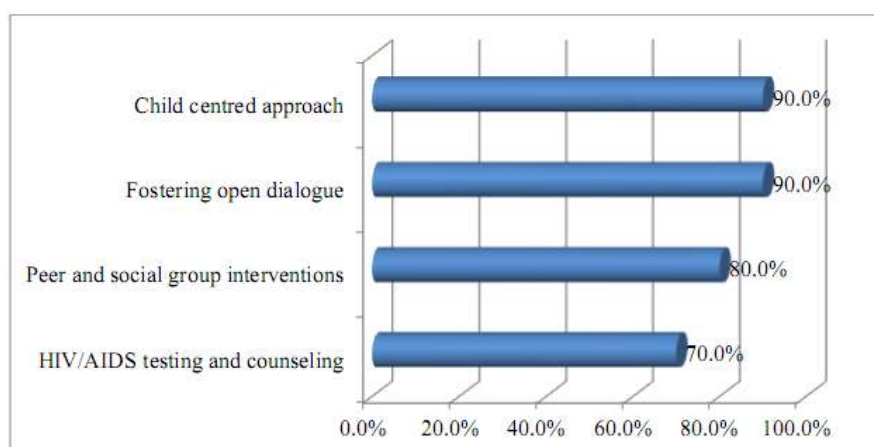

Fig-1: NGOs' Programs/Strategies for Empowering HIV/AIDS Orphaned Children in Dealing with Stigma and Discrimination

Fostering Open Dialogue among the Children

Fostering open dialogue among the children was cited by majority of key informants (90%) to be a key program/strategy used by the NGOs in empowering HIV/AIDS orphaned children in dealing with stigma and discrimination. These are activities involving youth clubs (40%) drama (30%) and music (20%) contains de-stigmatizing messages. The participants in the FGD argued that the messages conveyed in the open dialogues educate the HIV/AIDS orphaned children on how to deal with stigma and discrimination like fostering their self-esteem and refusing to be underestimated by peers. In these programs, the NGOs educate and encourage **HIV/AIDS orphaned children** caregivers' families to accommodate them in their families by treating them like their own. This neutralizes stigma and channels interventions appropriately. **The** NGOs provide care to HIV/AIDS orphaned children with a focus on psychosocial development through academic, cultural and artistic enrichment. The NGOs use a great deal of intentionality to design the program activities to minimize stigma and team-building, self-esteem building and community-building are stressed throughout the programs. The APHIA coordinator for Njoro Sub County who was a key informant in this study argued that:

*"We create infrastructure to identify and address the needs of HIV/AIDS orphaned children. Working with our community health volunteers, social workers and the rest of the staff, we facilitate regular workshops that address the needs of **HIV/AIDS orphaned children** that include psychosocial support".*

The above statement implies that the NGOs have implemented diverse programs to empower HIV/AIDS orphaned children deal with stigma and discrimination. This is an implication that NGOs in Njoro Sub County are doing a recommendable job to ensure children enrolled under their programs are stigma free.

Child Centered Approaches

Child centered approach was also cited by 90% of the key informants that it was a strategy used, to promote de-stigmatization and non-discrimination among HIV/AIDS orphaned children enrolled in various NGOs in Njoro Sub County. The key informants who formed 90% mentioned that they use a number of Child Centered Approaches like memory boxes or books, and psychosocial support for HIV/AIDS orphaned children to empower them deal with stigma. The approaches mentioned by the (90%) key informants are;

Memory boxes; this is an approach used by the NGOs under study to help HIV/AIDS orphaned children to come to terms with the death of their parents, communicate with their families and prepare for the future. They are like a treasure chest of family photographs, letters, drawings, stories and anything that holds special significance to remind the children about their families. It is a way of collecting information

about the family, which would otherwise be lost. Memory boxes or books give caregivers and the HIV/AIDS orphaned children an opportunity to talk to each other, tell each other how they feel and talk about the past and the future. These boxes or books enable caregivers inform the HIV/AIDS orphaned children that they care for their early lives, family origins and relatives. It also allows caregivers to express their own beliefs, values and aspirations to the children's future. The key informants (90%) also explained that the box is a good strategy to begin dialogue, which can lead to disclosure of status incase the orphaned child is HIV positive. Important issues such as inheritance, financial support and emotional support are usually included in the box by caregivers as a source of reference for children as they grow up. Most participants in the FGD insisted that it is best for the memory boxes to be prepared by the parents when they are alive and not sick so that they can think clearly and have energy to answer many questions and make it fun. However, one of the participants from the FGD who was a community health volunteer mentioned that;

"Because of fear and culture of most HIV/AIDS parents, the caregivers make many memory boxes when the parents are already dead. This is distressing but the NGOs do the best to ensure the HIV/AIDS orphaned children whose parents did not leave one behind have them, to help the children come into terms with reality of their parent's death".

The above statement implies that although some parents die without making memory boxes for their children, the NGOs take the responsibility of ensuring every child enrolled under their programs has one. The NGOs ask the caregivers to make memory boxes for children whose parents did not make one before they died.

Table 1: Peer and Social Group Interventions

Types of Peer and Social Group Intervention	No. of Respondents	Percentage
Kids clubs	10	100%
Safe social spaces for children	10	100%
Peer support groups	10	100%

Peer and social group intervention was mentioned by (80%) of the key informants as a strategy used by the NGOs to empower HIV/AIDS orphaned children deal with stigma and discrimination. This percentage of key informants explained that this intervention is usually school-based or take place through community organizations. The participants in the FGD mentioned examples of these interventions to be; kids clubs, safe social spaces for children and peer support groups. The key informants explained that the interventions solely consist of recreational activities.

This intervention provides psychosocial support, along with age-appropriate learning materials in reproductive health, nutrition, and HIV/AIDS prevention. In particular, the key informants informed the study that linking HIV/AIDS orphaned children to supportive local groups and, faith-based programs provides the children with both psychosocial support and protection. These key informants clarified this intervention to be a program whereby NGOs address topics of concern to HIV/AIDS orphaned children through plays, poems, stories, games, and interactive group therapy techniques, including approaches to problem solving and positive deviance. These groups are usually supplemented with monthly health examinations and treatment. Such support groups' lower anxiety, depression, and anger among HIV/AIDS orphaned children especially the HIV positive ones.

The participants in the FGD had a common view that creating dedicated social spaces for HIV/AIDS orphaned children has been a key strategy for changing their self-concepts and has proven as an effective approach for transforming circumstances that put them at risk of contracting HIV/AIDS like engaging in commercial sex. The spaces, which are established in community facilities like schools (after hours) and community centers, function as platforms for the delivery of new skills, increased social support, and greater opportunities for HIV/AIDS orphaned children to meet peers, consult with mentors, and acquire skills to help them mitigate cases of discrimination.

There was a widespread agreement among the participants in the FGD that the NGO's interventions to address issues of stigmatized HIV/AIDS orphaned children do not privilege one group over another where problems are shared. Instead, they develop interventions based on an understanding of what negative effects stigma might have on HIV/AIDS orphaned children, how they are caused, and therefore, what issues need to be addressed in broader programmes. In most cases, the NGOs address a range of different causes of challenges in a holistic intervention without singling out stigmatised groups.

The participants in the FGD further argued that to develop effective anti-stigma interventions for the children; requires the NGOs not to focus only on correcting knowledge and attitudes underlying

HIV/AIDS related stigma. In this regard, the NGOs focus on programmes for HIV/AIDS education, which are integrated into broader life skills, and health education programmes. The programmes are usually supplemented by human rights education aimed at tackling a range of issues including disease stigma, and prejudice. The NGOs have also established a poverty relief, in terms of support groups and rights-based advocacy programmes, which form part of anti-stigma interventions in Njoro Sub County.

HIV/AIDS Testing and Counseling

Voluntary counseling and testing (VCT) was mentioned by 70% of the key informants as one of the strategies used by the NGOs to empower HIV/AIDS orphaned children deal with stigma and discrimination. The (70%) key informants argued that HIV/AIDS testing and counseling is the most important consideration as far as stigma is concerned as it provides the HIV/AIDS orphaned children and the society around them with key information and encourage acceptance and sharing of their statuses. In addition, the larger community begins to see the HIV/AIDS orphaned children diagnosed as HIV positive receiving care and support.

The participants in the FGD held a common view that often a situation exists whereby a child is diagnosed as HIV positive and all members in the community watch this child die with no support or encouragement. In such a case, the NGOs offer a package of services that restores hope and removes the sentence of quick death. One of the social workers who was a participant in the FGD informed the study that;

"NGOs link families of HIV/AIDS orphaned children to active support service organisations and government safety nets. In such cases, the responsible NGOs on the ground provide HIV/AIDS orphaned children and their families with practical knowledge and skills for caring and counseling. This, together with up to date, accurate information on HIV and AIDS helps reduce stigma in their homes by reducing fears of transmission in the course of providing care incase the child is HIV/AIDS infected".

The above statement points towards the efforts put in place by the NGOs to train the children early detection of stigma in the community so that they may be in a better position to deal with it without affecting their emotional wellbeing.

This study found out that all the 47 children respondents (100%) were enrolled in various programs by the NGOs. All the children respondents (100%) further reported that there are various empowerment programs offered to them by the NGOs that help them deal with stigma and discrimination. Some of these services as mentioned by the children respondents are depicted in the Figure below;
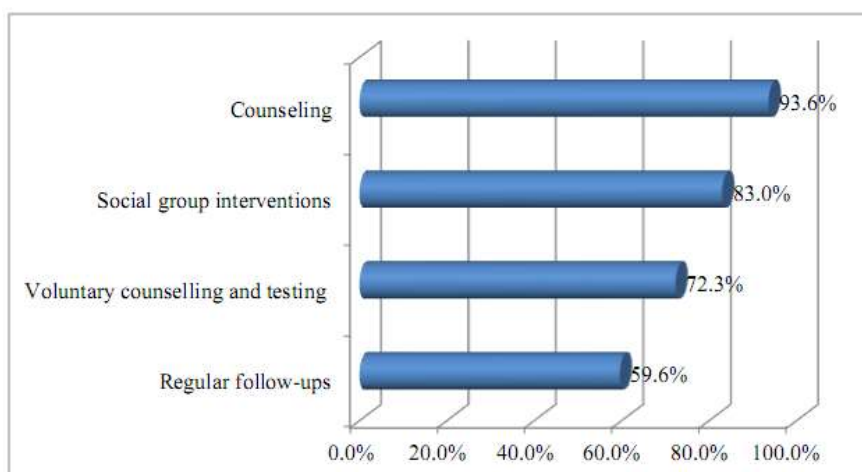

Fig-2: Empowerment Programs offered to the HIV/AIDS Orphaned Children by the NGOs to deal with Stigma and Discrimination

As shown in the Figure below, majority of the children respondents (93.6%) mentioned that the most key empowerment program availed to them by the NGOs was counseling. About 83% of the children respondents cited to have benefited from the NGOs social group interventions empowerment programs while 72.3% of the children respondents indicated that NGOs use voluntary counseling and testing (VCT) as a strategy for empowering HIV/AIDS orphaned children in dealing with stigma and discrimination. The study found out that the NGOs with programmes meant to serve HIV/AIDS orphaned children were doing regular follow-ups in a bid to reduce stigma and discrimination among the affected children as mentioned by (59.6%) of the respondents. All the 47 (100%) children respondents said that before they were enrolled in the NGO programs, they faced stigmatization and discrimination. Below is a list showing indicators of stigma they cited they faced immediately their parents died.

Table 2: Indicators of Stigma from the Children Respondents

Indicator	Frequency	Percentage
Shame	38	80.85%
Rejected	4	08.51%
Bullied	3	06.38%
Scorned	2	04.25%
Total	**47**	**100.00%**

Out of the 47 (100%) children respondents, 38 (80.9%) of them informed this study that they felt shameful to interact and play with other children before they were enrolled in the NGOs programs; 4 (8.5%) of them suffered rejection immediately their parents died; 3 (6.4%) were bullied and 2 (4.3%) were scorned.

Fortunately, every child respondent (100%) reported afterwards that the programs put in place by the NGOs have helped them learn how to live in a stigmatizing and discriminative environment while holding their self esteem high. These children respondents argued that whenever they felt stigmatized before they were enrolled in the NGOs programs, they avoided their peers by isolating themselves. All (100%) children respondents vividly reported that various programs on how to deal with stigma and discrimination offered by the NGOs have given them courage and can comfortably join their peers in plays and other activities.

All the children respondents 47 (100%) informed the study that the programs offered to them by the NGOs on how to deal with stigma and discrimination are regular. The respondents said that at least once in a month they gather for an empowerment talk or workshop on how to deal with stigma and discrimination at the NGOs. All children respondents (100%) also informed the study that although the NGOs have extended the programs to their caregivers and their local schools, the programs are irregular and have not responded well. Out of the 47 children respondents, 14 (29.8%) of them argued that it is over a year since the NGOs held the last meeting with their caregivers on how to deal with stigma and discrimination empowerment workshop.

The 14 (29.8%) children respondents reported that the NGOs hold counselling and other empowerment programs with their caregivers, some workshops are attended by both respondents and caregivers; the NGOs visit schools also to give the same programs after making local arrangements with the school administrations. However, all children respondents (100%) argued that the meetings are irregular, the turn up is poor and the dissemination methods are very poor. As a result, the programs have not been fruitful. The children respondents (100%) reported that proper implementation of the programs to the wider community can help their peers, especially at school who discriminate against them to know and understand that being HIV/AIDS orphaned is not a limitation and that everyone can be affected.

The study found out that stigma and discrimination is the main problem among HIV/AIDS orphaned children in Njoro Sub County. Although NGOs have implemented various programs to empower the children on how to deal with the condition, still some gaps emerged on what needs to be done to make the whole process a success. Regarding this, 70% of the participants in the FGD who were key informants in this study were of the opinion that the NGOs need to improve their expansion of their services to the larger society because HIV/AIDS orphaned children end up being absorbed in the community. Kalichman & Simbayi [18] argues that there has been some recent attention paid to the psychological needs of children affected by HIV/AIDS, a discussion in which stigma has featured prominently.

In addition, Thi *et al.,* [19] argue that HIV/AIDS-related stigma has been recognised as a key problem that needs to be addressed in HIV/AIDS interventions with children. This study confirms the views of Kalichman & Simbayi [20] as well as those of Thi *et al.,* [21]. This study hence confirms that stigma and discrimination remains to be a key problem that requires more interventional channels to mitigate it so that the HIV/AIDS orphaned children in the society can live in an environment that will favor them as other children with parents hence giving them an equal opportunity to grow and develop without psychological distress.

CONCLUSION

Regarding how NGOs empower HIV/AIDS orphaned children to deal with stigma and discrimination in Njoro Sub County, this study found out that the NGOs have successfully empowered the children to deal with stigma and discrimination as reported by all children respondents (100%). However, the same percentage (100%) of respondents reported that the NGOs have not successfully reached the wider community (caregivers, teachers and peers among others) to teach them on how to love and care without stigmatizing or discriminating against them. These views were supported by 70% of the participants in the FGD who mentioned unsuccessful empowerment of the larger community to live positively with HIV/AIDS

orphaned children as one of the challenges facing the NGOs empowerment programs.

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