

Turning the Camera Back: A Photovoice Project With Ugandan Children who are Orphaned and Living with HIV

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Abstract

There is limited literature describing the methodological and pragmatic considerations that arise when conducting participatory action research utilizing Photovoice with children, particularly within sub-Saharan Africa. We provide a case example of these considerations based on a qualitative exploratory design that was conducted in June 2010 with 13 children between the ages of 12 and 18 years who were orphaned and living with HIV in a group home setting in Western Uganda. The main purpose of this study was to explore the children's experiences while including them in a participatory way utilizing Photovoice to share their stories, define their issues, and propose their own solutions. Conducting research in another country where language and culture are different from the researchers' can pose many unique methodological, epistemological, and ethical challenges. These issues are discussed by reflecting on the process of the study. Key lessons will also be discussed regarding the methodological and pragmatic considerations with the aim of providing new insights for researchers who want to conduct research in a cross-cultural and multilingual setting.

Keywords

participatory action research, Photovoice, Uganda, orphans, HIV/AIDS

Participatory action research (PAR), often framed under the umbrella term of *community-based participatory research* (CBPR), is a frequently utilized research methodology in the social science field. PAR often draws on many theoretical sources including but not limited to critical social theory, feminism, systems thinking, complexity theory, and post structuralism, and ensures that the knowledge created benefits for those involved in its creation. Brydon-Miller et al. (2011) suggested that PAR is like Jazz as it brings together a group of individuals for “a collaborative process and is responsive to changing circumstances, adapting methods, and drawing on the resources of all participants to address the needs of the community” (p. 387). The main purpose of this study was to explore the experiences of children aged 12 to 18 years who are orphaned and living with HIV in a group home in Western Uganda, while including them in a participatory way utilizing Photovoice to share their stories, define their issues, and propose their own solutions. In this article, we focus on our reflections from the process of PAR and Photovoice.

Photography is one of the most common visual arts-based media and when paired with a motivation to document issues that are meaningful, and where change is possible, is referred to as Photovoice. Photovoice (Wang, 1999) is a participatory method that is designed to give interpretive control to the participants who take meaningful photographs. Marginalized

individuals and groups can thereby communicate, identify, and represent their community and circumstances (Wang, 2006). Photovoice as a PAR tool, provides individuals 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. This method is a way to bring voice to individuals or populations who are silenced or are silent out of the shadows. The photos and stories can be used to call for raising community awareness of an issue, public policy change, advocating for human rights, and even breaking down stigma. Freire (1970) believed that the visual image is one way of encouraging people to think critically about various social and political forces they encounter and influence in their day-to-day lives. A source of empowerment within a Freirian perspective comes from group dialogues that affirm individual's collective struggles and insights that can occur

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when creating the visual image (Wallerstein & Bernstein, 1988). Story-telling emerges from the sharing of photographs utilized by the Photovoice method that complements oral traditions in many African cultures (Fournier et al., 2007). Photovoice was chosen as the method in the current study because it is flexible, utilized across cultural groups, and with adolescents to identify challenges and strengths that affect their health, as well as a communication tool for policy makers (Wang, 1999).

The methodological and pragmatic considerations that arise when engaging in PAR utilizing Photovoice with children are not often explored or reported. Many Photovoice studies that have been published document the findings of the study with little attention to the methodology itself, including its strengths and weaknesses (Short, 2006; Skovdal, Ogutu, Aoro, & Campbell, 2009). In addition, conducting research in another country poses a new set of methodological, epistemological, and ethical issues. We will highlight these issues by discussing our reflections on the process of the study. Elsewhere, we report on the findings related to children's experiences of living with HIV illness (Fournier et al., 2014).

Background

In Uganda, there is a rapidly growing number of orphans (children below the age of 18 and with either a mother or father who has died), with estimates of around 2.5 million out of 17 million children less than age 18 (Government of Uganda [GoU], 2010). Of those 2.5 million, 48% were orphaned due to AIDS (GoU). It is reported that children orphaned by AIDS have higher levels of psychosocial distress, depression, post traumatic stress disorder, and experience more stigma (Cluver and Gardner, 2007; Joint United Nations Programme on HIV/AIDS [UNAIDS], 2010). Due to the crippling impact of HIV, customary and social structures have diminished as poverty has increased due to reductions in family labor force, land cultivation, income, food security, and educational opportunities (Economic Commission for Africa, 2006). HIV sero-positive AIDS orphans have a double burden. Not only have they experienced multiple losses but they also have a life-threatening illness. It is unusual for an orphaned child to live in a group home in sub-Saharan Africa, as this is often a last resort option and usually signifies a crisis situation where no one is able to care for the child (The United Nations Children's Fund [UNICEF], 2006).

Context

Study Location

The municipality of Fort Portal, an urban hub, is situated in Kabarole District and is approximately 290 km west of Kampala (capital of Uganda). It is also about 200 km from the border with Rwandan and about 70 km from the border

with the Democratic Republic of Congo. As of 2011, it had an approximate population of 47,000 people. There are three main ethnic groups: Banyankore, Batoro, and Bakiga. Cattle keeping, growing maize (corn), beans, bananas, coffee, sweet potatoes, and cassava are the economic activities of these groups (Ministry of Finance Planning and Economic Development, 2000). Kabarole district includes various levels of education institutions. There are an estimated 119 primary schools, 24 secondary schools, 3 teacher training colleges and 1 national technical institute (Uganda Bureau of Statistics, 2010). Also within the district, there are three hospitals which are government aided—Buhanga, Virika, and Kabarole.

The current HIV prevalence in Uganda is estimated at 6.5% among adults (UNAIDS, 2010) and 0.7% among children (GoU, 2010), with an estimated 1.2 million people living with HIV and approximately 150,000 children (GoU). It is also reported that 18% of the new HIV infections in Uganda are through mother-to-child-transmission (GoU). In Kabarole District it is estimated that the HIV prevalence is 11% (Kabarole District Local Government, 2012). However, previous studies in the municipality have shown even higher rates (19%-25.4%) especially when compared with other areas in Uganda (Kirungi et al., 2006; Konde-Lulu, 1995; Stoneburner & Low-Beer, 2004). The National HIV serosurvey report for 2004 to 2005 published that the Batoro ethnic group, which is the main tribe in Fort Portal, had a 14.8% HIV prevalence rate signifying the highest overall rate in Uganda. (Ministry of Health Uganda and ORC Macro, 2006).

According to a new report by the World Health Organization (WHO), there are approximately 200,000 people in Uganda taking antiretroviral treatment (WHO/UNAIDS/UNICEF, 2009). This represents only an estimated 39% of those in need as the need is greater due to the WHO guideline that recommends starting treatment earlier. The number of Ugandan children accessing antiretroviral therapy (ART) has increased tenfold in the past few years, however, the need remains extremely high (WHO/UNAIDS/UNICEF, 2011). Currently, only a fifth of Ugandan children who need treatment are receiving it (GoU). Stigma is reported to be one of the main reasons (GoU); however, the cost of transportation to medical facilities is also a barrier. The availability of antiretrovirals (ARVs) has been an ongoing issue; however, since 2010 Uganda has begun to produce its own generic drugs (WHO/UNAIDS/UNICEF, 2011) with the hope that this will reduce the cost as well as the possibility of running out of the drugs and increase geographic access. However, the ARV rollout in Uganda has faced many challenges due to shortages in healthcare finance, infrastructure, and human resources.

The Study

Uganda has been held up as a model for many other countries who have been striving to address the HIV/AIDS epidemic.

Although the rates of the disease in Uganda have decreased, stigma remains, especially in areas outside of the urban town. According to the partner nongovernmental organization (NGO) that supports the children in this study, the children have been repeatedly told in their home villages that they have “slim” disease (HIV/AIDS) and will soon die. 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 both being orphans and to living with HIV as well as the prospect that they are soon to die. They become involved in conflicts and fights at school and do not have an easy life. The findings from the current study demonstrated that the children face many hardships especially related to stigma and discrimination at school and in their community (Fournier et al., 2014). However, they also told stories about how the group home supported key protective factors in their everyday lives that promoted their well-being, and resilience for coping with challenges such as stigma (Fournier et al., 2014).

Study Design and Method

An exploratory qualitative design was used for the study and as such an open, flexible, and inductive approach was essential. We were guided by Paulo Freire's (1970) work on counter-hegemonic knowledge development with those who have been excluded from knowledge generation. PAR framed both the practical and theoretical foundation of the current study. Participant recruitment occurred in June 2010 and data were collected during a 1-month period. The target population included children 12 to 18 years of age, both male and female ($N = 13$, female = 5, male = 8) who were orphaned, HIV positive, and lived in a home run by a local NGO in Western Uganda. The NGO in Uganda was chosen based on an established relationship with a University and an NGO in Canada. Participants spoke their native language, Rutooro, fluently; however they are not able to read it well. Therefore, all the focus group discussions were conducted in Rutooro and all written materials were in English. Focus groups and Photovoice were the primary data collection methods.

Study Site and Research Assistants

All the meetings took place at the group home which is located at the outskirts of the town, in a semi-rural village area. The home provides basic life needs and psychosocial support for 30 children who are HIV positive and orphaned. The dining hall was the place for each meeting as it was seen as the most comfortable and familiar place where the children could share their experiences. The field research team consisted of the primary investigator (Bridge), and two Ugandan research assistants, who lived in the area, were fluent in the local language and one of whom was a trained mental health counselor. The research assistants, both female, were trained regarding the Photovoice process and activities

prior to implementation and provided recruitment, information, informed assent, and facilitation for all the focus group discussions. Each research assistant used the same guiding questions for the small group discussions to be consistent between groups. The Ugandan research assistants, who were paid a daily salary, were very familiar with qualitative research having previously worked for various Canadian Universities. They transcribed the taped discussions and translated them into English.

Data Collection

Data collection included a total of eight meetings with the children that can be divided into five phases: training sessions, devising themes, taking pictures, discussing photos, and display planning.

Training sessions. These sessions included information on how to use the cameras, how to take photographs, ethical issues of photographing people, how to get permission to photograph a subject, how to address safety concerns, and the rights and responsibilities of those using cameras. Subsequent sessions focused on taking photos and discussing them in groups.

Devising themes. PAR provides participants with the opportunity to decide the themes they would like to explore. However, considering the age of the children, and after consulting with key stakeholders it was decided that they would need some guidance. A worksheet in English titled “What matters to me” was provided to the children to help them think about themes they might want to explore. This worksheet asked the children to think about and write down the strengths they were proud of, things that they felt needed to change in relation to themselves and their family, home, and community. Children were asked to reflect about themselves and their experiences to help them think of themes they wanted to photograph.

Taking pictures. The children took photos during two afternoon sessions. They were instructed to try and take photos that represented their themes from the “What matters to me” worksheet. They were accompanied by Bridge and two research assistants. This was done to enhance safety and to ensure that the children had an adult present if they chose to photograph a subject. This was also done to ensure that proper consent was obtained from the subject and that any questions the subject had were answered accurately. The children laughed, ran around, and thought of what they thought would be good photos to take; some of them spent time setting up their shot, others worked more on impulse catching the moment.

Focus group discussions. Meetings with the youth served as a means for discussions using a participatory approach and

included four focus group discussions. Freire's (1973) three-stage process of participatory analysis helped guide the conversations. This process included selecting (choosing those photographs that most accurately reflected the youths' concerns), contextualizing (telling stories about what the photographs mean), and codifying (identifying the issues, themes, or theories that emerge). Photographs were chosen by the youth that they felt had the most meaning for them, and by doing so, directed the discussions. During the first session the children were asked to discuss their "what matters to me" worksheet. This was intended to explore the children's themes. In the second focus group discussion children discussed their first set of photos and to discuss their meanings and messages. A third focus group discussion was conducted to clarify the themes from the first session on "what matters to me." The fourth focus group discussion focused on the children's second photography session and their meanings and messages. The research assistants attempted to have the children frame their discussions of their photos by answering 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). However, adaptations were made to allow for more flexibility in the discussions.

Display planning. An additional session was held to ask the children to select photos that they wished to display. In line with PAR, the children decided who the audience would be. They decided to only invite the rescue home staff, fellow children, and staff from the local NGO as well as two visiting guests from Canada who were working with the local NGO. The children each chose a photo or two and personally wrote a "story" about the photo(s). The photos and stories were pasted on poster board and hung on the walls of their dining hall. Each child spoke to the audience about their photos and the meaning they had for them during a celebratory lunch. These stories were transcribed and also became data for analysis.

Data Analysis

Data analysis occurred on three levels. The first was with the participants utilizing the acronym SHOWeD as the framework for telling stories and exploring root causes with some modifications as the research assistants remained flexible to allow the children to discuss what was important to them. The second level was carried out using matrix methodology techniques described by Miles and Huberman (1994) for analyzing the transcripts, a personal journal kept by Bridge and field notes. A third level of data analysis occurred when Bridge and Fournier returned to Uganda to share the emerging themes with the research assistants, the director, and staff of the NGO, two senior public health and health research practitioners in the area, and Konde-Lule who is part of the research team. In separate meetings, the themes were

confirmed by agreement and some re-analyzed based on the feedback from the entire team.

Snap Shots of the Landscape—Lessons Learned

Although it was Bridge's second time conducting research in Uganda in the same municipality, there were many unknowns and unanticipated situations that needed to be carefully navigated. Many research studies have documented methodological, epistemological, and ethical challenges with Photovoice, (Prins, 2010; Wang & Redwood-Jones, 2001; Wiersma, 2011), in international research (Fournier et al., 2007; Mill & Ogilvie, 2002, 2003) and with children (Liamputtong, 2007; Morrow & Alderson, 2011). However, there has been limited attention in the literature regarding methodological, epistemological, and ethical challenges considerations when utilizing research assistants in the field. As an integral part of the research team and as a vulnerable group more light must be shed on the implications and consequences of including research assistants. In this section, we reflect on the methodological, epistemological, ethical, and practical lessons learned that emerged from conducting research in a cross-cultural and multilingual setting with an emphasis on utilizing research assistants.

Snap Shot 1: Translation and Interpreters

Epistemological challenges arose related to translation and the use of interpreters. Issues related to translators and interpreters have been well documented in the literature (Edwards, 1998; Neufeld, Harrison, Stewart, Hughes, & Spitzer, 2002; Temple, 2002). Temple (1997) stated that the use of translators and interpreters "is not merely a technical matter that has little bearing on the outcome. It is of epistemological consequence as it influences what is 'found'" (p. 614). This technical matter is often viewed through a post positivism lens where objectivity is the goal to find the "truth" or in this instance the "correct" version of the text (Edwards, 1998) and where contextual influences can be controlled or accounted for.

Back translation, also known as the Brislin (1970) model, is the technical method often used to ensure agreement between translators. The process includes two interpreters, one who translates the text in its original language into another language. A second interpreter back translates the text into its original language (back translation). The second interpreter is blinded to the original document. Agreement is finally reached when the text is deemed equivalent. More recently, researchers have been using a consensus approach to translation that includes focused discussions on the disagreements (Lee, Li, Arai, & Puntillo, 2009; Smit, van den Berg, Bekker, Seedat, & Stein, 2006). However, the epistemology underlying these approaches continues to be informed by positivism, where the process becomes a

scientific technical process without the acknowledgment of the influence of the translators' values. Although it is important to look at the process of translation, the influence of the translation on the knowledge generated, as well as the context and the translator themselves, must also be taken into account (Temple & Young, 2004).

The research assistants in the current study translated the tape recordings from Rutooro to English. Participants speak their native language, Rutooro, fluently but have difficulty reading it. All their schoolwork is completed in English. Therefore, the decision to keep all written material in English was made in collaboration with the research assistants. Our process of translation did not include back translation. Initially, the research assistants traded transcripts to cross-check for accuracy of the translations. There were no major discrepancies identified; however, there could be possible reasons for this such as the research assistants may have felt uncomfortable critiquing each other's work (a face-saving mechanism). It is much more difficult to reflect on the influence of the translation on the research outcomes, versus a more reflexive approach, while in the field. Although most of the transcripts were checked for accuracy, practical issues arose, such as time constraints, that affected the validation process of the last few transcripts. This was an unfortunate outcome related to time management and scheduling.

Snap Shot 2: Utilizing Research Assistants

In the current study, research assistants were utilized and given a broader role than just strictly translating and interpreting the data. They became part of the study by participating in the decision making during the different phases of the research process. After each group discussion the research assistants met with Bridge to debrief and prepare for the next group discussion. These "meetings" often occurred during their long walk together from the group home to the roadside where they waited for transportation to take them back to town. These walks were important parts of the research process as it gave Bridge and the research assistants a time to bond on a more informal level, gaining trust and building on their relationship. As well, it aided in the revisiting of what was shared in the focus groups so that the team began to get a sense of the data and what points they should pay more attention to in subsequent meetings. It was also a time to recall the nuances of things that were said and be able to reflect on them during their walks to the roadside. Epistemologically, the research assistants' knowledge was considered a legitimate form of knowledge and was integral to the research study.

Methodologically, challenges arose when the research assistants suggested that the first focus group session be split into two groups—one research assistant with the males and the other with the females to discuss their photographs. This decision was made for several seemingly good reasons at the time; however, it became a severe disadvantage. Bridge did

not have a research assistant to take field notes for her in English. Language became a severe limitation as she was not able to hear, listen, or understand what they were discussing. This severely inhibited her ability to offer suggestions or further questioning in the moment. Therefore, in subsequent sessions, one research assistant facilitated the discussion whereas the other took field notes in English.

Reflecting on these challenges, we realized that utilizing research assistants requires methodological and epistemological considerations. They must become part of the research team as collaborators in an iterative, discursive way. More attention to power issues through a three-part reflexive process, as Nicholls (2009) suggests from the onset, may have made the ground more fertile for greater collaboration. Giampapa and Lamoureux (2011) argue that as researchers in diverse settings, we need to build a critical reflexive practice pre-in-post field experiences that can respond methodologically and theoretically to the changing social worlds and the voices within them. In addition, critically examining and understanding insider/outsider roles, researcher identities, and positionality must form the broader examination of conducting field research in multilingual cross-cultural settings. Furthermore, these research assistants remain in the region-country and can bring the shared knowledge-research experience to others in both informal and likely unintended ways. Vara and Patel (2012) discuss how ignoring issues related to power can increase risk in the research process and suggest that one aspect of risk that is overlooked is the potential risk/harms posed to translators.

Reflecting on the ethical issue of risk/harms posed to the research assistants was the unanticipated impact the research had on one particular research assistant. There was a realization at the end of the project that the children in the group home needed much more counseling than they currently received. The one particular research assistant who was also a trained counselor discussed with Bridge how she wanted to continue to help the children by volunteering her time to counsel the children more regularly, and on an individual basis, as the current practice was once a week for a few hours in a large group. Bridge agreed with this idea and they took their suggestion to the director of the group home who was very supportive of the idea. Difficulties arose for the director when discussing this idea with a particular staff member who disliked the idea and felt that it was unethical for another person to be involved. The director regretted that they could not proceed. Bridge did not at first understand the reaction from the director and the staff member, however, at a later time, discovered the issue was related to social status and politics. The lesson that was learned from this experience was that there are often hidden social, cultural, and political influences that tie the hands of the people who try to keep the best interest of the children as a priority. Malone, Yerger, McGruder, and Froelicher (2006) observe that race/ethnicity, class, gender, and social status can affect how individuals and groups act or do not act to further their own interests. It

was a difficult lesson for Bridge, as what she perceived to be in the best interest of the children gave way to power dynamics and a particular view of what counseling should look like for these children. As a result, the research assistant was never allowed to volunteer her time to help the children in the group home. Worse was the fact that we never asked what harm may have come to the research assistant due to this political restriction.

Snap Shot 3: Ethical Issues of Consent and Justice

Although there are general guidelines, each study always faces its own unique ethical challenges that may not have been considered by internal review boards (IRB) or researchers prior to the start of the study. As the sociocultural contexts vary, researchers must be sensitive to cross-cultural ethical issues. In the field, obtaining consent was challenging as many of the children were orphaned (one or both parents died) which meant the research team needed to obtain consent from extended family or legal guardians. However, this was difficult in some circumstances: Many children did not have relatives we could easily access or find, or the relative had advanced AIDS or mental health issues, and one was deemed “dangerous” by the NGO office staff. The Director was consulted for guidance for each child’s unique family situation and it was decided for the more challenging or inaccessible family members that as the legal guardian she could sign for the exceptional children. Each child’s primary caregiver/relative at the time of admission to the home signed a legal document that gives the Director legal guardianship over the child which then is also signed by the magistrate and local government. Although this decision was a last resort solution, it facilitated the process to ensure all the children who responded to recruitment were able to start the study at the same time.

Principles of justice in ethics means there is a balance or fair share of both benefits and burdens of the research. It is unacceptable to ban a whole group (women, men, and children) from studies that might be of benefit to them. However, justice became an issue in a different sense. An unanticipated consequence of involving the older children and not the younger children was that the younger children at the rescue home felt very left out and were disappointed that they were not invited to participate. They were not involved in the formal project as they did not meet the recruitment criteria of being 12 years or older. These considerations were not thought about prior to the implementation of the field research. However, Bridge had extra cameras due to changes in the schedule and gave them to the younger children so that they could play with cameras and take some photos of their own. It was purely a fun activity for them and neither this activity nor their photos were included in the research project. Strategies were developed to ensure all children felt part of the process. This is an important

consideration when conducting research with groups of children who live together and not all the children fit the recruitment criteria.

Snap Shot 4: Cameras

Disposable cameras were given to each participant twice during the study. The use of disposable cameras had many benefits from the research team’s perspective, but also some practical limitations. In terms of benefits, the cameras were inexpensive, easy to transport, straightforward to use, generally produced adequate-quality photographs, were easily developed in the field, and could withstand being dropped or handled harshly. The cameras because they were disposable did not produce monetary incentive or coercion to participate as they were single-use and this also reduced the threat of theft by others. The use of cameras was a child-friendly and participatory experience for the children who were visibly engaged and enjoyed the process. This is in alignment with other literature that concludes that “visual methods allow a high level of child-led participation in research” and that they produce a relaxed, fun atmosphere (Young & Barrett, 2001, pp. 141-142). This same research also concluded that photography with street youth in Kampala had several benefits such as increasing their self-esteem and self confidence, accessing modern technology and keeping their photographs, creating their photo diary, and having fun kept the children’s interest (Young and Barrett). Even though the disposable cameras were thought to be less coercive to participate, the children were initially fixated on the disposable cameras/single use cameras. It seemed they could not grasp that the cameras were finished after one use, and wanted Bridge to bring the cameras back to them after being developed so they could somehow load film into them and use them again. The children suggested that “real” cameras would be better so that they could keep them.

Limitations of utilizing disposable cameras were related to the practical aspects of the camera itself. The chaos of 13 children running around, plus the younger children asking questions and wanting to play made it challenging to give directions that all of the children understood. When taking pictures indoors or in low light some of the children forgot to put the flash on the camera even after the training sessions and several reminders. This meant that some of their photos did not turn out well. Some disposable cameras were strictly for outdoor use, and although 90% of the time we were outdoors, the first day was very dark due to cloudy conditions so the first round of pictures did not turn out well. On one occasion, a whole roll of film did not turn out, likely due to faulty camera and/or film, which was very disappointing to the child involved. Some children also struggled to remember to keep their fingers out of the way of the lens while photographing or keeping very still. As well, the dexterity required to handle a camera was somewhat of a challenge for a few of them, although they did learn very quickly and improved

from the first to the second session. This is not a new phenomenon as Coad (2007) stated, “while some children and young people may not have used a camera at the beginning of a project and while this may be relatively few, they quickly pick up the skills often in an instinctive trial and error approach” (p. 492). The quick uptake of this skill could also be related to the novelty of first-time camera use.

Again on a practical level, the children were so excited and thrilled to take photos of their own, that it seemed they may have lost track of the themes they were going to photograph. Because the project had a broad purpose and a broad research question, this limitation may not be too significant; the children’s photos and discussions very likely represented their experiences and current lives. Coad (2007) reminded us that “arts-based activities require the facilitator/researcher to be flexible and creative without exercising too much obvious control” (p. 495). That said, briefing and discussing the purpose of the project at frequent intervals, and as reminders, could also be a useful strategy. Being true to the participatory part of the project, Bridge was mindful never to direct what the children should photograph.

Reflecting on indigenous ways of knowing in Uganda (Dei, 2000; Smith, 1999), perhaps cameras were not the best tool for the children’s culture—where typically song, dance, and skits or plays are created to share knowledge. Many children in Uganda would never have the opportunity to use cameras in typical daily life, especially in rural areas. This being said, culture is dynamic and changing, and it was noted anecdotally that some of the children had skills and experience using cell phones, digital music devices, watching videos, and using computers. Therefore, it is difficult to really say definitively whether the use of cameras was a harm, as many of the children widely discussed how much they enjoyed learning about cameras even though they did not get to keep a camera or own their own camera.

Snap Shot 5: The Photo Display

Sharing photographs with policy makers or having a public presentation is one of the steps in the Photovoice method (Wang, 1999; Wang & Burris, 1997). This step is an important part of the “action” piece of PAR and is a place to communicate change to the community. However, when it was discussed how they would share their photographs, the children were not open to inviting family, school, church, or other community members to their photo display. They only wanted the other children from the group home and the staff to participate. The research team had to make an ethical and methodological decision—to be true to the Photovoice method—and somehow try to communicate the importance of inviting the broader community to the photo display or to remain flexible and honor the children’s desire.

At the root of the children’s resistance was stigma. While the issue of stigma had arisen earlier in the project when the research team suggested going to the school to conduct the

focus group sessions (as the children have 1 hr of free time per day), the children said they did not want the research team to come. They were concerned about drawing more attention to themselves as they could face harassment and teasing if a White woman and others came to their school to work with them. It was only during the dissemination phase of the study, while Bridge and Fournier were back in Uganda, that it was discovered the group home was labeled by the community as a home for HIV positive children, which created a stigma before they even left the home to walk to school.

In the end, the team felt it was important to honor the children by having them be in control of making decisions about the study even if it was at the expense of not being “true” to the methodology and method. However, integral to any PAR study is the letting go of the researchers’ agenda and enabling the participant’s ownership to take root. It was a difficult decision given that the children’s life experiences, especially regarding stigma, impacts their life in such negative ways and thus needs to be shared so that possible change can occur not only at the individual level, but at the organizational (school) and community levels as well. Although the display to the broader audience did not happen, the team was satisfied that their collaborative process resulted in a decision that was in the best interests of the children. In addition, the research team felt that other forms of appropriate dissemination could reach the broader community.

Photovoice Outcomes

The Photovoice project provided six types of benefits to the participants. First, the project provided an opportunity for change by allowing the children to identify, on their own terms, which photos were most important to them and how they wanted to share their stories. Visually documenting their lives appeared to be a meaningful form of participation in which the children’s voices and ideas were valued. Second, one of the most important outcomes that can be realized in PAR is whether or not the participants themselves feel they have benefited. The children developed some mastery over using their cameras from the first session to the second. Third, they exhibited pride in their photos and after discussing the developed pictures, they kept copies of all of their photos, carefully put them in albums and showed them to each other and to the staff at the group home. The whole place was buzzing with excitement on those days. The children seemed empowered in their new skill and desired to continue learning about cameras, asking Bridge to bring “real” cameras so they could keep practicing and not lose their skills. They appeared empowered and proud when sharing their stories as people listened to them and cared about what they had to say.

Fourth, in speaking publicly to the group home staff and fellow children about their photos during the photo display day, the children developed new skills and confidence. Public

speaking was challenging for some of them but hearing the audience's applause and appreciation of their stories brought pride to their faces. The Photovoice display allowed the children to share important things in their lives and was also an opportunity to give commendation to the group home staff, their peers, and voice their appreciation. It felt celebratory in nature.

Fifth, there were challenges in growing self and social awareness. For example, when discussing issues and "what they could do about it" in their focus group discussions, the children seemed not to know how to answer this question. The researchers wonder whether perhaps the children felt they were not allowed, or not able to take action themselves, perhaps because that idea had never been presented to them before as a possibility. It is also possible that the complex social issues they had described were too difficult to solve when asked on the spot. Growing up in a social system that typically believes "children should be seen but not heard" may also have a huge impact on their cognition around taking action, or advocating for themselves. Questions that still linger for the researchers are: Do they feel that they have an internal locus of control, or do they feel that they only have external locus of control, or both?

Sixth, the project indirectly advocated for individual mental health counseling for the children at the home, in addition to the group counseling that was already taking place. At the time of writing up the research, and in collaboration with the Ugandan NGO director, an additional counselor was hired, as the original staff member who disliked the idea moved to part-time work. This outcome will hopefully support the children's psychosocial development.

Recommendations and Future Research

Many lessons were learned regarding conducting research in another country and utilizing Photovoice as a method. Research assistants, translators, and interpreters must be included in the project as team members and collaborators. As such, researchers need to build a relationship with them, especially as they are often individuals the researcher has never met before. As well, a dedicated research assistant for the field researcher is required to interpret moment to moment the discussions between the participants and the other research assistant who is facilitating the focus groups or interviews. This would allow the field researcher to utilize probing questions or ask for clarification. However, additional funding would need to be allocated to employ a research assistant in this role.

Utilizing disposable cameras for the most part worked well with the children once they understood how they worked. More pre-use camera training is needed for the children, especially for those who have never held one or taken a photo. A full day of training should be allocated which would allow time for the children to practice and have fun with the

cameras so as to wear off the novelty of having a camera, and allow them to then focus on what's important to them to photograph in future sessions. One-on-one interviews would have also enhanced the focus group discussions by allowing each child to discuss their photographs in more depth without any influence of their peers. We recommend that researchers supervise children as they venture into the unknown with their cameras. The accompaniment can serve two purposes: increase safety and enable in-depth and on-the-spot discussions regarding why the child chose a particular picture to take.

To be truly participatory, a first-level analysis of the data could have involved the children more actively. This is recommended by Noland (2006) who stated that "working with adolescents to include more of their voice in the analysis" (p. 13) is important to grant participants more power and to increase the research's authenticity. In addition, the research assistants could have also had a more active role in the data analysis process, thus building research capacity and increasing the collaboration between them and the researchers.

Closing Thoughts

Photovoice can be an effective and creative method to help children discuss and share their life experiences. The method helped the researchers to understand more about the experience and lives of children who are orphaned and living with HIV in a group home setting as well as their self-described challenges and coping strategies. Important methodological, epistemological, ethical, and practical considerations emerged as a result of utilizing Photovoice and conducting research in a cross-cultural and multilingual setting. Photovoice engaged the children in the research process as partners and many of them were able to make decisions about their own destiny, albeit on a small scale. Change occurred within each participant, however organizational and community change was at a standstill. This was likely due to the stigma that still exists around HIV and the underlying power issues that surfaced during the study. A greater level of preparation is necessary including an awareness of power dynamics such as social status of the participants in the study and outside influences.

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