



The Perceived Needs of AIDS-Affected Orphans in Rural Uganda: A Qualitative Examination

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INTRODUCTION

HIV/AIDS continues to dramatically reshape the lives of children around the world. An estimated 2.3 million children under 15 years old are infected with HIV, while 15.2 million children under the age of 18 have lost one or both parents to the disease [1]. In Uganda, a country often referred to as a "model" in its fight against HIV/AIDS [2], over two million children have experienced the death of at least one parent, one million having been orphaned by AIDS [3]. Yet, these figures fail to capture the extent to which HIV/AIDS-affected children have been made vulnerable through experiencing poverty, homelessness, school dropout, separation from siblings and friends, increased workload, social isolation, discrimination, and loss of life opportunity [4].

Located in the Wakiso District of rural Uganda, Namugongo Fund for Special Children (NFSC) subscribes to a community-based approach to working

with HIV/AIDS-affected children by reaching nearly 1000 children each day through multi-site breakfast centers, after school programming, nursing supports, scholarships, and child sponsorships. NFSC reports 27% of children they care for are HIV positive, while all experience the far-reaching effects of AIDS.



Out of necessity and limited capacity, many interventions in low resource settings target children's most pressing physical needs such as clothing, food, medical care, and shelter. Yet, traumatic and life-altering events associated with

AIDS, coupled with an absence of adequate coping skills and social supports, can have profound effects on a child's current and future mental health. Such effects may result in clinically significant levels of psychosocial distress including depression, anxiety, and withdrawal [5, 6], which may impede children's development, complicate medical treatment, and prevent them from becoming productive members of their communities.

The research presented here is one segment of a larger project (conducted during Summer 2007) which collected information from multiple stakeholders - including children - to fully understand the situation facing this particularly vulnerable pediatric population. This project was sponsored by the Griffin Foundation in partnership with The SPARK Center at Boston Medical Center.

PURPOSE

The present study aimed to capture the most salient concerns of children living with HIV/AIDS in NFSC's catchment area in order to begin building an evidence base for intervention and effective advocacy.

METHODS

Using a qualitative participatory methodology consistent with a child's 'right to participate' [7] the researchers worked alongside their Ugandan colleagues to develop, translate, and pilot a focus group script into the local language (Luganda), ensuring that the nature and constructs embedded within each question were presented in a way that was culturally relevant and age-appropriate while preserving the dignity of the individual.

For the purpose of this analysis, four key questions are presented:

1. What worries do children your age have?
2. Is there someone children talk with when children have a worry or problem?
3. If you had a special and private time to meet with other kids and a counselor in order to talk about worries or struggles in your life, would you like it or not like it? Why?
4. If Namugongo Fund for Special Children did not exist, how would your life be different?

Focus group facilitators (FGFs) were recruited from local organizations and universities. Most had previously received university-level training in human services and were familiar with the situation facing children in the community. FGFs were proficient in Luganda and English. Working in teams of two, they served as 'cultural brokers' by administering focus groups and translating children's responses for each question into English.



Children were invited to participate in focus groups following one of three community meetings that were held for children and their guardians enrolled at NFSC. These meetings occurred at schools where many of the program's children attend. Pending informed consent by their guardian, children were

presented with an opportunity to participate in a focus group.

To identify emerging themes from the raw data, valid responses were double coded by two members of the research team. Their codebooks were compared; differences were resolved through discussion; and the agreed upon domains were further validated by a blinded cross-cultural research team who independently arrived at similar conceptual categories using the original data.

All research activities received approval from the Institutional Review Board at Boston University School of Medicine.

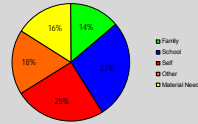


RESULTS

Demographic Summary

Children	Total #	Mean	Age		Sex	
			Min	Max	Boys (%)	Girls (%)
	143	11.4 (SD=1.8)	8 to 17	88 (61.5)	56 (38.5)	14

What worries do children your age have?



Children reported a wide breadth of concerns in their community including preoccupation with many basic needs such as school (I am worried to be sent away for school fees) and material needs such as food, shelter, and clothing. Children's responses described a range of fears about personal safety of the 'self' including anxiety about getting sick (I worry of diseases like AIDS), being abused, being raped, and dying. Fourteen percent of children's responses indicated anxiety about a caregiver or family member becoming sick or dying (I worry that my mother might die because she's always sick). Other worries included fears about status as a second-class citizen status in non-parental



households, and fears that talking about problems at home could lead to beatings and stigma. While it was beyond the scope of this analysis, many respondents reported multiple worries.

Is there someone children talk with when children have a worry or problem?

The majority of children (88%) identified someone in the environment that children could talk to when they have a worry or concern. Of those who reported that there was someone to talk with, over 60% felt they could turn to a relative such as a parent, sibling, or other family member for support. Children who reported that there was not a person to talk with (12%) cited the absence of a caregiver (My father died and I have never seen my mother) or a worry about telling someone about their problems (If I talk to them they just abuse me).

CONCLUSIONS

This study revealed the pervasive anxieties of OVCs living in the region, even within the context of NFSC's creative service delivery to a large community. The enormity and variety of children's expressed worries suggest that effective interventions for HIV/AIDS-affected children must not only address children's material needs, but should also include attention to their emotional lives.

While the majority of children generally identified someone in their environment that they can talk to about problems, most children responded positively to the idea of having a safe and private group time with a counselor to speak about their concerns and worries.

Further exploration into caregiver and community leader perceptions of children's situations will help determine the degree to which adults in the community are sensitive to the range of needs as identified by the children themselves.

PUBLIC HEALTH IMPLICATIONS

A 'pre-baseline' open-ended methodology that solicits the input of the client population may go far in helping to inform interventions that truly reflect people's felt needs and perceptions.

When approached respectfully and carefully, children have an emerging capacity to articulate their needs, including their emotional preoccupations and worries.

Orphans and vulnerable children in low resource settings require interventions that meet the full spectrum of physical and emotional supports including mental health supports that have been 'standards of practice' for children with HIV/AIDS in other countries

Applied research must continue to explore the psychosocial and emotional dimensions of children's lives for the purposes of implementing evidence based therapeutic interventions.



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