Research as intervention? Exploring the health and well-being of children and youth facing global adversity through participatory visual methods

Abstract (201)

Over the last decade, global health research has taken a turn towards using knowledge generated through translation (from health professionals to the community) and dissemination (from research results to the wider audience). However, Greenhalgh and Wieringa (2011) suggest 'that while "translation" is a widely used metaphor in medicine, it constrains how we conceptualize and study the link between knowledge and practice' (p. 501). Often the knowledge garnered from such research projects comes from health professionals rather than reflecting the lived experiences of people and communities. Likewise, there has been a gap in 'translating' and 'disseminating' the results of participatory action research projects to policymakers and medical practitioners. This article will look at how using participatory visual methodologies in global health research with children and youth facing global adversity incorporates the multiple functions of translation and dissemination so that research becomes a means of intervention. Drawing from a literature review of participatory visual methods as media, content and processes of global health research, this paper raises practical, theoretical and ethical questions that arise from *research as intervention*. The paper concludes by exploring what lessons emerge when participatory visual methodologies are integrated into global health research with children and youth facing global adversity.

Keywords: Arts-based research; Children in adversity; Digital storytelling; Drawing; Ethics; Global health; Image theatre; Participatory video; Photovoice; Research as intervention;

Introduction: Marginalized Youth and Visual Methods

Globally, many children and youth face challenges to their development and well-being through exposure to extreme adversity. Global adversity for children and youth can be broadly characterized to include structural conditions such as poverty and marginalization, as well as life disruptions such as violence, disaster, and war. Children and youth living within these contexts of global adversity may be threatened not only with the potential for loss of life, but a myriad of long-term, adverse psychosocial issues (Betancourt & Khan, 2008; Pfefferbaum & North, 2013; Pedersen, 2002).

While practitioners have carried out numerous health interventions in conflict zones, there is a substantial gap between translating and disseminating research results at the policy and practitioner level. Participatory visual methodologies, which use visual and experiential art to understand, address, and engage with the lived experiences and realities of children and youth facing profound adversity, can be a form of research intervention that is 'collaborative, relevant, cost-effective, and generate[s] "innovations"' (Greenhalgh & Wieringa, 2011, p. 507).

Although research has begun to document the importance of using arts-based methodologies (Mitchell, De Lange, Moletsane, Stuart, & Buthulezi, 2005; Kanji & Cameron, 2010), information on their applicability with children and youth facing different forms of global adversity remains in its infancy. Nonetheless, emerging research has highlighted that arts-based methods may allow children and youth to represent their experiences in contexts of reduced stress (Harris, 2007), promote activism and empowerment (Moletsane et al., 2007), and be particularly

successful with younger children who have limited vocabulary to verbalize their feelings (Gangi & Barowsky, 2009).

For the purposes of our discussion, we draw from Panter-Brick, Lende, and Kohrt (2012)'s definition of children facing global adversity as "young people who face significant economic poverty, life disruption, violence, and social inequality within larger-scale processes of sociopolitical crises or rapid socioeconomic transformation demanding intervention" (p. 603). Further, for the purposes of our paper, we define children and youth affected by marginalization, poverty, violence, disaster, and/or war as "children and youth facing global adversity". Based on this delineation, we ask:

- What is the role of these participatory visual methodologies in research as intervention with children and youth facing global adversity?
- Within the 'toolbox' of arts-based methods, what approaches are most appropriate to studying this population?
- What are the strengths and limitations of employing arts-based methods?
- What ethical, practical, and theoretical questions arise when research is also a form of intervention?

To answer these questions, we first interpret the notion of research as intervention. We then examine methods such as photovoice, participatory video, drawing, Image theatre, and digital storytelling, and their potential to enhance the quality of data collected, and engage and empower child and youth participants. After reviewing these approaches, we provide a discussion on the strengths and limitations of employing arts-based methods, as well as the conceptual, ethical and practical questions that arise when research is also a form of intervention.

Research as Intervention?

In reviewing research on promoting heart health, Haalboom, Robinson, Elliott, Cameron, and Eyles (2006) suggest that research can also contribute to capacity building in health promotion: 'Research as intervention entails purposefully using aspects of a research process and results feedback to contribute to desired changes in knowledge and practice of research participants and stakeholders' (p. 292). Research then becomes not only a means to gather data, but also a potential health intervention.

McNamee (1988) examined research as intervention in a systems context. Here, research is focused on facilitating change, not just observing or accounting for how change occurs. This requires an understanding and application of systems theory, termed 'systemic epistemology' (Bateson, 1972). McNamee underlines that if we look at research as a *social* intervention, the role of the researcher-as-intervenor becomes complicated. When the process of researching as an intervention in the system being studied is at the center, the researcher's active participation in the system is emphasized, which subsequently allows us to think that a researcher can stand outside of another social system and observe it objectively. Systems theory, coined and developed by cyberneticist Norbet Wiener (1948), is particularly relevant here. The emphasis in a systems perspective is on how the whole arises from the interrelations among the parts. Minute changes, operating in *feedback loops,* evoke systemic changes. Arts-based research as intervention is an example of a feedback loop evoking systemic change through art.

How might this play out in real communities with real health issues? Barndt (2009) writes that, when talking about community arts as research and intervention, '[t]he researcher/artist may structure processes to engage participants in creative inquiry, but if the process is to draw on the

knowledge, skills and visions of community members, there must be space for this to happen' (p. 360). Put more simply, research using the arts can facilitate change while at the same time provide evidence of such changes. Participatory visual methodologies engage participants by producing a representation of their experiences of health and well-being, while also exploring what these representations mean and how they may contribute to change. In this way, the arts in general and participatory visual methods in particular become both the medium and the representation through which to investigate health and well-being.

Arts-Based Research with Children and Youth

Advances in research methodologies with children and youth call for innovative and adapted research techniques while emphasizing their competence. Given the myriad ethical issues involved in conducting research with children and youth affected by global adversity, employing suitable methodologies to meet their diverse needs is vital (Boyden & de Berry, 2004). Historically, methodological approaches to research with children have tended to view children in largely passive ways as merely 'objects of research' or as 'vulnerable' and 'incompetent' (Clark, 2010). Drawing on a rights-based approach, which recognizes children and youth as capable of making sense of and affecting the world around them, this paper seeks to examine research methodologies that seek to both empower and actively engage children and youth in the research process through participatory and arts-based methods. More specifically, we trace the potential of photovoice, participatory video, drawing, Image theatre, and digital storytelling as both method and intervention.

Photovoice: Enabling Empowerment, Healing, and Group Cohesion

The use of photography in research has become recognized as a means of empowerment among marginalized youth and 'groups of people who do not normally get to speak' (Mitchell, 2011, p. 51). Within the toolbox of photographic methods, photovoice has emerged as an important methodological and community empowerment tool. Photovoice is a community-based participatory research method that combines photography, community awareness building, group discussions, and social action (Wang & Burris, 1994; 1997). First developed and implemented by Wang and Burris in research with women villagers in rural China, the method draws on 'community photography' (Spence, 1995) – a way in which ordinary people photograph each other and their social environment.

Photovoice has three main objectives. First, participants receive training to become community researchers and ethically conscious photographers. In these new roles, they document, through photos images, issues of personal and community concern. Therefore, it seeks to enable individuals and groups, particularly those who face marginalization and disempowerment, to record and reflect upon their community's strengths and challenges through photography. Second, using group discussions of participants' photographs, written photo narratives or captions of the photos, photovoice aims to promote critical dialogue and knowledge about important community issues. Through the ongoing data collection process, via photography, participants come together as a group to discuss and analyze what they have documented and to support each other. Finally, through the dissemination of their photographs to the wider community, and through such practices as exhibitions of the photographs, photovoice seeks to reach policymakers who have the power to implement changes within that community (Wang & Burris, 1997).

De Lange and Mitchell (2007) position photovoice within the broader category of 'visual methodologies for social change' and document the transformative possibilities of the process as photographs help people to 'reflect on their own lived experiences…framing their ideas for change' (as cited in Burke, 2008, p. 26). Photovoice has been documented as a powerful research tool to engage communities and enable a deeper understanding of the lives of marginalized youth (Burke, 2008). Photovoice may also hold powerful 'intervention' capacities with marginalized youth. First, it has the capacity to serve as a platform from which youth are able to develop skills such as photography techniques, team building, cooperation, leadership, and critical thinking skills (Wang & Burris, 1997). Second, given its emphasis on group work and team building, photovoice offers a format that can alleviate the sense of isolation often associated with social marginalization (Denov, Doucet, & Kamara, 2012). Through group meetings and discussions inherent to the photovoice process, youth participants can begin to develop and nurture a sense of belonging and collective identity and foster a sense of empowerment within the project. Third, photovoice, and arts-based projects in general, can provide a venue to deal with emotions rarely addressed in conventional research methods, such as shame, guilt and feelings of accountability (Harris, 2010). Moreover, sensitive issues may be easier to address through the lens of a camera, allowing as much proximity or distance from the topic as necessary. Finally, photovoice allows participants to create and establish the research agenda, ensuring greater control over the methodological process (Burke, 2008).

The intervention capacity and potential of photovoice has also been highlighted by various researchers. Denov et al. (2012), for example, conducted a photovoice project with a group of former child soldiers in Sierra Leone living in an urban settlement community, who reported experiencing various forms of rejection, stigma and marginalization in the post-war period. The study highlighted the post-conflict lives of former child soldiers and their complex experience of reintegration into mainstream society. Denov et al. noted that at the end of the project, all participants reported that the project fostered a gradual change in community members' perception of them. They reported that community members began referring to them as 'professional photographers', which instilled pride and confidence. Other participants noted that prior to the project, they did not have 'good reputations' in the community; the photovoice process helped to show skeptical community members the positive potential of participants, thereby challenging preconceived views. Blackman and Fairey (2007) argue that photovoice holds much promise in terms of intervention. They maintain that participants in photovoice projects gain confidence in their ability to assert ideas and engage in self-advocacy, have improved self-esteem from skill building, and offer an opportunity to influence decisions that affect their lives.

Since its original use with women in rural China, photovoice has since been adapted to a range of communities. While the focus in much of the literature has been on the method's inherent ability to capture the lived realities of complex individuals, communities and contexts, photovoice also appears to hold 'therapeutic' capacities, enabling empowerment, healing and group cohesion.

Participatory Video: Developing Skills and Illuminating Experience

The use of participatory video (PV) has increasingly emerged as a 'unique empowering process that enhances the political capabilities of grassroots communities to influence those with power over them' (Colom, 2010, p. 1). PV, as defined by Lunch and Lunch (2006) is:

a set of techniques to involve a group or community in shaping and creating their own film. The idea behind this is that making a video is easy and accessible, and is a great way of bringing people together to explore issues, voice concerns or simply to be creative and tell stories (p. 10).

In using PV to understand violence and how people respond to it, Wheeler (2009; 2011) emphasizes how PV is a process that encompasses the construction of knowledge from those who participate, 'expanding boundaries of knowledge, from the self to the group to the community, to beyond' (Wheeler, 2011, p. 53).

Like photovoice, PV participants are provided with access to, and training in, the use of video recording equipment (Jewitt, 2012). PV is used to delve into individual's lives and according to Jewitt (2012) generates three kinds of data: '1) the video "as product", 2) the process of its production – which itself is often video recorded, and 3) the process of video editing' (p. 3). These forms of data become the focus of further exploration and study, although some PV research prioritizes one over the other or may emphasize the interaction between them (Jewitt, 2012).

The PV process gives power to, and provides a group with, the opportunity to elucidate their own difficulties and to communicate their needs and ideas to others, such as decision-makers or other groups and communities (Lunch & Lunch, 2006). Likewise, Lunch and Lunch (2010) advocate for a rights-based approach to PV that can be an effective tool to engage and mobilize marginalized people and to help them implement their own forms of sustainable development based on local needs. In other words,

by asserting the right to self determination, rights-based approaches demand that the powerful (duty-bearers) seek out and listen to less powerful people (rights-holders) and incorporate their needs and values, their "home-known" rights into policy. This obligation also asks decision-makers to make room for the feedback and contribution of those less powerful at their decision-making table (p. 35).

Furthermore, PV permits working with children and youth as research partners rather than research subjects, and serves as a way to address the 'over-didactic, centrally controlled and one-way information flow approach commonly found in traditional health education/promotion practice' (Chiu, 2009, p. 14). With participants in control of the process, PV provides children and youth with an opportunity to freely record what they see through their own eyes, presenting a child-based representation of knowledge that is grounded in their community (Pink, 2001; Sandercock & Attili, 2010). PV is also seen as an 'equalizing' tool, minimizing reliance on literacy skills and communicating a message without a reliance on writing or reading (Okahashi, 2000).

In this way, the process of videotaping, editing and screening can be an effective tool for social change (Sandercock & Attili, 2010). PV can provide children and youth – especially those who have experienced various forms of global adversity – with a voice. PV can empower children and youth who previously may have had no control over what is reported about them and their experiences (Garrett, 2011; Sandercock & Attili, 2010). Furthermore, encouraging children and youth in research and encouraging their right to have a voice, 'has long term implications for participatory citizenship' (Pascal & Bertram, 2009, p. 249).

In a longitudinal study on the use of PV to build an archive of children's and youth's experiences of growing up in a disadvantaged neighborhood, PV was used to challenge 'preferred

identities, aspirations and passion', thus allowing the participants to highlight their characteristics, individualities and personalities while illuminating other parts of themselves not always present in their relationships with adults, especially those in positions of authority (Luttrell, Restler & Fontaine, 2012, p. 164). Recognizing the importance of listening to the perspectives of children and youth and supporting their meaningful participation through methodologies such as PV can lead to action and social awareness, which has the potential to help children and youth feel empowered, to think and act on the conditions that shape their lives, and ultimately contribute to greater agency and wellbeing (Pascal & Bertram, 2009).

Drawing, Painting, and Mapmaking: Alternative and Therapeutic Means of Collecting Data

As described above, the trend in visual research has emphasized pictorial representation, particularly through photographs (such as photovoice) and video (such as PV) (Banks, 2001; Pink, 2007; Prosser, 1998). But visual research can also include non-photographic illustrations. This section considers non-photographic illustrations such as drawings, paintings, maps as a specific form of visual evidence within the wider category of visual material, and reviews the literature on how this form of visual research method can be a means of intervention for children and youth affected by global adversity.

Non-photographic methods such as drawing, painting, and mapmaking are increasingly being used with children and youth affected by global adversity in order to better understand their experiences and worldviews. Their capabilities can be made more readily accessible by the use of visual image-making than by sole reliance on typical methods of information-gathering, such as interviews, surveys, and questionnaires (Leitch, 2008; Veale, 2005). Whereas these methods focus on verbal or written data, younger children (Thong, 2007) or children who have experienced distressing events may not be able to communicate in this manner. Therefore, drawing, painting, and mapmaking are alternative ways to effectively gain meaningful participation of these children and youth. Furthermore, these visual tools create an environment where they may be more at ease, where they feel more able to express themselves freely, and where they do not feel as much of a risk of giving a 'wrong' answer. Coates (2004) suggests that the care and concentration which children give to their illustrated representations indicates that the content has a real significance. Therefore, it can be viewed as an intentional practice and an important part of their understanding of his or her own experience. Leitch (2008) notes that these visual representations, used sensitively in combination with methodologies that elicit some contextualizing narrative, have the potential to help children and youth effectively convey aspects of their lived experience.

These methods have also been effective in addressing children's emotional well-being (Hamilton & Moore, 2004). Traditionally, drawing, painting, and mapmaking has been used in clinical and diagnostic research such as art therapy (Linesch, 1994) or to better understand children's knowledge and experience in contexts of global adversity due to protracted political violence (see for example Akesson, 2015; Akesson, 2014; Boğaç, 2009; Marshall, 2013). Nevertheless, no evaluations have demonstrated that expression of emotion in art is therapeutic for children and youth (Thomas & Silk, 1990). Furthermore, despite the relevance of using drawing, painting, and mapmaking in research with children and youth, especially those who have experienced global adversity, there are few studies that address this type of visual representation as an intervention that can improve health and well-being. For example, Miles (2000) conducted a study with 60 unaccompanied refugee children (ages 9-16 years) in southeast Asia. The study integrated drawing accompanied with writing in order to learn more about

children's understandings of their futures. Nevertheless, the research did not include an element to determine the therapeutic impact of art-making. Arts-based research studies examining the psychosocial experiences of children affected by global adversity are more likely to include drawing, painting, or mapmaking as actual interventions, rather than conceptualizing them as research *as* intervention. For example, Gupta and Zimmer (2008) describe the Rapid-Ed intervention for war-affected children in Sierra Leone, including trauma healing activities such as storytelling, drawing, small group discussions, writing essays about their experiences, role-playing, singing and performing, and music-making. Ironically, and despite such rich arts-based intervention, the authors still use a verbal and written research methodology, administering pre- and post-test surveys to the child-participants in order to evaluate the arts-based intervention.

There is much written about the value of integrating drawing, painting and mapmaking into research processes with children and youth (Miles, 2000; Theron, Mitchell, Smith & Stuart, 2011), especially those who have experienced global adversity. Yet data on the value of using drawings and maps in research as a therapeutic process is anecdotal. One example comes from Volker and Kellogg (as cited in Junge, Alvarez, Kellogg, & Volker, 1993) who conducted research with refugee families from Central America who had migrated to Los Angeles. The researchers found that the drawings helped the research participants 'to explore the uprooting, the migration, and the relocation' and 'the opportunity to address their traumas and to integrate them' (p. 153). Even though it is implied, this research did not explicitly connect the expression of these drawings as being therapeutic for the research participants. Similarly, one study conducted with a third-grade class of first- and second-generation immigrant and refugee children (Rousseau & Heusch, 2000) used drawing combined with storytelling to help children work through emotions. Through the rich visual data, the authors found children used the drawings and stories to 'make sense of traumatic experiences and dislocation to devise their own culturally acceptable adaptive strategies' (p. 39).

Based on the above studies and others, it is likely that arts-based methods such as drawing, painting, and mapmaking can not only serve as a data point, but also as a potential means of intervention for research participants. For example, in Akesson's (2014) research with Palestinian children and families affected by political violence in the West Bank and East Jerusalem, parents expressed gratitude to the research team for encouraging their children to create art as a part of the research process, noting that it helped their children express their feelings and included them in the research process. Nonetheless, we need more than anecdotal evidence and the positive feedback from adult research participants to support this assertion.

Image Theatre: Embodied Imagery as Catalysts for Research

Image theatre (Boal, 1979; Linds & Vettraino, 2008) enables participants to use their bodies as a particular visual language to convey their lived experience.[1] One method involves an individual telling a story with others silently using their bodies to visually represent a key moment in the story. Once the image (also known as tableau) emerges it can be manipulated in many ways through, for example, fast-forwarding to the future or rewinding to events in the past. This enables a manipulation of time and space.

Images created through Image theatre can 'offer a screen onto which a group can project a variety of ideas and interpretations' (Boal as cited in Jackson, 1992, p. 174), inviting both the individual and the collective to problem-solve. If a group has varying levels of verbal or linguistic ability, Image theatre levels difference and becomes a common visual language.

Kuftinec (2009, 2011) has effectively used Image theatre in research with youth in the conflict situations of Afghanistan, Israel, and Macedonia. In Kabul, Kuftinec's work centred on transforming a culture of violence, a common concern among Afghan youth, while also developing strategies to address this. One strategy focused on the core conflict in the image, discussing precipitating factors, subsequent events, and potential means to transform the situation to avoid future conflict. Kuftinec found that the 'image-making provided the youth with a way to both create distance from and illuminate the ethos of violence in which they are steeped' (p. 114), enabling an exploration of possibilities for change from, and through, the embodied image. This is what Boal (quoted in Jackson, 1992) calls a 'rehearsal for reality' (p. xxi), activating the youths' imagination of a world without violence and how to get there.

In Jerusalem, images 'clarified the competing paradigms through which Israeli and Palestinian youth understood the conflict situation in their own communities' (Kuftinec, 2011, p. 110). Alon, Kuftinec and Turkiyye (2010) and Viewpoints Theatre used Image theatre with children and youth to develop ways of communicating between groups who have historically been in conflict. Their method used images to make concrete the differences in perception between two groups. Once a group defined an identity category that divided the whole group in half, each group made an image of how they see themselves and how they thought the other group sees them. Then, the groups engaged in dialogue about the perceptions of themselves and of the other group.

Kuftinec (2009) shares a similar process from a workshop with a group of Macdeonian, Albanian, Kosovar Albanian, Kosovo Serb, and Roma youth in Macedonia in 2004. Cultural mapping groups were formed based on particular categories: for example, non-national identity, self-selecting relationships, and month of birth. Participants made a map of the room based on where they were born and where they now lived (or where they felt comfortable). Each group then silently created an embodied image of their situation. Articulating 'a violent trauma beyond language' (p. 240), the groups illustrated the tensions in the Balkans, still present years after the war, followed by intense discussion of the realities of war and inter-ethnic tension in the region. Group discussion of the image revealed as much about those outside the particular image as those inside it as it focused on the aesthetic space of the image and the process of talking about it. Therefore, Image theatre slowed down the conversation and directed it away from a heated discussion.

Relevant to research on the health and well-being of children and youth affected by global adversity, the interpretation of the embodied image comes from those watching, thereby becoming another data point. When there are multiple and competing worldviews like in Israel or Macedonia, asking the storytellers to explain their image is also helpful as 'decodings [interpretations] serve as projections rather than authoritative definitions; participants put more energy into interpretation and reflection than argumentation' (p. 238).

Sloane and Wallin (2013) worked with families and youth affected by global adversity who had fled zones of war and conflict to create a 'theatre of the commons' where image formed the basis of plays about the participants' lives after immigration. Photo elicitation processes identified significant illuminative moments (Stringer, 2004), which became prompts for interviews about what enabled participants to have a voice. Participants named what they struggled with, analyzed the power relationships in their experiences, and generated individual and collective actions to overcome what they were facing.

As we have noted, embodied storytelling through Image theatre enables the acquisition of understanding through both psychological and kinaesthetic processes as 'stories show what is possible in impossible situations' (Frank, 2013, p. 133). As a form of research as intervention,

Image theatre becomes a process of articulating and transforming 'dominant ideologies at the level of communities and individual bodies' (Perry, 2012, p. 103).

Digital Storytelling: A Safe Space to Express Marginalized Voices

With the advent of increasingly available multimedia tools and a wide array of social network platforms, children and youth have greater opportunities to share their narratives by using their own voices through digital storytelling. According to Burgess (2006), '[d]igital storytelling is a workshop-based process by which 'ordinary people' create their own short autobiographical films that can be streamed on the Web or broadcast on television' (p. 207).

Over the last two decades, this method has gained prominence in the fields of education and public health by encouraging children and youth to express themselves creatively and fostering a sense of individuality, agency, and ownership over their creations. Digital humanist Jason Ohler, asserts 'digital storytelling helps students develop *creatical thinking skills,* merging creativity and critical thinking, to solve important problems in imaginative, thoughtful ways' (2013, p. 13). Children's narratives, based on their own interpretations and perspectives, are expressed using a combination of methods such as drawings, images, music, videos, and voice to create a three to five minute digital story (Alexander, 2011; Rossiter & Garcia, 2010). This multimodal, child-led production can be a transformative experience due to its potential for their meaningful engagement with their topic and engagement in deeper learning, critical reflection, meaning-making, self-expression, and effective communication.

Digital storytelling grew as a phenomenon in the 1980s based on the works of Dana Atchley (who coined the term) and Joe Lambert, which led to the creation of the *Center for Digital Storytelling* (CDS) (Rebmann, 2012). The CDS proposed seven elements essential to digital storytelling (Lambert, 2013; Robin, 2006; Kajder, Bull & Albaugh, 2005) including: point of view, dramatic question, emotional content, gift of voice, power of soundtrack, economy, and pacing. Following the production of the digital story with these elements, there are numerous options for dissemination such as social networking sites (Facebook, Twitter, YouTube), television outlets, collaborative community projects (Life Stories of Montrealers Displaced by War, Genocide, and Other Human Rights Violations[2]), websites (Mapping Memories: Experiences of Refugee Youth[3]), and workshops (Learn-Récit[4]). For underrepresented and marginalized digital storytellers, such as children and youth facing global adversity, this form of dissemination can contribute to their 'empowerment, voice, and dialogue' (Garcia & Rossiter, 2010).

Though highlighted as an effective arts-based method for intervention with children and youth in public health (Guse et al., 2013; Sawyer & Willis, 2011), the capacity of digital storytelling to serve as intervention for youth affected by global adversity, specifically as a tool for peacebuilding, is gradually being realized. Hanebrink and Smith (2013) note that participatory methods such as digital storytelling 'can enable transformation, both individually and communally, of their realities from the wreckage of war towards acceptance and a construction of peace that includes social rehabilitation and conflict prevention' (p.195). This concept of peace education through digital storytelling is further explored in *Voices Beyond Walls,* a series of digital storytelling workshops conducted with children and youth (aged 10-16 years) in six refugee camps in the West Bank, East Jerusalem, and Jordan. Due to the availability and accessibility of digital tools, young Palestinians in the West Bank have used participatory arts-based methods, such as digital storytelling, to produce short videos on their day-to-day experiences. The *Voices Beyond Walls* workshops conducted from 2006-2008 had four

objectives: first, to enable youth to conceptualize personal narratives through storytelling; second, to create storyboards and scripts for digital media projects; third, to learn digital media production techniques; and fourth, to produce media projects in the field (Voices Beyond Walls, 2006). In a span of three years, sixty digital stories were produced and sixteen were showcased through the project's website[5]. Norman (2009) asserts that such media involve 'amplifying young people's voices on issues of importance to them' (p. 251). As a form of intervention, the digital storytelling workshops empowered youth to explore and express their emotions as well as their hopes and aspirations on a wide range of issues, from education and water shortages to tensions between Israelis and Palestinians in their communities. Buckner and Kim (2012) argue that digital storytelling, as a form of peace education,

> allows children to not only bear witness to the experience of childhood amidst conflict and develop an awareness of life on the other side of the conflict, but also helps build international awareness of the realities of conflict generally and the Israeli–Palestinian conflict specifically (p. 12).

Similar workshops have been conducted in different parts of the globe, such as the student-led peace project, *Voices of Kashmir*[6]. Such examples of digital storytelling illustrate how participatory arts-based methods are effective in attempting to understand the lived experiences of children and youth facing global adversity, creating a safe space for young people to express their marginalized voices and ideas, interact with each other, and engage in a critically reflective process.

Implications: Raising Conceptual, Ethical, and Practical Issues

As we have previously stated, children and youth who grow up within environments where they experience global adversity through experiences of marginalization and exposure to poverty, violence, disaster and/or war, may be threatened not only with the potential for loss of life, but with numerous long-term mental health issues (Betancourt & Khan, 2008). In examining a number of participatory arts-based methodologies that seek to both empower and actively engage children and youth in the research process, we have empathized that these methods allow the representation of the lived realities of children and youth by incorporating the multiple functions of translation and dissemination and in turn, that research becomes a means of intervention.

Additionally, in an era of increased awareness of human rights in response to the multiple forms of adversity that continue to affect children and youth, there is also increased attention to the specific ethical concerns raised when working with marginalized children and youth. Those who are often denied basic human rights are the very children and youth whose voices should be heard in programming and research. However, there are often complex conceptual, ethical and practical issues that arise because of the nature of working with visual methods with marginalized children and youth.

Conceptual Issues

Drawing from western conceptions of childhood and its association with vulnerability and the need for protection, much of the theoretical and conceptual literature on children and youth affected by global adversity has tended to construct them as dependent, helpless, and as objects of assistance rather than agents of their own welfare (Honwana & de Boeck, 2005). While

victimization invariably characterizes the experiences of these children and youth, failing to explore their rights and capacity to overcome adversity provides a skewed picture of their reality. Participatory visual research methods, such as those described in this paper, aim to promote more egalitarian methods whereby children and youth can participate in research, thereby returning a sense of control to the child. Participatory approaches turn upside down the traditional research paradigm by transforming participants from passive objects of research, into active agents, enabling a research environment in which children are at ease, are able to express themselves freely, and do not feel the risk of giving a wrong answer (De Lay, 2003). Visual methods capitalize on children's and youth's strengths: their local knowledge of their contexts and environments, their attention to detail, and their visual and verbal communication skills. However, using participatory visual research methods can challenge traditional adultist assumptions about children's and youth's experience in the context of global adversity. In particular, embarking on participatory approaches and visual methods require researchers to relinquish their roles as unequivocal controllers, owners, and knowledge constructors, requiring a fundamental conceptual shift in approach. Moreover, because children and youth have much of their lives dominated by adults, they may anticipate adults' power over them. In this sense, children and youth are not used to being treated as equals by adults, particularly in the context of research. In line with the shifting paradigm of participatory approaches, it is thus critical that children and youth are provided space to feel accepted and able to tell their story through arts-based methods such as photovoice, PV, drawing, Image theatre, or through digital storytelling.

Ethical and Practical Realities

Within participatory, visual approaches there may be complex ethical dimensions that have not yet been contemplated. For example, how do researchers ensure sensitivity? How do we stop the zealous researcher or practitioner from immediately displaying the work when the child who produced the drawing or photo or the story through Image theatre may have no idea of what 'making public' means and has no power to say no? What are the ethical implications when meaningful transformation is, at best, challenging or, at worst, an impossibility? In such cases, participatory research can have potential adverse and detrimental effects. Ethical issues, therefore, hold an important and vital place throughout the research process.

We have previously (Akesson et al., 2014) identified four critical ethical issues that represent specific challenges in relation to using visual methods with children and youth affected by war:

(1) *informed consent* whereby researchers need to develop specific approaches that ensure children understand the benefit of participating voluntarily in research and that consent is informed and an ongoing process;

(2) *truth, interpretation, and representation* which acknowledges that the arts-based research process uncovers multiple truths whereby children and youth become co-constructors of knowledge, and its interpretations, with adult-researchers;

(3) *dangerous emotional terrain*, which asks us to consider the implications of portraying and/or embodying experiences, for both the child-participant and those watching, which are both critical to ensure participant safety; and

(4) *aesthetics*, which raises questions of what is 'good research' (and who decides this) when you are dealing with artistic representation.

We suggest that researchers should consider these elements when assessing the risks and benefits of children's and youth's participation and to develop specific ethical protocols and safeguards to

ensure that participants understand the benefit of participating in research, that the participation is voluntary, and that the informed consent process (which can be presented visually to children and youth (see for example Ruiz-Casares & Thompson, 2014)) is ongoing.

A goal for participatory arts-based methods is often to reach policymakers who have the power to implement systemic change within communities. What are the ethical implications of employing methods that seek transformation where such transformation can in no way be guaranteed? This means being transparent in voicing these limitations with participants. Researchers should be conscientious that in actively engaging participants in a research project - whereby disclosing of an issue or topic can lead to isolation and/or distrust and suspicion on the part of the other community members - that this might be a possible consequence in participating. That is, in some instances, because of the type of disclosure, it may lead to sanctions rather than systemic change or social justice. As Bergold and Thomas (2012) have stated,

> this gives rise to the dilemma of having to choose whether to defer the publication of problems that are in urgent need of public discussion or to publish them for that very reason. If the latter option is chosen, counter-strategies must be developed with the research partners. (109)

Boydell et al. (2012) suggest that "determining the goodness of art in terms of its role in research is even more complex, requiring attention to the aims of the research and the context in which the research is being conducted" (p. 12). By examining the ethics of any use of visual methodologies a complex inter-relationship of aesthetics, context, and purpose emerges that needs to be taken into account. For example, the use of youth participants' smart phones to photograph the results of a particular visual process might be ethically appropriate in one way, but in another way, if the ramifications of the use of the data (for example, the easy capability of being shared on social networks) are not discussed in light of purpose and context, an ethical challenge has arisen.

The above-noted realities underscore that when working with their visual representations of their experiences, children and youth must be allowed to provide insight into the representation part of the process—essentially becoming co-constructors of knowledge with adult researchers. Furthermore, the research process should allow child and youth participants to challenge the researcher's interpretation. In our desire to document their experiences, we should ensure that children's and youth's agency and voice and the diversity of their lived experiences is rightly noted and represented.

As we have previously highlighted, as researchers we require 'tools for reflection' (Akesson et al., 2014, p. 85) so that we may think about how we work collaboratively with these tools and how these tools have an impact on children facing global adversity in terms of power and participation. In other words, ethical issues are not something to consider after designing research, but rather are an intrinsic and ongoing part of the design and implementation processes.

Conclusion

In this paper, we reviewed multiple forms of participatory visual research methods with children and youth affected by global adversity. Honoring means and methods of knowledge production that are suited to children and youth can lead to better ways of knowing and understanding them and their experiences. In this sense, children and youth are social actors in their own right, and they should be recognized as active participants rather than objects in the

research process (Pascal & Bertram, 2009). In addition to gathering rich and valuable data, using visual research methodologies in research with children and youth affected by global adversity has the potential to make a positive difference in the research participants' lives. In other words, arts-based methods can serve as data points, but also as potential means of intervention for research participants. Use of these methods – photovoice, participatory video, drawing, painting, and mapmaking, Image theatre, and digital storytelling – offers a potential opportunity to engage in *both* research *and* intervention to ultimately improve the health and well-being of children and youth affected by global adversity.

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[1] We use the capitalised Image theatre to indicate the concept of using the bodies to tell a story, and image to indicate the representation of the story itself.

[2] http://www.lifestoriesmontreal.ca/en/experiences-of-refugee-youth

[3] http://www.mappingmemories.ca/

[4] http://www.learnquebec.ca/en/content/professional_development/workshops/

[5] http://voicesbeyondwalls.org/

[6] http://voicesofkashmir.com

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