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MINI REVIEW

Strengthening Community Care-Based Options for Children Orphaned by HIV and AIDS in Zambia: A Nexus of Cultural Competency and Translational Research

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Abstract

HIV and AIDS have had a devastating impact on Zambian families and communities. For more than two decades families and communities have been struggling with finding effective ways of providing effective community-based care to children orphaned as a result of the HIV and AIDS epidemic. Unlike in the past when children orphaned by AIDS received readily available community care options, today the situation is different as children impacted by HIV and AIDS do not receive the appropriate and ready care they need. Although HIV and AIDS infection rates in Zambia seem to have stabilized, the number of children orphaned by AIDS keeps on increasing. These children face a plethora of social-economic and emotional and challenges.There is need to improve the quality of community-based care options for them. One way this might be accomplished is through use of cultural competence and translational research as frameworks for scaling-up available care options.These two approaches are innovative and have potential to improve orphaned children's overall well-being. For example culture competence could serve as platform for providing relevant skill sets to families and communities providing care to orphaned children. Further, as families and communities grapple with the challenges of care for orphaned children, translational research could serve as a suitable approach that might make it possible for communities as well as families share essential lessons within and between themselves. The outcome of using these two frameworks could improve the well-being of orphaned children impacted by HIV and AIDS.

Key words: HIV and AIDS, orphaned children, cultural competence, translational research, community-based care.

Introduction

Zambia's first AIDS case was identified in 1984 and at the end of 2001 there were 150,000 Zambian children ages 0 to 14 affected by HIV and AIDS (Garbus, 2003). Since then the impact of HIV and AIDS on Zambian communities, families and individuals has increased (Gopal, 2002; Namposya-Serpell, 2000). The scope and gravity of AIDS as a disease occupies an important place in Zambia's development agenda (United Nations Children's Fund [UNICEF], 2007). For more than 25 years communities in Zambia have been struggling to recover from the ramifications brought about by the HIV and AIDS pandemic. Recent studies (Goma et al., 2000; Mwewa, 2000; Manda, Kelly, & Loudon, 1999) have documented the impact of HIV and AIDS on Zambian communities and, have pointed out the devastation brought about by this scourge. Arising from this scenario is an emerging population of orphaned children who need to be

cared for in the most effective and efficient ways possible.

The challenges orphaned children face are very evident in communities hardest hit by HIV and AIDS (Fox, 2001). Grainger, Webb and Elliot (2001) have, for example, pointed out how Zambian children affected by HIV and AIDS continue to face serious socio-economic challenges. It is not uncommon to witness children as young as five living in ways that are not consistent with acceptable cultural norms. For example, young orphaned children are forced to cook for themselves and sometimes work odd jobs on urban streets for survival. This phenomenon highlights the gravity of HIV and AIDS and further raises the need to critically review and improve existing community-based care options for them (Grainger et al., 2001; Guest, 2001).

Challenges Faced by Children Orphaned by HIV and AIDS

Zambian children orphaned by AIDS grapple with a plethora of social, emotional and physical challenges (Matshalaga, Rita, & Powell, 2002; UNICEF, 2009a).These children have neither the capacity nor the ability to face or manage the challenges of daily living. If unresolved, these challenges could hamper their physical and emotional development. For instance, as children watch their parents become incapacitated due to an assortment of AIDS- related illnesses; lose their jobs; become stigmatized and eventually die, their emotional and psychosocial well-being is compromised. The impact of these social, emotional and physical challenges on children's well-being is a dire situation that calls for availability of improved and strengthened care options within families and communities.

Community-based Care Options

There is consensus regarding the definition of community-based care options. This term recognizes that almost all children affected by HIV and AIDs have connections with systems of care within their immediate and extended families (James-Wilson, 2007). Today in Zambia there are several care options available to children impacted by HIV and AIDS. All of these different types of care options take place within communities and are connected in one way or the other and, hence are referred to as community-based care options. Some of the most common and existing community-based care options include the family; extended family; foster care; care by grandparents; care by child headed households; and orphanages. The following sections provide short reviews of each of these care options.

Care by Family

Family willingness to ensure that care is made available to orphaned children in Zambia is high (Esu-Williams, 2006). The family in Zambia, as is the case with other African countries, is central in the provision of care to children impacted by HIV and AIDS (Nampanya-Serpell, 2001). Families provide the necessary building blocks and an appropriate cultural framework for children to grow up in and develop into responsible and productive adults. It is within families that children are nurtured, socialized and learn acceptable cultural norms and values (Sayson & Meya, 2001). It is critical to note that in Zambia families are considered as the norm in which children get the best lifelong education. However, with the negative impacts of HIV and AIDS, many families have been severely burdened to the extent that their capability to adequately address the needs of their HIV and AIDS impacted children has been diminished (Sayson & Meya, 2001). Consequently, the need to improve available care options needs to be at the forefront and in ways that could make care options efficient, effective units of support to children orphaned by HIV and AIDS.

The extended family is another care option that is very central in the provision of care to orphaned children.

Care by Extended Family

The extended family in Zambia has continued to occupy an important place and role in the provision of care to orphaned children.

According to Nampanya-Serpell (2001), the extended family serves as the premier and frontline safety net for HIV and AIDS orphaned children. In the past the extended family has acted as a traditional social security and its members have been responsible for the protection of children affected by AIDS. At the same time and, as highlighted earlier, the extended family acts as a conduit of traditional and social values (Foster et al., 1997) for children. Despite the negative impacts of HIV and AIDS on the extended family, it remains as the most viable and the sole provider of care to orphaned children.

The strength of the extended family lies in the multilayers of support that often emerge from different elements within the extended family structure (Esu-Williams et al., 2006). However, as noted previously the extended family has not been spared by the negative impact of the HIV and AIDS pandemic. The AIDS scourge has syphoned from the extended family structure able bodied family members who had the will to provide care to their suffering children. As more members of the extended families are siphoned out of the extended family structure many challenges that make it impossible for the extended family to operate in an optimal fashion emerge (Matshalaga & Powell, 2002).

The foster family is the other care option available to orphaned children.

Care by Foster Family

In a study of separated children, Mann (2001) has argued that child fostering takes place for many reasons. In societies where resources, claims and responsibilities are shared, fostering is the best care option for orphaned children. Fostering children is common in Zambia today and it is socially unacceptable for a man to refuse to care for his deceased sibling's children. The culturally acceptable way of distributing and sharing obligations and responsibilities of care for HIV and AIDS affected children is a rewarding experience that exemplifies cultural norms and values (Siaens, Subbarao, & Wodon, 2003). The scenario however, seems to be changing with the increased number of children orphaned by AIDS. Where foster care is available it is not uncommon nowadays to witness family members refusing to take in orphaned children of their siblings or other family members. Sometimes this refusal is fueled by a lack of financial assistance to ease the burden of caring for extra children (Siaens, Subbarao, & Wodon, 2003). This is compounded by the death of many young and able bodied adults, a situation that creates gaps in the types of care available to orphaned children.

Care by grandparents is another care option available to orphaned children.

Care by Grandparents

The role of grandparents in providing care to children orphaned by HIV and AIDS has grown exponentially in recent years (Nyambedha et al., 2003). Most of the grandparent carers are those who have lost children that have left younger grandchildren behind. Grandparents feel obliged to provide this gap in care and consequently find themselves at the frontline of support. Some studies (Nyambedha et al., 2003; Ntozi, 1997) have suggested that grandparents come under significant pressure as they seek to provide care to younger orphaned children left behind. Many accept this responsibility out of sympathy to their younger children and as a way of fulfilling unfulfilled dreams of not having provided enough for their deceased children. Others do it out of a sense of pride and as way of upholding strongly held cultural beliefs and values. As the effects of HIV and AIDS continue to be felt as evidenced by the burgeoning number of orphaned children more needs to be done to support grandmothers with skills that could help improve care to their grandchildren.

Another emerging care option for orphaned children is care by child headed households.

Care by Child-headed Households

It is common in Zambia to see children in child-headed households providing care and nurturance to younger siblings (Luzze, 2002). Luzze (2002) and Nampanya-Serpell (2001) have noted that child-headed households exist for several possible reasons, among them HIV and AIDS and poverty. AIDS has altered the structure of the family and has led

to a proliferation of child-headed households. Kwofie (2003) has documented that periods of poverty and limited resources have resulted in limited resources for supporting child-headed households. The existence of child-headed households is a phenomenon that demonstrates the limited capacity traditional households have in coping with the challenge of providing care to orphaned children. Children in child-headed households may have extended families who are burdened in their own family situations, and who are therefore unavailable to them.Lacking traditional family options, families of youngsters are being constructed without adult supervision or the necessary support to consolidate their efforts to live independently.

Luzze (2002) observes that child-headed households need a supportive environment for normal development. While there has not been serious examination of the issues of these households in Zambia, there has been discussion of the circumstances of such households by non-governmental organizations particularly in regards to the establishment of services targeted at child headed households. For example, in recent years international bodies such as the United Nations (United Nations Children's Fund [UNICEF], 2007) have increased their recognition of the strengths and difficulties of child-headed households.

That there are children living in child-headed households demonstrates the strength and capacity of these households. Findings of a study by Luzze (2002) support this position and suggested that children in these households demonstrate the strength to survive as families even without the protection, support, and benefits that are potentially present in the lives of other children. Yamba (2001) supports this argument further and comments that children in child-headed households take on the task of caring for themselves and others, and often make "important decisions about their lives" (p. 45). The need to support them cannot be overemphasized.

A new phenomenon that has emerged in the care options to HIV and AIDS orphaned children scene is orphanages.

Care by Orphanages

Recent years have seen a proliferation of orphanages as a means of addressing the needs of Zambian children affected by HIV and AIDS. The late 1990s saw a mushrooming of small orphanages run by local volunteers, community based organizations, and women's groups, particularly in the big cities of Lusaka, Kitwe, Ndola, and Mufulira. However, the sheer lack of professionalism, failure to meet required ethical standards, lack of adequate resources, extremely poor conditions, and repeated reports of child abuse and neglect forced many of these orphanages to close. Several studies have documented the negative impact of orphanages on child development (Judith, 1994; Luzze, 2002; Preble, 1990). A study by UNICEF (2004) linked lower child intelligence quotient (IQ) to children that spend a larger portion of their lives in orphanages.

Other studies have reported the association between institutional care and post-traumatic stress, mental health problems, developmental delays, and insufficient preparation for healthy adulthood (Roby & Shaw, 2006; Judge, 2003). Children placed in orphanages have increased risk of death, illness, language delay, socio-economic disorders, and personality dysfunctions. Richter, Foster, and Sherr (2006) have observed that there is a greater likelihood that institutionalized children, meaning those children in orphanages and who don't have families, grow up disconnected from their culture, extended families, and communities.

Williamson and Robinson (2006) have underscored the capacity of families and communities and advocates against caring for children in institutions. A statement released by UNICEF (2003) declared "for children who cannot be raised by their own families, an appropriate alternative family environment should be sought in preference to institutional care, which should be used only as a last resort and as a temporary measure" (p. 102). According to Subbarao, Mattimore, and Plangemann (2001), a major constraint of orphanages is that costs tend to be very high while its capacity to absorb orphans

is very low.Similarly, Sengendo and Nambi (1997) have commented that, given that most type of orphanages rely on outside funding by governments, non-governmental organizations, or others, it would be difficult to make them self-sustaining.

The fundamental challenge as UNICEF (2003) suggests remains, therefore, to improve, support and sustain orphanages in ways that are beneficial to orphaned children.

Limitations of Care Options

Mann (2004) has highlighted concern for the situation of children orphaned by AIDS in Zambia and has pointed to an increasing body of information on the needs and circumstances of children affected by HIV and AIDS.The need to improve the current care options as opposed to relying on the small, ad hoc, and uncoordinated programmatic services has been highlighted (Nampanya-Serpell, 1999; Yamba, 2001; United Nations Children Fund [UNICEF, 2007; 2003]). Unfortunately many of the available care options are based on limited evidence from research or with minimal or lack of sensitivity to the particulars of children as well as the local culture.

Over the last decade, communities across Zambia have begun to deeply understand the plight of children affected by HIVand AIDS and the need to improve the quality of existing care options they provide to orphaned children. However, and as noted by Foster (1998), the response by local communities to offer adequate and improved care to orphaned children has been limited. Levine and Foster (1998) further describe the situation by noting that in many instances, communities have mobilized and they have collectively defined their strongest concerns and identified how they could address these concerns.Although community mobilization efforts are there and inclinations evident, they are overshadowed by limitations within the available care options (UNICEF, 2007).

Using Cultural Competency to Improve Care Options

Given the extent of the HIVand AIDS problem including its negative impact on orphaned children care options discussed previously can only provide limited and partial care and assistance to AIDS impacted children (UNICEF, 2004). Despite the severe challenges faced by families and communities, the available careoptions have the capacity of being improved through enhanced community skill sets (Odhiambo, 2003). One way this could be accomplished is by use of care options that are guided and driven by a cultural competency framework. What is a cultural competency framework and why can it be a critical tool of improving care options to orphaned children?

Julia (2001) defines cultural competency framework as one that uses a set of skills that allow individuals and communities to increase their “understanding and appreciation of abilities, assets, and cultural differences and similarities within, among, and between groups of individuals in order to reach a common goal” (p. 56). The definition calls for a willingness to draw on existing knowledge and local cultural values, traditions, and customs that could improve the different types of care options available. Cultural competency might also make it possible for families and communities to identify the best knowledge, skills and values that could improve the overall social and emotional being of children.

This definition by Julia (2001) identifies two important elements that are important in understanding ways in which families and communities could be supported with knowledge and skills required to strengthen support to HIVand AIDS impacted children. Using a perspective similar to Julia’s, Kim and Ruben (1988) have posited that cultural competency as a framework is a learning and growth process where new knowledge, attitudes, skills and capacities gained create new ways of functioning. In order to allow for real and meaningful application of knowledge, cultural norms, skills and capacities important steps will have to be implemented. These steps will involve local communities and

multi-disciplinary professional teams working in concert with families and communities in targeting and improving existing care options noted previously. Important tools such as training workshops, community seminars and informal cultural gatherings could serve as essential conduits for identifying appropriate skills, suitable knowledge, values, customs, attitudes, and acceptable cultural community norms to improve care. In executing these elements the following cultural competency considerations might be useful;

- Recognizing the value of cultural norms and centeredness of the family and affirm the culture differences that might exist within the types of care options.
- Identifying the qualities and necessary expertise that families, orphaned children and com munities should possess, and
- Promoting care option components by using translational research in addressing specific challenges affecting children affected by HIVand AIDS.

Using Translational Research to Improve Care Options

Translational research is an approach that could work best when enhancing the capacities of different care options. Translational research could address how basic behavioral processes might inform care options (National Institute of Mental Health, 2005). An important element of translational research is the recognition of the need to build linkages and relationships between care options in different communities or contexts (Rogers, 2003). Zambia communities hardest hit by HIV and AIDS could utilize translational research in improving, sharing lessons and scaling-up care options. When used with well-defined goals translational research could generate a collaborative process with families and communities through which care options are further explored, assessed, refined and enhanced with a view to effectively targeting and addressing needs of orphaned children. In the long run and with effective utility this process could improve a shared understanding within and between communities as well as families of how best to improve care options for children impacted by AIDS (Holmes & Mathews, 1993).

Conclusion

Orphaned children are the future of Zambia and as such need the best empirically validated and culturally attuned care options. In Zambia, as in many other African countries, families and communities play a central role in shaping lives of children. It is within families that children affected by AIDS are socialized and learn norms and values essential for their critical development. Families provide the appropriate social structures in which children orphaned by HIV and AIDS might grow up and become responsible and productive citizens. In this regard and as suggested previously families need to be strengthened and supported with necessary knowledge, values and skills to assist and best support orphaned children within their proximities.This approach should be encouraged in especially high HIV and AIDS-affected communities. On a different level communities are central in providing essential elements of care to orphaned children. They could serve as storehouses and conduits of knowledge and because they offer a sense of shared culture, they could provide the best platform for enabling a deeper understanding of orphaned children experiences. As highlighted earlier, care options occur in the context of community and family and as such could be refined and improved by using cultural competency and translational research as frameworks for improved care outcomes. These frameworks have potential of improving available care options and of allowing lessons within and between families and communities to be shared. Use of these frameworks could lead to improved overall well-being of Zambian children orphaned by HIV and AIDS.

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