



# Hear our voices: A Photovoice project with children who are orphaned and living with HIV in a Ugandan group home



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## ABSTRACT

In June 2010, we conducted a qualitative participatory research study to explore the experience of orphaned, HIV seropositive children who live in a group home in semi-urban western Uganda. Photovoice was used as a participatory method to enhance storytelling with children between 12 and 18 years ( $n = 5$  girls;  $n = 8$  boys). In previous project work done by the research team in Uganda, children's affirming experiences in their group home suggested an extension to the dominant view that favors extended family placements, and raises the need for further inquiry regarding institutional care. Children in this study revealed how the group home supported key protective factors in their everyday lives that promote well-being, and resilience for coping with challenges such as stigma. Children expressed how their group home fostered a sense of belonging and appreciation for nature, home, resources and community. Children also described their hardships stemming from stigma, including associated psychological, emotional and social challenges. This forces us to re-think the role of institutional care for orphaned children who are HIV seropositive, guided by the unique perspective of children themselves. This research extends our understanding of key protective factors, while also challenging the dominant view to include institutional care as an effective placement option for those that require specialized care and support. Moreover, findings demonstrate that HIV seropositive orphaned children who live in a group home setting experience protective factors supporting their psychological, emotional and social well-being.

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## 1. Introduction

The purpose of this study was to explore the experiences of orphaned, HIV seropositive children who live in a group home in semi-urban western Uganda utilizing Photovoice. Children's perspectives are central (Pritchard Kennedy, 2012) to understand the local meanings of psychological, emotional and social well-being, and coping strategies to inform effective supports and interventions, including institutional caregiving. This is important as the AIDS pandemic is having a profound impact on the health of children in Uganda. It is occurring directly through child HIV infection, and indirectly through effects on families, communities and the social and economic functioning of the country (Barnett & Whiteside, 2002; Bridge, Kipp, Jhangri, Laing, & Konde-Lule,

2006; Bridge, Kipp, Raine, & Konde-Lule, 2006; Foster & Williamson, 2000). Estimated HIV prevalence in Uganda is 7.2%, with 1.5 million children and adults living with HIV (UNAIDS, 2012). Over 190,000 are children aged 14 years and under (UNAIDS, 2012). Although there has been progress and increased access and funding for HIV, treatment demand remains greater than the availability of antiretroviral therapy (ART). In 2011, only 313,000 Ugandans who are living with HIV infection and require ART have access to treatment (World Health Organization, 2013).

Children orphaned by AIDS and living with HIV require specialized support to address their psychosocial well-being. Living in a small group home is one solution to providing the care and support that they need. However, institutional care has long been questioned as a place that can provide such care. Debates about the value of institutional care versus extended family and community care can be traced as far back as 5 decades (Williamson & Greenberg, 2010). However, it is suggested that this debate move beyond the dichotomized categories by contextualizing local norms and models.

We review the empirical literature that explores the complexities of care for orphaned children in sub-Saharan Africa including HIV stigma.

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We then describe psychosocial issues most often researched in this population. Finally, we report on the findings of the study, exploring the perspectives of children living in a group home, including how their institutional care facilitates key protective factors, and should thus be considered as an effective placement option.

### 1.1. Care for orphaned children

As the HIV and AIDS pandemic enters its third decade, caring for orphaned children continues to pose many complex challenges especially in Uganda. At the macro level, country politics often plays a role in the complexity of care and Uganda is no exception. The orphaned and vulnerable children (OVC) policy (2004) for Uganda highlights that OVC should be provided their human rights and supported with socio-economic security, food security, psychosocial support, education, health and child protection, but the implementation of these priorities is less clear (Uganda Ministry of Gender, Labour and Social Development [UMGLS], 2004, pp. 9–11). *Strengthening Human Resources and Financing Childcare and Protective Services* is an issue paper produced by the same Ministry that developed the OVC policy in Uganda which recommends various strategies (UMGLS, 2011). However, on a closer look, the paper requests from the Ministry of Finance in Uganda to increase its budgetary allowance to help support the OVC priorities. It is paradoxical how one Ministry can appeal to another for funding as the Ministry of Finance does not have powers to grant such increases without the directives from the President. This draws attention to the larger complex political landscape that must also be navigated when working to address issues of OVC.

At the meso and micro levels, community and extended family capacities have been exhausted in many highly affected areas, and there remains a lack of financial resources to support community care (PEPFAR, 2006). Uganda's orphaned and vulnerable children policy outlines that the family and the community should be the first line of response (UMGLS, 2004, p. 5). There is international agreement among governments and non-governmental organizations (NGOs) that anything other than family care should be a last resort (see UNAIDS, UNICEF and USAID, 2004; UNICEF, 2007; PEPFAR, 2006; UMGLS, 2004; Csáky, 2009). However, policy documents espousing these guidelines make little if any mention of the circumstance around utilizing institutional care or produce any guidelines to direct this type of care. Embracing community care as an overall strategy without first understanding the local context and local meanings may cause more harm to children. Additionally, in the research literature, family is often romanticized as a safe, nurturing and supportive environment for children orphaned by AIDS (Madhavan, 2004). In child-headed households, van Dijk and van Driel (2009) question the role of adults (extended family and neighbors) in being able to provide support for this group of children. van Dijk and van Driel (2012) found that the children's idea of support depended on the quality of the relationship and on their assessment of a person's ability to offer support. Cluver and Orkin (2009) found that children living with extended family may also experience discrimination, abuse, and neglect related to HIV stigma.

#### 1.1.1. Stigma

Stigma is a complex social phenomenon, and effects on children may vary in severity depending on many individual and contextual factors. Stein (2003), in her literature review on the psychosocial impact of HIV/AIDS on orphaned children in sub-Saharan Africa states that "the stigma associated with HIV/AIDS is perhaps the greatest obstacle to their future well-being" (p. 26). Deacon (2006) distinguishes between stigma (understood as negative ideologies or attitudes) and discrimination (negative behaviors). Children living in an extended family can be stigmatized by other adult family members such as a stepmother/father, an aunt or uncle or by other children such as a step-sibling or a cousin. HIV continues to be viewed in many sub-Saharan African communities

as a disgraceful disease and as a result families often feel shame. For some families this shame manifests itself in discrimination (Harms, Jack, Ssebunnya, & Kizza, 2010) and reduced care (e.g. education, nutrition etc.), support and love from their caregivers (Funkquist, Eriksson, & Muula, 2007; McGraw & Wameyo, 2005). It is this inadequacy of care from their extended family (rooted in stigma) that calls attention to the role that institutional care can play and why it should not be entirely rejected as a viable and perhaps short term option for some children. Community-wide stigma reducing programs are necessary and are still in their infancy in Uganda. Children need access to safe social spaces, free from stigma and discrimination while waiting for these stigma reducing programs to materialize in the community.

#### 1.1.2. Institutional care

Institutions such as orphanages, group homes, or residential care facilities are settings often considered a last resort for care in sub-Saharan Africa (SSA) and can be easily identified as "AIDS homes" for HIV seropositive children. Living in such settings, children are subject to stigma by community members solely based on the label given to the home in which they live. Additionally, researchers have reported the devastating effects of institutional type care on children's cognitive and psychosocial development (Jackson & Kerkhoven, 1995; Madhavan, 2004). However, the existence of these institutions in Uganda for this particular population illuminates the challenge of finding alternatives for caring and supporting them at the extended family and community level. Although orphanages, group homes, and residential care facilities are not a common first-line model of care, a 'home' or 'family-like' environment that has the potential to foster children's emotional, social and spiritual needs and may mitigate compounding challenges faced due to being HIV seropositive and orphaned. Small group residential care is argued to be suitable for a small range of children or as a short term solution for those who may require specialized support and care such as HIV (EveryChild, 2011; Mann, Long, Delap, & Connell, 2012). It is also recognized by a few that formal community-based structures are still "needed for those children who cannot be placed elsewhere" (Desmond, Gow, Loening-Voysey, Wilson, & Stirling, 2002, p. 447). This recommendation is also supported by EveryChild (2011) who believe that a range of care options must be developed to support all children who cannot be cared for at the family level.

Madhavan's (2004) examination of fosterage patterns in South Africa explored how history, poverty, social trends and contexts are essential to examine when understanding orphan care. Madhavan (2004) contends that "without a solid conceptual grounding of caregiving in particular communities, we run the risk of not only wasting resources but worse, exacerbating conflicts to the further detriment of children's well-being" (p. 1451). Norman (2011) also argues that conceptualizations of childhood in the era of HIV and AIDS have been marred by "crisis" discourse and recommends a holistic approach when examining the issues faced by children. These are important points that highlight the need to actively involve children, youth and families to hear their stories and involve them in addressing their issues.

### 1.2. Psychosocial Issues

In addition to issues of orphan care, the psychosocial impact of HIV and AIDS on orphaned children has been identified in the literature (Harms et al., 2010; Killian, 2004). Studies have reported that children who are orphaned due to AIDS experience psychosocial distress (Nyamukapa et al., 2008), post-traumatic stress disorder (Cluver & Orkin, 2009), and depression (Atwine, Cantor-Graae, & Bajunirwe, 2005). The literature has also pointed out that children are at greater risk of sexual abuse and sexual risk behavior (Killian, 2004; Operario, Underhill, Chuong, & Cluver, 2011).

Specific to Uganda, research has shown that children orphaned by AIDS in rural Uganda demonstrated greater anxiety, depression and anger as compared to children who are not orphaned (Atwine et al.,

2005). They concluded that material support such as food, shelter, clothing and school fees, are not enough to support these children (Atwine et al., 2005). These findings are similar to research conducted in Zimbabwe and South Africa, which showed that children orphaned by AIDS have higher levels of psychosocial distress, depression, post-traumatic stress disorder, and experience more stigma than children who are not orphaned (Cluver & Orkin, 2009). However, these particular illnesses and challenges are predominantly defined and understood from a Western perspective; thus it is important to seek evidence that defines such experiences from the Ugandan children themselves.

The vast majority of research on children affected by HIV and AIDS has focused on emotional, social and psychological distress and “employs decontextualized norms or models of childhood and mental health” that is driven by western definitions and it is “essential that we begin to focus on local meanings of mental health, coping strategies and pathways to psychosocial well-being” (Skovdal, 2012, p. 462). Therefore, ensuring that children's voices are central and actively involving them in the research process is an important consideration (Pritchard Kennedy, 2012). By contextualizing norms and models, stakeholders may better understand children's specific needs and strengths and be more equipped to assess and evaluate interventions to ensure that they are providing meaningful support. Our study offers new insights into the complexities of children's lives affected by HIV and AIDS through supporting local understanding and experiences of a small group of children in institutional care.

## 2. Context

In collaboration with a semi-urban Ugandan group home, our Photovoice project was conducted near a small city. This group home is supported by a local non-governmental organization (NGO), whose mission is to support orphaned and vulnerable children in a semi-urban area in western Uganda. The group home is a small part of the overall activities of this NGO and the home provides care for 30 children who are all HIV positive, orphaned, and in desperate need of support, such as children who spent their time on the streets often begging for food and money. An orphaned child is defined in the current study as a child below the age of 18 and with either a mother or father who has died of HIV (UNAIDS, 2011). Children living in the group home are from 6 to 18 years of age, 55% are male and 45% are female, and are all able to attend local public schools. Material resources such as shelter, clothing, and nutrition are provided. Children sleep at the home in dormitory style bunk-beds, and have access to clean latrines and bathing facilities. A mobile health team and local hospital outpatient clinic provides medical care to manage children's HIV, as most of them are taking antiretroviral therapy. Children also receive psychological counseling to help them express their feelings and experiences. The group home is supervised 24 h a day, 7 days a week by locally hired nurses, cooks, and maintenance and security staff. Children return to their villages, extended family, or foster care during school holidays if these supports are available.

The Director of the NGO identified concerns for the mental, emotional and social well-being of children in the group home which became the impetus of the study:

Many of the children that they care for have been repeatedly told in their home villages that they have “slim” disease or HIV/AIDS, and are soon to die. The children struggle with self-esteem and hope. When they go to the health clinic for treatment they discuss with each other which friend has died since the last visit. In school they also experience bullying related to being orphaned and also related to living with HIV. They get involved in conflicts and fights at school and do not have an easy life. The group home is the only secure place that the children have ever known (personal communication, Director of NGO, April 14, 2009).

These concerns informed and shaped the development of the research study in question.

## 3. Design and methods

Photovoice and focus group discussions (FGD) were determined to have the best fit for our study given local priorities, contextual issues, literature review, and subsequent research question: *what is the experience of orphaned, HIV seropositive children living in a group home in Uganda?* Photovoice provides participants the opportunity to create and discuss photos as a way to share their views, ideas, and experiences, and to record, reflect, critique, and take action on personal and community issues (Wang & Burris, 1997). The photos and stories can be used to call for raising community awareness of an issue, public policy change, advocating for human rights, and addressing stigma. The process of creating visual images is empowering, as are group dialogues that affirm individuals' collective struggles and insights (Wallerstein & Bernstein, 1988). Photovoice also involves a form of story-telling, important in African cultures that are rooted in oral traditions (Fournier, Mill, Kipp, & Walusimbi, 2007). This method was appropriate to gain understanding about what the children at the group home perceive matters to them regarding their family, home and community. Photovoice has also been used as a method in numerous research studies involving children in Kenya (Johnson, 2011, Skovdal, Ogutu, Aoro, & Campbell, 2009), youth in juvenile detention facilities (Arendt, 2012; Osseck, Hartman, & Cox, 2010), and school children affected by HIV in South Africa (Khanare, 2012).

### 3.1. Participants & research team

The target population for the study was all children between the ages of 12–18 years living at the group home. Thirteen children were invited to participate and all children (n = 5 girls; n = 8 boys) accepted this invitation. Children gave their informed assent in written form, attended all the pre-photo taking training sessions, and had a guardian's consent to participate (a competent living parent, extended family member or foster guardian). Children were in a stable medical condition during the course of this study. Ethical approval was granted from two institutions in Canada: Mount Royal University and the University of Alberta. Additionally, in Uganda ethics approval was obtained from Makerere University and the Uganda National Council for Science and Technology.

### 3.2. Data collection

All the training sessions and FGD discussions were held at the group home in the dining hall, exclusively with the study team, including children and the field research team members. The children's role in the process was to take photographs, share photograph interpretations through FGD, and provide ongoing feedback with the field research team on study processes. The field research team consisted of the primary investigator, and two local Ugandan research assistants, one of whom was a trained mental health counselor. Research assistants carried out all information exchanges, recruitment, collection of informed assent and consent. They also facilitated the FGD in the vernacular, tape recorded, transcribed, and translated to English. Research assistants worked with children to provide cultural perspectives and insights that were critical to the success of the project. Using disposable cameras, children's photography sessions were held around the group home, and in the nearby vicinity. Children were accompanied by a member of the field research team if they wanted to photograph outside of the grounds of the group home in order to ensure their safety. The six part Photovoice process included:

- 1) Training Sessions: safe and ethical use of cameras, as well as direction for generating photograph themes were discussed with the children. A worksheet titled “What matters to me” was provided to children to help them think about and write down strengths about themselves, their family, home and community. The worksheet also encouraged



the children to add their perspective on what they felt needed change in themselves, their family, home and community. Completing the written worksheet was challenging for a minority of the children, but they worked with a peer to read and write in either English or the vernacular. The worksheet was also explored verbally during a FGD.

- 2) First Photo-taking Session: children took photographs at the group home and vicinity. 2 h was allocated to this session.
- 3) FGDs #1–3: once photos were developed, a series of three FGDs were held. During the first session, children were asked to discuss their “what matters to me” worksheet. This was intended to explore children’s themes. In the second FGD children discussed the meanings and messages in their first set of photos using the acronym SHOWeD: What do you See here? What’s really Happening here? How does this relate to Our lives? Why does this problem or strength exist? What can we Do about this? (Wallerstein, 1987). A third FGD clarified the themes on “what matters to me”.
- 4) Second Photo-taking Session: children took photographs at the group home and vicinity (2 h).
- 5) FGD #4: children discussed their second photography session, meanings and messages.
- 6) Photography exhibition: children’s chosen photos were displayed on the walls of the group home dining hall. Each child was free to choose any photo that they wished and personally wrote a story about their photo. The photos and the hand written stories were mounted on poster paper (see Fig. 1). Children selected the audience for their photo exhibition. They decided to limit invitations to the group home staff, fellow children at the home, NGO staff and field research team members. Each child spoke to the audience about their photo and story (approximately 5 min each) during a celebratory lunch.

### 3.3. Data analysis

Utilizing the SHOWeD framework, the children were involved in a root cause questioning process to analyze the stories that they were telling from the photographs. Another level of data analysis occurred using matrix methodology techniques described by Miles and Huberman (1994) to analyze the tape recorded and transcribed FGD data as well as the children’s photo display story. The children in the study were not directly involved in this stage of the data analysis. First level analysis was used to assign a descriptive code (label) to a segment of the data to give it meaning. As the researchers become more familiar with the data, pattern coding was used to label emerging themes. An inductive

approach was used to analyze the data involving iteratively coding and identifying themes and discovering relationships among themes via systematic comparisons using negative cases and extreme cases. Methodological decisions and analytic insights were also documented, and two members of the research team traveled back to the region to consult and seek feedback on the analysis from local experts and stakeholders in the area after preliminary analysis was completed.

### 3.4. Limitations

The study involved a unique group of orphaned children being cared for in this special home that is supported by a non-governmental organization. Therefore, the findings that emerged may not represent the views of other orphaned children living in the community or in other types of institutions.

Utilizing Photovoice was relatively inexpensive. Forty-five disposable cameras and film processing for two photo taking sessions with 13 children cost approximately \$253 USD. The cameras were purchased in Canada for \$225 USD. Film processing in Uganda was relatively inexpensive at \$28 USD.

There were three limitations related to the methodology. Firstly there were not enough cameras available to conduct three photo taking sessions as the younger children at the home felt left-out of the process, and so were given a camera each for “fun”. This limited the number of photo sessions and focus group discussions.

Secondly, the primary investigator also had a tight time-line when in Uganda. The investigator spent nine weeks in the country, but had to wait three weeks before the final in-country approval was obtained to start the project. This may have inhibited the children’s ability to process, reflect on and understand the purpose of Photovoice and creating their themes, photos and “actions”. Time also limited the ability to have the children partake in a formal evaluation of the project.

Thirdly, it would have been important for the team to have brought the data analysis back to the children for their participation and collaboration. Unfortunately, logistical and budget challenges prevented this. Further details about the research process and methodology of this study are documented elsewhere (Fournier et al., 2014).

## 4. Findings

Two major themes emerged from the data analysis: protective factors and hardships. While these themes are reported as distinct headings, it is important to note that these themes were often interrelated.

### 4.1. Protective factors

As an element of resilience, protective factors are considered to be those that may reduce or mitigate the negative effects of adversity on child outcome (Kim-Cohen, 2007). They can operate at the individual, family, and community level and may vary depending on the child’s developmental stage, age, or gender, as well as the type of adversity or hardship being faced (Masten & Reed, 2002). In the resilience literature, defining protective factors varies across a broad range of risks while other factors may only be protective in the context of certain risk conditions (Vanderbilt-Adriance & Shaw, 2008).

#### 4.1.1. Nature as a resource: “This tree helps us in different ways”

Children had many photos that were snapshots of nature or the natural environment. They described the value of nature, that the natural world is “created by God”, and highlighted how essential these resources are for life and survival. One child described their photo of vegetation (Fig. 2) by saying “These papyrus ... act as a home for aquatic animals and we get fish from here, dig it and grow food and sometimes



Fig. 1. Photo and story exhibition.



Fig. 2. Papyrus tree.

we get herbal medicines in case you have stomach upsets". In another photo, this same child says:

This tree helps us in different ways, like building, split into firewood for cooking, and the birds we see use them as shelter. We even get some ropes to tie up sacks of charcoal .... We depend on these plants so we should not destroy them ... our life is supported by plants because they bring out oxygen which we use in breathing ... if it was not for the plants, us people would not be living because we breathe out carbon dioxide and they breathe out oxygen we breathe in.

In summary of his photo the child says "They help us a lot in building houses, making fences ... there's a lot of money you can get the papyrus, make mats and sell them to get money".

#### 4.1.2. Hopes and dreams: "I will build a house"

Almost all of the children's photos and discussions depicted their hopes and dreams. When discussing their photos they described their desire to be successful, contributing members of society. One child described that they "have to work hard to achieve something". Another child described their desire for future occupations: "I want to become a counselor. I have gone through many problems and I know some people can learn from me." Another stated: "I want to become a doctor and treat patients." Others dreamt of being self-employed (see Fig. 3): "After getting money, I will build a house. Then start my own business. I want to be self-employed. I will be the happiest person in the world." These



Fig. 3. Dreaming on the grass: After getting money, I will build a house.

quotes typified hope. One child declared that "if I take my drugs well and study hard, I know I will get all I need."

Desires to be successful and respected in their community were recurring sub-themes in the FGD as one child stated:

When you study hard, you can achieve your dreams. For example after completing studies you can get a good job, become rich, buy a luxurious car, and gain respect from villagers. After death, your name won't be forgotten; the community will keep remembering you though dead, because of your wealth and education. But when you're poor, people disrespect you and consider you to be useless to the community. You have to build a name when you're still alive so that you can be known and loved by everyone when you study hard.

#### 4.1.3. Material resources: "I love the cow"

A prominent theme was children's appreciation of being provided with basic life needs and material resources at the group home. One child described his photo (see Fig. 4): "The cow [at the group home] helps us in giving us a source of milk at the home for drinking, it is why I took this photo to mean that I love the cow and the one who bought it."

And another described their photo: "I want to talk about the house [group home]. It has helped so much, it has saved many people's lives ... giving them school fees, food, drinks, they can play ... it knows all the problems they have, it has helped so much ... it even has a water heater, that helps warming water for bathing." The material resources at the group home were a stark contrast to some of children's previous struggles as one child described: "Most of us are orphans, if some had stayed in their villages, some would have been beaten to death because you can be tempted to steal because you cannot find food."

Another child described: "If you don't have a house where to sleep you can sleep out .... Mosquitoes bite you, it rains on you and you can get sick and you die. There's also a bicycle. It helps us so much. We can use it to fetch water and carry other things." Before living in the group home, many children had experienced complex challenges related to survival and daily life.

#### 4.1.4. Social support: "If you don't have friends you walk as if you are not walking"

In addition to material resources, children's photos and discussions highlighted the importance of friends in their lives. They discussed feeling cared about, accepted and supported by the adults and other children at the group home. A child described the importance of friendship by stating: "If you don't have friends, you feel lonely and you cannot be happy at all ... you walk as if you are not walking. But if you have someone, you feel strong and in case you have any problem, that friend can help you."

Another child described the social support at the group home by saying: "Why I took this photo is that there is love between us children and staff [of the group home]." An older child discussed the younger children at the home by saying: "I love these little children [at the home] so I gathered them and I took a photo together with them ... I want them to always be happy ... I had my aunt ... she loved me so much, would always carry me. That reminds me that I should try to do to the little children what my aunt did to me."

#### 4.2. Hardships

Although the majority of children's photos and discussions were related to the positive aspects of their lives, children also discussed situations and experiences that can be described as hardships. Hardships can be defined as something that causes suffering or privation (Collins English Dictionary, n.d). Experiences of stigma and discrimination, struggles to cope with their emotions related to stigma, as well as



traumatic situations in their communities were described. It was clear that these hardships impact their psychological, emotional and social well-being.

#### 4.2.1. Stigma and discrimination: "Pointing fingers"

The various forms of stigma that children face in the broader community and its impact were a recurring theme. Children spoke about over-hearing people in the community talk about others with HIV and AIDS. They also described their experiences of being personally signaled out as having HIV and AIDS. One child stated: "the thing that hurts me most is when people point at me, that I am suffering from HIV and AIDS ... it hurts me so much. People should stop talking about that." The "talking about that" referred to people who would not only point fingers but also whisper to another, or say something out loud that the child had HIV and AIDS. One child overheard someone in the community saying "that one is finished with his/her AIDS", and then went on to say: "if you hear that, even if they are not talking about you, you can even collapse and die ... HIV and AIDS came, but people should stop pointing to the infected people." Compounding this issue of pointing fingers at HIV positive individuals, the group home is also a place where fingers are pointed with its label of being an "AIDS home" by community members.

The impact of stigma on children was also discussed. A child stated, "I hate discrimination and this makes you feel worthless. Another thing is that they should stop pointing fingers to people with HIV and AIDS." Another child expressed that "most HIV victims are desperate and when you annoy them they can commit suicide or do anything bad which endangers their lives." These statements describe how they feared for their fellow children at the home, and worry about the impact of stigma on themselves, their friends, and other children that they care about.

In addition to HIV and AIDS related stigma, children discussed wishing to avoid social situations that would have a negative impact on social-status. These included wishing to avoid being singled out in the community by the local government, or being labeled un-sanitary, a thief, uneducated or poor. A child described why a latrine was so important by saying:

This toilet helps us dispose of our feces ... some homes which don't have a specific place to put their feces are dirty homes. The local council ... those responsible for health ... used to arrest people in the villages who didn't have latrines. Some children would start making fun of those children whose parents were arrested for not having latrines. When I build [my own home], the first thing to do is have a latrine.

A female child described the social stigma of being unsanitary by saying: "You can leave your house dirty and disorganized, shabby with plates near the toilet door, then on your way to work you get an accident and they take you to hospital. But going back to your home to look for blankets and other equipment to use at the hospital, they find a house in a mess. You can be embarrassed." For some children there was a stigma connected to being labelled a thief, as one child stated about his photo of a pig: "[Without a pig] you can suffer a lot. You can even die of hunger or go ahead to steal people's food and everyone will be pointing at you that you are a thief."

#### 4.2.2. Psychological, emotional and social challenges: "Go bury your mother"

Children described the various psychological, emotional and social challenges that they experience. Experiencing anger was described frequently, and was related to being abused, bullied in school, being wrongly accused of a crime, and witnessing other children suffering. They also described feelings of distress related to remembering their past and present losses (such as the loss of parents), being abused by extended family and coping with their fears and challenges related to



Fig. 4. Photo of a cow.

living with HIV. One child said: "I get really angry when someone insults me by abusing me that I should bury my mother, yet she died a long time ago and I buried her." And another described coping with fears of death by saying: "Friends can help you in many things. This helps you not to be alone and stop thinking of many things like that you are going to die." And another child discussed not wanting to feel sad by saying: "I don't like being sad all the time. So I love playing football. It helps me not to get lost in thoughts". This sentence also described the child's positive coping mechanism (see Fig. 5). (See Fig. 4.)

The children described social issues related to orphan-hood by stating: "HIV positive orphans are being left alone, neglected by rich relatives" and they also experience property grabbing or issues of gaining access to inheritance. One child stated: "those who have taken land from children should give it back because they are the ones making them thieves." Some children spoke fondly of their extended family, while others described being verbally abused and neglected. One child stated: "Whatever they [extended family] do, they remind me of my [deceased] mother. When I have maybe offended one child, they all turn against me. They keep on saying that they will now see where I run to. I used to run to my grandmother, but she also died."



Fig. 5. Photo of playing football.

## 5. Discussion and recommendations

Findings from this research project highlight the often unheard voices of children who are orphaned and living with HIV. Their photos and talk were about their resources, the positive factors in their lives and their hopes and dreams. The group home was a key protective factor in their lives and offers new insights into institutional care by drawing on local meanings of what it is like to be a child, and a child who is orphaned and living with HIV. Their stories also offered insights into their hardships.

### 5.1. Resilience

Our findings show that the children in the study have many protective factors in their life that help them cope and manage their life situation. By drawing on local representations and meanings, children are more able to evaluate their difficult situation more positively (Skovdal & Daniel, 2012). Our findings support such a conceptualization as children's representation of their natural environment, hopes and dreams, material resources, and social support provided an opportunity to appreciate these resources in their lives and make meaning in a positive way. The research shows that the children draw on a range of coping strategies that help build their resilience. Children's ability to cope relies on their ability to participate in community life and engage in social support (Skovdal & Daniel, 2012).

The children's focus on their natural environment highlights a sense of control over their lives. Natural resources, such as water, plants, trees, and air, were referred to as resources and assets that provided a pathway to their livelihood and for their everyday living. According to Chambers and Conway (1992) a livelihood comprises capacities, assets (material and social resources) and activities required for a means of living or supporting life and meeting individual and community needs. The children were able to see a positive future in their natural environment. The data showed that being orphaned and HIV positive did not deter the children from imaging the best possible future when they discussed their hopes and dreams. Being optimistic about the life that they will have facilitates their coping in the face of adversity. Additionally, the children chose photos that showed how material resources from the group home support their basic life needs such quality food, good drinking water, and safe and secure shelter. The findings showed that the group home is a key asset that is helping to reduce the children's vulnerabilities and enhancing their resilience.

The children identified social support as another protective factor or asset in their lives. Resiliency literature has shown that social support is one of the most important factors in predicting resilience and that it comes from "enduring and reciprocal caring relationships" involving adults and peers from community, school, and family circles (Killian, 2004, p. 36). The children in this study spoke most often about their relationships with their peers in the group home but also discussed important relationships with the adult caregivers in the group home, drawing attention once again to the important role that the group home plays in their lives. A few children mentioned positive extended family relationships. These findings reinforced that they had social competence (Bernard, 1993) by having positive, caring relationships with peers and adults.

The research supports the growing literature that argues that resilience is a result of the processes and mechanisms that children take part in and learn from (Skovdal & Daniel, 2012). Based on our observations, taking photos and subsequently describing them provided an opportunity, a social space, for the children to participate in exchanging knowledge and meaning making through reflection. This may have enabled them to build on their resilience and develop it in other areas.

#### 5.1.1. Institutional care

Our data show that the group home was a major protective factor in these children's lives. As argued in the beginning of this paper,

institutional care should not be entirely abandoned as a viable option without first understanding the local context. For this specific group of children the group home provided a safe and supportive social space to be a child. These findings challenge the widespread belief among policy makers and practitioners that institutional care is harmful for all children. Undoubtedly, there are complex challenges related to providing care for orphaned children in Uganda at the macro, meso and micro levels. The quality of care, material resources and social support networks that children have at this group home did appear to support their resilience, but it is not clear if it was enough to help them address complex the psychological, emotional and social needs related to their individual experiences with grief and loss, and stigma.

Interventions to support the unique needs of orphaned children living with HIV in this particular group home could include consistent individual psychological counseling. This would assist children to process their losses, grief, fears and psychological effects of living with HIV as well as continue to promote their resilience. They would also benefit from consistent, current and evidence-informed HIV and AIDS counseling, life skills to assist them in healthy development while living with HIV, and future life planning. As the children in this study were adolescents 12–18 years of age, the concept of transitioning into adulthood and out of a group home environment presents additional attention when considering sustaining resilience in the children over time. The body of knowledge and literature related to transitioning youth from out of home care is growing but there are many challenges to support knowledge exchange and context-sensitive transition processes especially in low income countries (Pinkerton, 2011).

### 5.2. Hardships

The research findings of this study also demonstrated that these children experience hardships related to stigma, the impact of stigma (psychological and emotional) and social challenges.

#### 5.2.1. Stigma

Children in this study faced complex forms of stigma related to being HIV positive, orphaned and being poor. Deacon and Stephney (2007) hypothesize that HIV and AIDS related stigma towards younger children is "affected by discourses about poverty, street children and orphanhood" (p. 38) and are typically seen as "innocent" as they are assumed to have contracted HIV via mother to child transmission. On the other hand, adolescents may be seen as "guilty" of contracting HIV due to their own sexual activities (Deacon & Stephney, 2007). Alternatively, children may be stigmatized and blamed for the perceived sexual "mis-behavior" of their parents. The findings showed that the children experienced stigma from the broader community however, the group home helped the children cope by being a supportive environment where the children could be themselves in a loving and caring home-like atmosphere. Stigma remains an ongoing challenge in Uganda (Mburu et al., 2013) despite Uganda's swift response in the early 1980s. Stigma reducing programs for children are critical; however, most target adults with little emphasis on programs for children. The People Living with HIV Stigma Index (International Federation of Planned Parenthood, 2008) has been adopted for use by UNAIDS and the National Forum of People Living with HIV Networks in Uganda as an assessment and a community engagement tool. However, the tool does not take into consideration the perspectives of children thus silencing their voice and program development that can help reduce the impact of HIV stigma.

A critical point was raised in relation to stigma and institutional care when a community stakeholder stated that people in the community where the group home is situated are aware that all children at the home are HIV positive. Even though the findings showed that the group home offered protection and respite from the stigma that the children faced in the community, the stakeholder argued that creating group homes for HIV positive orphaned children may perpetuate the

stigma and isolation that they experience. It was suggested that group homes should instead offer care for all significantly vulnerable children regardless of their HIV sero-status. This reinforces an important point related to exploring contextually, culturally relevant and community supported models of care for all children who require it (Madhavan, 2004).

**5.2.1.1. Stigma and school.** A significant finding was that children did not discuss their relationships or experiences at school. Children rarely spoke of their school environment outside of the importance of education. Children were hesitant to involve anyone from their school in the project, and refused to invite teachers or any others associated with their school to their photo display. During the research project, a few children disclosed to the research team the challenges and problems that they experience at school related to HIV and AIDS stigma and discrimination by both teachers and school mates. Research has shown that disclosure of a child's HIV positive status at schools can either positively result in greater support for the child if done by a caregiver or result in stigma and discrimination if disclosure is done through gossip and rumor (Weiner, Mellins, Marhefka, & Battles, 2007). As children spend the majority of their time in school, a safe, supportive, caring school environment is critical to supporting their well-being and building resilience. It is difficult to know the impact that stigma played at school has on the children since they did not want to discuss it. Further research in this area is needed to understand the complexity of stigma experienced at school.

**5.2.1.2. Psychological, emotional impact and social distress.** Our findings showed how experiencing stigma directly or indirectly made them feel worthless, emotionally distressed, or even wanting to consider suicide. Children also described their own emotional distress, fear, sadness, and anger. Their feelings were discussed initially as being related to bullying or teasing in a way that reminded them of the fate of their deceased parents. The common saying "go bury your mother" was an abusive phrase used by other children and extended family members, and this phrase became a distressing reminder to children that they had lost and buried their parents. This offers a glimpse into the ongoing grief that children live with related to experiencing multiple losses. While children were hesitant to discuss all their fears and worries, some did mention their fear of dying and that they worry about many things. Some children were also confused and misinformed about what living with HIV meant for their life expectancy and life outcomes. This finding is consistent with the literature that discusses the significant psychosocial and emotional impact that "walking the HIV road" has on the life of children (Killian, 2004, p. 39).

Children also described their distress over many social issues, such as poverty, abuse and issues of inheritance that were likely connected to their past experiences. However, children were not forthcoming with ideas on how these issues could be resolved in their communities, thus it is worthwhile to engage in further exploration to find out why the youth did not offer ideas how to solve these issues. We wonder if the children needed more time or guidance to consider how to problem solve such complex social issues.

## 6. Conclusion

From the data collected in this Photovoice project, children revealed their experiences in their family, home and community. They described the protective factors in their lives as well as their hardships. Children viewed their group home as a caring and safe environment that provided them with their basic life needs such as natural and material resources, and a strong social support network. This included positive adult role models in the group home, and high expectations in terms of education, goals and achievements. The group home was also a supportive environment where their hopes and dreams could be shared and encouraged. Outside the wall of the group home, stigma,

discrimination and abuse were prevalent. These findings are important and force researchers, community organizations and policy makers to think about the role of institutional care for certain groups of children such as children who are orphaned due to AIDS and are HIV seropositive. While we are not promoting institutional care for all populations, it is important to consider that group homes may also present an effective option when such placements support key protective factors, and facilitate resiliency to cope with stigma.

It is essential for the community and stakeholders to continue to listen to the voices of the children and to work with them to promote protective factors, strengths and resilience, as they strongly desire to have the opportunity to develop into successful, caring, productive members of society. This can be facilitated through continued and genuine engagement with children, promoting the development of caring relationships, promoting positive school and community environments, material resources, ensuring mental health counseling, introducing stigma reduction and OVC care strategies that include institutional guidelines and thoughtful transition out of any group home or institutional setting. Addressing these issues first requires contextualizing norms and models and then ensuring coordinated, multi-level interventions with children, adults and community stakeholders working together.

Within this contextualization and multi-level coordination of care, we recognize a basic need for all children, including orphaned HIV seropositive children to be happy, loved and understood. This study respects the voice of children themselves, and their own shared experiences of how their group homes facilitate such basic needs by promoting key protective factors for psychological, emotional and social well-being, further supporting their resiliency for coping with stigma. Thus, we are called to include effective institutional care as a placement option for orphaned HIV seropositive children.

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