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Challenges for orphans in sibling headed households. Assessment of interventions to reduce stigma in Rakai District, Uganda.

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Abstract

This paper is based on a study carried out in Rakai District, Uganda. The assumption of the study is that orphans living on their own face much greater material and psychosocial challenges and stigma than other orphans and other vulnerable children, and thus the main objectives were to initiate, and evaluate, interventions that could improve the situation for the children in child-headed households and the community as a whole. This paper emphasizes the interventions initiated and an evaluation of the interventions.

Material and methods: *All data in the study were collected through interviews, focus group discussions, written narratives and observations. Heads of households, local leaders, teachers, community members, health workers and religious leaders gave the base line information necessary to initiate interventions and contains the participants' description of the situation of the orphans inhabiting sibling-headed households, their requests and their suggestions for actions. Different types of interventions were initiated: 1) Repairing or building houses for those most in need of this, 2) paying school fees including lunch, scholastic materials, uniforms, etc. 3) helping to start income generating activities, 4) providing counseling and guidance for children and adults in the community carried out by a Ugandan community psychologist--this also included counseling about HIV/AIDS and its impact on orphans and the society and, 5) a workshop for people at all levels in the district to create awareness of the situation of orphans in child-headed households, to inform about the interventions and to evaluate and discuss the way forward. The interventions were assessed after eight months or more utilizing the same data collection tools as for the base line information, except narratives. The workshop, carried out two years after the first interventions were initiated served as an intervention as well as an assessment.*

Results*: The interventions initiated have in most cases resulted in a better relationship between orphans and other community members, and the children have a brighter view about their future. Their self-esteem has become higher. The actions of material character have decreased the children's psychosocial worries and survival anxieties. The children feel more welcome in their own community and some adults even reported that they now saw the orphans as a resource (like other children) rather than just as a burden.*

Conclusions: *Interventions initiated must be based on needs presented by those for whom they are intended to help. The initiation of a comprehensive and multifarious set of activities, including material, educational, psychosocial and informational support, is important to improve the situation of orphans in child-headed households and to reduce stigma and the distance between orphans living on their own and community members. Interventions must also be evaluated frequently to make certain that they work as intended and because, as situations change, interventions might need adjustment as well.*

Introduction

This paper is based on a study carried out in Rakai District, Uganda. The assumption of the study is that orphans[1] living on their own face much greater material and psychosocial challenges and stigma than other orphans and other vulnerable children (OVCs). A study carried out in 2005 and 2006 describes and maps the situation and challenges faced by orphans heading households in Rakai District, Uganda (Dalen, Nakitende, & Musisi, 2009) creates the basis for interventions that are described and assessed in this paper. Thus the main objectives in this study are 1) to initiate, and 2) to evaluate, interventions that aim at reducing levels of stigma and improving the situation for the orphans and in the community as a whole. Some findings from the baseline data collection is presented in this paper in order to make all the parts of the study clear to the reader.

HIV/AIDS broke out in Africa more than 25 years ago, and one would think that since millions of people have lost those dear to them, since a vast amount of attention has been given to the pandemic and since so much information about the disease has been provided in urban centers and the smallest villages, stigma should no longer be a major issue of concern. But it is. Stigma remains a huge problem for many people infected and/or affected by HIV/AIDS. It is especially an issue for orphans living in sibling-headed households, both of whose parents have died from AIDS.

1 An orphan is a child below 18 who has lost one or both parents. Double orphan is a child who has lost both parents. A single orphan has lost one parent (UNAIDS, UNICEF, & USAID, 2004:6).

Orphans due to HIV/AIDS continue to be stigmatized in African countries like South Africa and Uganda (Cluver, Gardner, & Operario, 2008; Ntozi & Mukiza-Gapere, 1995). The former UNAIDS Executive Director, Peter Piot, said in 2002 that *"Discrimination and stigma continue to stand as barriers..Stigma harms. It silences individuals and communities, saps their strength, increases their vulnerability, isolates people and deprives them of care and support. We must break down these barriers or the epidemic will have no chance of being pushed back" (United Nations Foundation, 2002:1).* In the more recent Report of the Commission on HIV/AIDS and Governance in Africa (UN Economic Commission for Africa, 2008: see f.ex. p. xxvi) stigma features throughout the report as a key issue, as important now as ever. According to UNAIDS (2008) the total number of children orphaned by HIV/AIDS in sub-Saharan Africa is 12 million and the number is increasing. Most countries with high numbers of orphans do have national strategies to support them but the programs reach only a few of the needy children (UNAIDS, 2008:20).

HIV and AIDS in Uganda

The first AIDS case in Africa was reported in 1982 in Kasensero, a landing site in Rakai District (Hogle, 2002). The district borders Lake Victoria and Tanzania in the South. Rakai District is the worst hit by HIV and AIDS in Uganda. The highway from Tanzania crosses through the district which has caused an easy access to commercial sex. Before AIDS struck, Rakai District suffered for many years due to civil strife[2] which might also have caused that this district was particularly vulnerable to a new "disaster" (AVERT, 2009).

The Government of Uganda responded with an effective and major AIDS control program but not until 1987, after the end of the Civil War[3] in 1986. The HIV prevalence in Uganda peaked in 1991 with a prevalence of 15 % among adults and over 30 % among pregnant women. Although Uganda has been considered the "success story" in overcoming HIV/AIDS (USAID, 2002) by bringing the national HIV prevalence rate down to 6.4 % but is still very high and the prevalence in Rakai District is 14 %, which is twice that for the rest of the country. According to UNAIDS, HIV prevalence in Uganda may be rising again (UNAIDS, 2006). Theories about

2 Due to internal factors such as King Kabaka, Idi Amin and Milton Obote and to external factors such as the 1994 genocide in Rwanda.

3 Also called the Bush War, from 1981 to 1986 by the National Restistance Army (NRA) against the government of Milton Obote and later of Tito Okello. The war eventually led to Yoweri Museveni becoming president.

why this happens are that the government shifted its program from the so-called "ABC" (Abstinence until marriage, Be faithful and use Condom) to emphasizing Abstinence only in 2003 and that antiretroviral drugs may have changed people's attitudes and behavior since the disease is considered treatable (AVERT, 2009). According to a recent study among HIV positive adolescents in rural as well as urban areas in Uganda they are still sexually active and they pay little attention to preventive practices. In addition, the rate of disclosure of their HIV status to their partners is low i.e. 38 % (Birungi, Mugisha, Obare, & Nyombi, 2009:187).

The orphan challenge in Uganda

There are around two million orphans out of a total population of 28 million people in Uganda (Uganda Population Reference Bureau, 2007). Slightly more than half of the orphans have lost their parents due to HIV/AIDS (Wakhweya, Kateregga, Konde-Lule, Mukyala, Sabin, Williams et al., 2002:17). Exposure to HIV/AIDS is a prevalent hazard in Uganda, and because of the relatively poor capacity, methods and possibility of treatment in low income countries (WHO, 2008:94) the probability for a child who has lost one parent to lose the other parent too is great. Therefore areas and countries with high levels of HIV/AIDS will continue to have an increasingly higher number of double orphans as the pandemic advances. *"Without HIV/AIDS, the number of double orphans would have declined from 1990-2010. Instead, it will triple"* (Kasper, 2008:695). Child-headed households were noted in Rakai District as early as in the late 1980's (Rakai Councellors' Association, 2006).

The increasing number of people dying due to AIDS in Uganda leads to a growth in the total number of Ugandan orphans. Unless community members or others intervene to avoid it a larger proportion of the orphans will end up in child-headed households (Rakai District Local Government, 2004, 2008; World Vision, 2007).

Research has found that the children living in child-headed households are often not welcome in their communities. They are stigmatized through association with HIV/AIDS, they are bullied, and lack (significant) friends and adults to take care of them and contribute to their network of social relations necessary for healthy child development. Orphans are often regarded to be "wasting money" (Bond, 2006; Dalen et al., 2009; Musisi, Kinyanda, & Nakigudde, 2004).

A changing society

Most theories on child development, social interaction and communication

are developed based on the "normal" family and a "normal" society, meaning that most children grow up with at least one parent and are able to interact and communicate with people in the community. People in many African societies are still culturally and mentally attached to a collectivistic communal way of living (McKay & Wessells, 2004; Muhwezi, Agren, Neema, Musisi, & Maganda, 2007). The tradition in Uganda has been that community members and the extended family have taken care of orphans. The extended family is still the principle orphan-care unit but the HIV/AIDS epidemic has eroded the traditional "system" of absorbing the orphans and the deep-rooted kinship care system has become extremely stretched and many people lack the capacity to take care of any more children. The HIV/AIDS pandemic has had social and economic consequences and according to the Rakai District Local Government one of the factors for the increasing number of orphans and other vulnerable children living on their own is that the combination of poverty and the increasing intra-household dependency ratios have eroded socio-cultural values (Rakai District Local Government, 2008).

These are but some of the reasons why an increasing number of double orphans keep living in their past parents' home. Other reasons are that these children are afraid that other relatives or other people will take their property – as has occurred to some extent (ie. Wakweya et al, 2002). Some children said they had promised their parents to stay and to take care of their belongings, and thus the siblings try to avoid being split up by being taken care of by different relatives. Some stay at home because they are not welcome in any other places or they refuse to leave their homes because they fear they will become house servants, and treated differently than other children in the same household. (Foster, Makufa, Drew, & Kralovec, 1997; Luzze & Ssedyabule, 2004). Some children are migrants[4] and cannot trace their relatives (Dalen et al., 2009; Neema, Ssekiwanuka, & Ssedyabule, 2000). One study in Rakai District found that assistance from NGOs have indirectly caused a reduction of community assistance and therefore have generated an increasing number and more overall suffering in child-headed households (Luzze, 2002:56-57).

Stigma and its implications

A child's development, and thereby the child's behaviour, is most often dependent on, and a result of, interactions with significant other people such as parents (Bronfenbrenner, 1979; Giddens, 1993; MacIntyre, 1999). A child for whom the socialization process has become "infringed" because

4 There are some refugees from Rwanda because of the 1994 genocide.

the significant others have died may develop a behaviour which is unwanted and different from what is expected in a particular society. According to Goffman (1963) the stigmatized are those who have a discrediting discrepancy between the virtual social identity (what is expected) and the actual social identity (the way the person actually behaves) (Goffman, 1963:57). Some explanations for why people living with HIV/AIDS are stigmatized, such as association with illicit sex or injecting drug use, can in a way make sense, but it is still not so easy to understand why people stigmatize innocent children whose parents are dead. It is noticeable that when Goffman (1963) focuses on the individual aspects of stigma, Parker and Aggleton (2003) and Becker (1963) emphasizes stigma as a social process and the creation of social groups and not the quality of some individual's act or behavior (Ogden & Nyblade, 2005; Parker & Aggleton, 2003).

1) The different and undesired behaviours can be one reason for why orphans living on their own are often stigmatized.
2) Another reason for the stigma may simply be because their parents are assumed to have died from AIDS, and this, according to the "collective stereotyping stigma theory" tarnish people with certain identities (ie. children whose parents have died from AIDS) with a broad brush, not dissimilar to what Goffman called the tribal identity form of stigma. This is also akin to the main idea in labelling theory (also known as social reaction theory) by which it is the surrounding social environment that "labels" an individual, or group of individuals, as deviant compared to his or her society's norms (Becker, 1963; Goffman, 1963).

Other possible explanations bring us to

3) Lack of knowledge (some might even say, ignorance) about HIV/AIDS and consequences for children not having adults around, where HIV in some cases is explained by supernatural causes,
4) Fear – often caused by "irrational ignorance" or lack of knowledge (as mentioned above), lack of understanding of the disease and its impacts which makes people frightened, and frightened people do not behave rationally, and
5) Poverty; "HIV related stigma and discrimination are fuelled by the practicalities of limited resources and narrow options" (Bond, 2006:181), often combined with
6) power inequity caused by such things as the fact that some HIV-affected people get assistance and others do not.

Even after more than 25 years of HIV/AIDS we still meet denial of the disease and, if acknowledged, we still meet people who are stigmatized due

to being infected and/or affected by the disease (Dalen et al., 2009; Lie, 2008) The following quote describes some of the complexity in the stigma concept: "*Once placed in a risk category, individuals are separated from other sources of identity, henceforward stigmatized and degraded by definition. Creation of alterity, or "otherness" allows those in power to dehumanize, to scapegoat, to blame, and thus to avoid responsibility of sufferers*" (Kalipeni, Craddock, Oppong, & Ghosh, 2003:19).

Study design and study site

The baseline findings for this study were collected from 43 children in eight different villages in Rakai District and are mainly presented in Dalen, Nakitende and Musisi (2009). In addition, information was collected from interviews and focus group discussions among village adults, health workers, teachers and local- and religious leaders. All participants contributed to create the information needed for being able to plan what kind of interventions would be appropriate in order to reduce stigma and to improve the situations for orphans in child-headed households and for the people in the villages.

While this paper presents some base line information, it mainly focuses on the interventions initiated and the evaluations of these interventions.

The study took place in eight different villages in three counties, Kakuuto, Kyotera and Kooki, in Rakai District in Uganda. Permission for the study was obtained by the Uganda National Council for Science and Technology (UNCST).

Uganda has a five-tiered local administrative system of elected Local councils (LCs) and executive committees. LC1s are on the lowest administrative levels and responsible for the villages while the LC5s are the highest levels and have the responsibility for the districts. Each local council at every level (1-5) includes an executive committee of nine members. The term "LC1" or "chairman" in this paper refers to the leader of the LC1 committee in a village.

Villages in which the study was carried out were selected randomly. The village chairmen gave us permission to collect information from children and adults in their villages. The chairmen were also the ones who guided us to most of the child-headed households. All participants were carefully informed about the study. Information was given in English and Luganda (the local language) both in writing and orally. All participants signed or thumb-printed a written consent form.

For the baseline information all together 43 orphans between ten and 21 years of age who were heading households participated through inter-

views, focus group discussions and some of the orphans wrote narratives. Six village adults and two relatives and three health workers were interviewed. Four focus groups with LC1s and four with teachers were carried out. The focus groups consisted of between seven and eleven participants.

Interviews and focus group discussions were carried out with the help of Ugandan research assistants who spoke Luganda (the local language). The research assistants were trained before and during the data collection. The main researcher was present all the time.

Baseline findings and suggestions for interventions

Based on feedback from the participants in the baseline data collection (Dalen et al., 2009), interventions were discussed and subsequently initiated. It became clear that the problems or challenges had different causes. Suggestions and ideas for solving or approaching them were therefore various.

The children themselves emphasized education, food and material things in order to reduce their worries and what may be called "survival anxieties." Statements like "*Not knowing what to eat tomorrow makes me worried and disturbs my sleep"* and "*I am worried about the future because I cannot go to school, I have no money. My parents used to pay my school fees. Education is so important"* – were quite common and showed that their lives were difficult and marked by immediate and future challenges. Some adults confirmed this by saying that *"these children do not have food. They spend most of their time working in the villages to get something to eat."*

The children also emphasized that they felt the adults did not understand the reality of their daily life. They were clearly disappointed that they could not depend on their closest extended family members at a time when they were traumatized by the death of their parents, alone, afraid, uncertain about the future and confused about what had happened to them. Many of the children said they did not know if, let along what, they would eat the next day. Younger siblings came home and cried because they were hungry and the older siblings did not know what to do; there just wasn't any food in the house. The children felt that both they and the adults had a need to be more clearly informed about their situation and which possibilities existed to improve their circumstances.

The children, but mainly adults, expressed the need for raising awareness in the community about the orphans living on their own and about the challenges that, in particular, the breadwinner experienced. *"How can we help them? We don't know what all the problems are"*. One teacher said: *"The community members should stop certain people from going to the child-headed*

households, since some of them have bad intentions". It actually became quite clear that some people exploited the orphan girls (and boys), many of whom are continuously starving, by giving them a little money or some food as payment for sexual favors.

Many people requested information and counseling about how to help the children and how to overcome the HIV/AIDS problem in the community. Teachers requested education so as to be able to focus on this particular issue in their educational institutions.

Some adults were very negative about the orphans and thought they had no right to be with others in the community, probably had AIDS too and behaved badly. People clearly showed lack of knowledge, believed in bad spirits as the cause of the disease, showed ignorance about the problem or challenges of orphans as well as about HIV/AIDS and claimed as stated by one chairman that *"people die from tuberculosis and pneumonia, they always did. There is no AIDS".* In some villages the so-called "COTOs" (Children On Their Own) were regarded as a burden and the community members clearly did not like them.

The overall conclusion after having analyzed and discussed the findings of the baseline data collection was quite overwhelming. It would be unfair to say that most people *"don't care what happen to them (the orphans)"* but what is of concern is that some, actually quite a few, still look at orphans not only as a burden but also as a threat to the community.

Even though many have died, and continue to die as a result of HIV/AIDS, the impact is still as brutally vivid each time a child, often no older than eight years old, lose first one, and thereafter the second of his parents. Left behind is a young boy or girl with several younger siblings who are now in their care. And these children experience being teased, bullied and marginalized because their parents died. In such a situation how can their society then expect that these children "should be well behaved"?—not to steal from others but to behave, be clean and neat and attend school as other children. Since many of these children are unable to maintain patterns of the life they lived while their parents were alive, and to obtain food, they begin to behave in a way that diverges from what "is expected" by their society and they are thus increasingly excluded and stigmatized.

Interventions initiated

The first interventions were of a rather simple and practical character whereas the assistance initiated later demanded a more thorough consideration before start-up. Even if the knowledge among people and the situation among different orphans seemed different it was important not to let these differ-

ences stand in the way of initiating interventions (Ogden & Nyblade, 2005:37).

Education and basic needs

In the first year, starting in February 2005, 60 children from child-headed households were helped back to school and as of February 2009 a total of 130 have been and are being helped. School fees were paid and the children were given uniforms, lunch and scholastic materials. The children have attended primary, secondary or vocational schools. A few children who had been away from school too long to "fit in" were assisted in starting income generating activities such as breeding goats or chickens, running a small shop or growing crops. The children were asked to prepare their gardens and to build enclosures for the animals before we brought them. Some of the children, whose houses were in extraordinarily poor conditions, had them repaired or rebuilt. The planning of the building or repairing of a house was always discussed with the LC1, neighbors, relatives or other close adults if available. This was done to create a relationship and trust among us, the children and their closest community members. The houses were always built or repaired according to the local procedures and only local workers were used. The point is not to build a bigger or nicer house, but a safe and useful house. This is to avoid, or at least to reduce, jealousy to a minimum.

Community psychologist

In October 2006 a Ugandan community psychologist with a Bachelor Degree from Makerere University, Kampala was employed by the project to work in Rakai District. Her work has been to travel throughout the district to speak with as many people as possible about the orphans and the challenges they face, and also about HIV/AIDS and how the epidemic affects individuals throughout the society. She has had information sessions in schools and among children and adults in local communities and she has been a person with whom everyone could talk. Many of the children have now gotten a person who cares about them and with whom they can talk about a great range of issues. Subsequently, a male teacher was also employed as a discussion partner for those who find it difficult to speak with a young woman about some of these issues. Both of these project workers live in Rakai District.

Workshops

Two workshops were arranged in March 2008. The workshops gathered children, teachers, community members, religious, local and district leaders. The aims of the workshops were two-fold, namely to inform people of the research and to let them assess the interventions initiated so far and to discuss "the way forward". The workshops took place in two different schools, one in Kooki and one in Kakuuto counties and they gathered approximately 250 participants. Among the participants were representatives from the District Ministry of Education, the District Ministry of Health (MoH) and also from the National MoH.

Support for the initiatives

One assumption of this study was that there was a need to initiate interventions. Such interventions need support – even help for self help need support. Thus money was obtained from colleagues and friends, and from a few corporations, in Norway, to support the initial interventions. It was soon realized, however, that such support needed to be less ad hoc. Thus a foundation – The Phoenix Children Foundation – was formally established in Norway in August of 2007 to fund these initiatives for the benefit of the double orphans living in sibling-headed households in Rakai District (The Phoenix Children Foundation, 2007).

Assessments of the interventions

The assessments of the different interventions took place in three steps; 1) Approximately one and a half year after the first interventions were initiated i.e. "education and basic needs", 2) Eight months after the community psychologist started her counseling work, and 3) A set of two workshops.

Education and basic needs

For the first assessment twenty four randomly picked heads of households[5] and eighteen adults (community members, LC1s and teachers) from different parts of the district were interviewed individually. Most of the community members said that the children were better behaved and therefore that it was easier to communicate and associate with them. People registered less stealing and they claimed that "*When they attend school there is some bit of control and discipline".* Feedback from the children as well as from the adults gave a strong impression that the fact that somebody actually cared about them was very important and gave them a higher self-esteem. They felt less "different" even

5 Who were included in this study

though they still face many challenges in the community as well as at home. *"We have friends at school but not at home"* a 14-year old boy said and explained that earlier, when he did not attend school, he and his siblings had no friends. Both community members and children felt that the interaction between the two "groups" had improved. A 15 year old girl who said that *"Some people even greet us"* must have had a hard time before since that some people greeted her should be a surprise worthy of special mention is remarkable, especially when realizing that greeting people you meet (or just pass) is part of a common code of conduct in Uganda.

It was quite clear that both children and adults regarded education and attending school as very important. Because the children in many cases did not really have other adults to associate with, the teacher could act as an alternative or substitute and could offer at least some of the upbringing and socialization process that their parents can no longer give them and thereby make them feel more protected. All the teachers who were interviewed (eight) could confirm that the children actually attended school on a relatively regular basis. The children seemed to have improved their socialization skills. Their performance at school was improving, but many still had a great deal of non-school work to do at home.

Among the negative impacts of the assistance given was jealousy, mainly because there are so many other children and adults who also need assistance: One community member said that *"There are so many children who aren't helped so this brings out discrimination and unfriendliness among those not helped".* This reaction was of course a very undesirable effect of the intervention but not surprising as other studies have described jealousy as a negative impact of assistance (Thurman, Snider, Boris, Kalisa, Nyirazinyoye, & Brown, 2008). However, it gave an even stronger message about the importance of information and counseling people about the problems in the communities and about what the intention of the assistance was, namely to improve the situation for the community as a whole. And, of course, – the need for more assistance, as stated by a community member: *"I am very grateful for the assistance given. I request for more assistance as far as orphans are concerned. We have lost so many people".*

Another issue, that in particular seemed to worry teachers, was that some organizations assisting children could suddenly stop the support without giving any explanation or other options for the children. They emphasized that we must make sure that we did not start assistance without being sure we could follow through because the children who had experienced being dropped out of a program, really got problems; they ended up in a vacuum not knowing what to do or who to turn to.

Community psychologist

The community psychologist's work was assessed in two sessions. The first was a self-assessment carried out by the community psychologist herself after she had worked for eight months. The second assessment was done by a clinical psychologist with a Masters Degree (who had been working as a research assistant during the data collection for the base- line information) and she assessed the impact of the work of the community psychologist after ten months. Both of them utilized interviews and focus group discussions and the participants were teachers, community members, LC1s, children heading households and some of their schoolmates.

Almost everyone interviewed in the assessment parts was positive about the presence and work of the counselor. Some teachers considered it possible that the work and presence of the community psychologist had caused improvements, however they also mentioned that there might be other explanations but something had definitely happened;"*In particular in the group sponsored, there is a big change".* This could be interpreted that the sponsored children had received more attention and support than others. That was the intention, but it would have been desirable if people experienced a collective improvement in the society. Among all the feedback – this was the most negative, or least positive, one about the counseling work.

Other community members were very pleased about her work because she encouraged the children to go to school, to behave well and she also *"tells them that no one is going to come from out of nowhere and provide for them".* It is very important that this particular issue was brought forward by the psychologist because it is a core aim of the interventions that the children little by little learn to manage life on their own.

The community psychologist also talked to the children about subjects that community members find difficult to address, such as *"talks about things that we can't tell them about, like sex and the danger of that".*

Other children and schoolmates were also interviewed during this assessment and it became clear that the community psychologist managed to gather many children, orphans and non-orphans, and speak to them and discuss with them about important things in life for young people. Her discussions with all children in classes and with adults in school as well as in the community has loosened some barriers and created more openness between people. One student at school said that *"there are a number of children who have joined school who used to keep at home because their parents died and had no one to pay for their school fees"* which shows that other children have become aware of at least some of the challenges these orphans face.

Workshops

The two workshops gave further information about how the interventions had affected most parts of the communities. Since 250 people took active part through group discussions the workshops were valuable additional contributions to the assessments. Four of the heads of households supported through the project presented their stories and answered some questions from the psychiatrist who chaired the workshops. At first the impression was that the children were mainly concerned about material and practical issues. However, it seemed now as if the value of people's caring, talking and really listening to them had become a more core issue than before. One boy spoke in a way that explained the importance of a complex set of interventions and how this had "changed his life." Since the foundation came into his life, his school fees had been paid, scholastic materials provided, he could now eat at home and at school so he did not have to fall asleep in class. He said he was also provided soap and salt at the beginning of school term (like all the children in the project and some others). He said: "*My friends and I can now study with vision because we have another chance at a good future, the psychologist counsels and supports us. We are no longer worried that we shall die tomorrow because our parents died, we have a purpose and a vision".*

For the discussions the participants were divided into four groups; 1) girl pupils, 2) boy pupils, 3) community members and LC1s, and 4) teachers, administrators and health workers. The pupil groups contained both orphans and non-orphans. The groups were asked to discuss three questions: i) In what way have the interventions changed your life/situation?, ii) In what way can you contribute to create a better situation for children living on their own in your community? And iii) What is the way forward? Groups 1 and 2 were asked to discuss questions i) and iii), while groups 3 and 4 were asked to consider questions ii) and iii).

The girls and boys had a relatively similar impression about the effects of the interventions and how they had changed lives. The following were mentioned: Education, improvement of standards of living, help to avoid bad peer groups and promoting social relations among orphans; uniting them with community members and school mates to reduce stigma and giving information about how to avoid HIV/AIDS. All groups of students claimed that the interventions had "*taken away sorrows and worries by giving us what we needed"* and that they had gained self esteem and self reliance. *"Stigma among the orphans is reduced; they used to feel out of place in the society"* (Boys group in Kakuuto).

About "the way forward" the student groups agreed that orphans had to do dedicated work both at school and at home, to be polite and to help

others who could use their help. The children emphasized that they respected and appreciated those who helped them and they tried to create their own income generating projects to fight poverty and to help other children.

The adults' responses to the interventions were also positive. Their main task was to come up with suggestions on how they could contribute, in addition to giving ideas to the foundation on how to proceed. All adult groups emphasized the importance of a sustainable project and they also requested an extension of the assistance and that more research on the situation among orphans should be carried out and the results should be presented for people in the areas of concern. They felt that counseling both children and adults in the communities will boost the total community knowledge and contribute to better involvement in problem identification and problem solving and thereby reduce stigma in the communities.

Critical considerations

The outcome of the intervention assessments seem overwhelming positive. There are probably several biases. The fact that both children and adults were given attention as well as lunch and a small amount of money for transport for the workshops might have given some participants a reason to evaluate the interventions better than they otherwise would. However, the interventions provided were evaluated in four different sessions over a period of almost two years and different people gave feedback. This is not to deny that there is room for improvement. Luzze (2002) evaluated World Vision's (WV) interventions in Rakai District and found that their program was partly responsible for an increase in child-headed households since WV's interventions caused a reduction in community support to the orphans. This may be because the status of child-headed households *"targeted by WV tended to grow beyond that of neighboring households"* (Luzze, 2002:42). This makes it critical that we are vigilant that the support we give child-headed households does not cause distinctions between these households and that of the rest of the community because they might have become too affluent. This has not yet been thoroughly investigated and it needs to be, especially since the great majority of households in the villages studied are living on less than US $ 3 per household per week. At this level of welfare any assistance to some rather than all households, no matter how needy, could cause inequities.

Conclusions and recommendations

This study has attempted to understand and, most importantly, to improve the situations of double orphans living on their own, and to reduce the

distance between these orphans and the people living in their communities. The results of the research and of the assessments of the interventions are meant to guide other interventions to improve the situation among orphans and people in similar settings. This has been a small intervention project, which has combined different types of actions. A strength in this study is that the orphans who are stigmatized and the villagers who stigmatize orphans have participated and are given the opportunity to guide the interventions initiated in their own villages. Thus this project has tried to translate research into action that can help the children and the communities studied. The project is far from perfect, and continued assessment is needed, but it concludes that these interventions have made a few changes in the right direction.

The study has indicated that stigma related to HIV/AIDS and orphans is still an issue of concern, and that stigma is still an important barrier in combating HIV/AIDS and in improving the lives of those infected and affected by it. According to Peter Piot "*HIV stigma comes from the powerful combination of shame and fear. Shame because the sex or drug injecting that transmit HIV are surrounded by taboo and moral judgment, and fear because AIDS is relatively new, and deadly. Responding to AIDS with blame, or abuse for people living with [or affected by] AIDS, simply forces the epidemic underground, creating the ideal conditions for HIV to spread. The only way of making progress against the epidemic is to replace shame with solidarity and fear with hope"* (Piot, 2001:1).

The study can conclude that initiation of a comprehensive and multifarious set of activities, including material, educational, psychosocial and informational support is important to reduce the distance between orphans living on their own and community members. By approaching children and adults in this way, an understanding of each others' challenges may have the possibility of creating a common platform from which they can solve their problems which, considering their own culture, is actually a collective responsibility (McKay & Wessells, 2004; Muhwezi et al., 2007).

Though there are commonalities, different communities, districts and countries probably face these problems of double orphans living on their own slightly differently. Therefore one specific approach that might work in one place might not necessarily work other places even if the problems seem similar. It is therefore of great importance that interventions initiated are planned based on "grass root" needs and to realize that one single way of addressing a complex problem might not be sufficient. *"The way forward for children in difficult circumstances is not just by the direct provision of services…Energy and resources must be allocated towards creative and context-*

specific approaches that engender community support" (Thurman et al., 2008:1556-57).

However, the interventions must also be in accordance with the local and/or national plans and authorities. Interventions must also be evaluated frequently to make certain that they work as intended and because as situations change the interventions might need adjustment as well.

The main messages from this research are that interventions must be based on needs presented by those for whom the interventions are intended to help, and as many as possible in a community must be reached, listened to and included in order to improve the situation in that specific context.

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