

CHAPTER 14

DRAWING THE BIGGER PICTURE: GIVING VOICE TO HIV-POSITIVE CHILDREN

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INTRODUCTION

South Africa is home to the largest number of people infected with HIV and living with AIDS (UNAIDS, 2008). Children, in particular, represent one of the most vulnerable groups exposed to the harsh consequences of HIV and AIDS. In 2007 alone, 270,000 children died from AIDS (UNICEF, 2010), and at the same time, 280,000 children were living with HIV (UNICEF, 2009). In addition to the large number of children infected by and dying from the pandemic, many are affected by the loss of parents and guardians, which, in turn, results in child-headed households and a significant number of orphans (Richter, Foster, & Sherr, 2006; UNICEF, 2009).

South Africa is therefore confronted with many challenges regarding these children. One of the most important is to ensure that children who are infected by HIV receive treatment through proper health-care systems and are educated and correctly informed about treatment adherence and well-being. This will play a pivotal role in preventing the progression of the virus into AIDS or at least prolonging the progression. Inconsistent treatment adherence can have serious repercussions; the virus multiplies and causes further deterioration of the immune system. As a response to the concerns of doctors and others that HIV-positive children often experience difficulties with treatment adherence, we developed an intervention called “Hi Virus”.

The Hi Virus intervention is discussed in this chapter in order to illustrate the role that drawings can play in educating HIV-positive children about treatment literacy and treatment adherence. We discuss, too, the role of the young artists and their drawings in the compilation of a storybook that consists, in part, of these drawings and that serves as a vehicle of information transfer within the wider community in its attempt to spread awareness and knowledge of HIV and AIDS and treatment adherence among South African children. The storybook serves as a record of the thinking of these children as translated through their drawings. The focus is on how drawing can function as a form of participatory art to impart accurate information to HIV-positive children about consistent treatment adherence. In exploring drawings as a tool to foster awareness, knowledge sharing, and knowledge transfer, we focus on both the educational *and* the entertaining nature of drawing: Drawing is unveiled as a participatory form of Entertainment Education (EE).

DRAWING FROM THE VISUAL

From the initial HIV&AIDS interventions in the early 1980s through to the late 1990s, television and radio transmission were the predominant mass media communication strategies used to inform and educate. The escalation in the effects of the epidemic, however, begged for a reassessment of how prevention, treatment, care, and support could be more effectively and appropriately communicated at an interactive and participatory level, primarily for children. Africa, especially, needs to consider more active participation as a possible remedy to the many failures of HIV prevention strategies (Govender, 2010). Despite the transition from the didactic, top-down communicative processes for knowledge transmission to what appears to be more participatory initiatives, the real voices of people infected and affected by HIV are still pervasively silenced. Children, in particular, lack the opportunity to express themselves or openly discuss the realities of living with HIV and AIDS. Diane Melvin explained, in regard to the Phila Impilo! Project, that although children are disproportionately affected by HIV infections, their voices and views are often not sought or heard (as cited in Kruger, 2008).

The question, then, is this: How can participation and dialogue among children be encouraged, and can drawing play a role in this active child engagement? A model developed by Harry Shier (2001) illustrates that child participation involves providing children with platforms from which their voices can be heard and opportunities for their opinions to be discussed. Amid the many potential platforms and opportunities that exist, visual art has been researched widely as a means of encouraging expression among children (Mitchell, 2008; Mitchell, De Lange, Moletsane, Stuart, & Buthelezi, 2005; Rao et al., 2009; Wallace-DiGarbo & Hill, 2006). In particular, art has proven to be effective in addressing sensitive issues with children, such as trauma, abuse, and HIV and AIDS (Gerteisen, 2008; Hrenko, 2005; Pifalo, 2007). In this chapter, however, the focus is on how drawings were used to implement an HIV&AIDS educational and participatory intervention to encourage awareness and knowledge sharing related to the particular challenge of treatment literacy and treatment adherence. Although drawing was consciously used as a participatory tool in the Hi Virus intervention, an unintended aspect of drawing also emerged: The process of drawing proved to be not only participatory but, more specifically, a participatory form of Entertainment Education (EE).

This chapter is written within an interpretative paradigm reflecting the first author's¹ workshop experiences, participant observations, journal notes, and informal group discussions over an 18-month period. The methodologies explored were used to take the children through a process of discovery and learning through telling their stories, sharing their experiences, learning together, and taking action to live more positively.

BACKGROUND TO THE 'HI VIRUS' INTERVENTION

The Hi Virus initiative was introduced by the Centre for HIV/AIDS Networking (HIVAN), established by the University of KwaZulu-Natal in 2001. The project

formed part of the Children's Resource Book series, created by HIVAN'S Highly Effective Art programme (HEART), which focused on using participatory art approaches with children to address HIV and AIDS. The Hi Virus initiative was conducted by facilitatorsⁱⁱ from HEART with a group of 7 children between the ages of 11 and 14 years from a care centre for HIV-positive children in Durban, KwaZulu-Natal. Hi Virus workshops were conducted over three weekends during which the children were taken away from their rural environments to a camp site to address issues of treatment literacy and treatment adherence. The workshops were child-centred and focused on involving the children in the entire process of knowledge sharing and learning in order to develop a deeper understanding and practical application of treatment adherence.

WORKING FROM THE GROUND: METHODOLOGICAL CONSIDERATIONS

Participatory Action Research (PAR) was adopted as the methodological approach for Hi Virus because it entails a process in which the children engage in collective, action-based projects that reflect their own knowledge and mobilise their desired actions (Vio Grossi, 1980; Wadsworth, 1998). The facilitators and children worked together to define the most practical and feasible ways for them to participate, with the majority of the children choosing art-based methods as the medium they wished to work with for the three workshops. In this context, participation was, as McIntyre (2008) put it, a choice, and not an imposition. The workshops took an inductive approach: We worked from a position of discovering possibilities towards empowerment. Hi Virus exhibited characteristics of a grounded theory approach since it allowed for building from the patterns, discussions, and observations during the workshop toward establishing some of the theoretical considerations of using art-based methodology for HIV&AIDS knowledge sharing.

It is useful to conceptualise PAR not as one particular research method but rather as a diversity of approaches that include elements of participation, action, and research (Spaniol, 2005). The participation element ensured that the children were given a space to engage in all levels of the project using art-based methods that they selected. The action aspect allowed for critical dialogue and discussion that translated into the children becoming more aware of the importance of treatment literacy and treatment adherence. The research element was a co-generation of knowledge and ideas from the children and facilitators in relation to the various issues discussed.

The complete workshop process took place over a period of 18 months, commencing with weekly meetings with the children and their guardians to share collectively the challenges attendant on the lack of treatment adherence. Ongoing meetings were conducted with the children for almost 6 months prior to the workshops so that we could understand what they knew about adherence and also decide collectively on how to approach the problem of inconsistent treatment adherence. The workshop programme was discussed with the children's caregivers, counsellors, social workers, and psychologists and strategically designed in consultation with the children. Through discussion groups and play activities, these

children became more enthusiastic about drawing, painting, and making things as a way of learning about HIV and AIDS. The workshops were conducted over a 2-month period, with follow-up sessions held once per week during which the children could review their drawings and make desired revisions.

The Workshop Journey

During the workshop weekends, participants had the opportunity of engaging in a variety of creative activities, including participatory games, role-playing, storytelling, puppet making, collage, drawing, and fabric painting, to help them engage in dialogue about specific issues around treatment adherence. Central to the workshop process was engaging the children in this participatory process. Drawing is both a means of communication as well as a problem-solving tool through which children can see what they are thinking and play around with and transform their ideas (Brooks, 2009). Creativity emerged strongly during the drawing process in the Hi Virus workshops. According to Prescott, Sekendur, Bailey, and Hoshino (2008), drawing can be a useful tool in providing a distraction from dealing with painful circumstances and can also provide the opportunity to reshape reality and formulate future goals.

First, through a role-play process, the children shared detailed stories of their experiences of diagnosis, treatment literacy, and some of the challenges of adherence to treatment. The role-play session was based on the children's knowledge about HIV, and any misinformation was corrected with the help of the facilitator as the role plays developed. The children developed storylines, decided on the characters, and made innovative use of various materials and basic clothing to create their own props for their characters. The role plays about their lived experiences were then documented through a process of drawings. The children drew pictures of the characters they had created for the role plays as well as pictures of scenes from them, such as a meeting between a doctor and an HIV-positive character. The purpose of these drawings was, first, to serve as a tool for knowledge sharing among the members of the group because as the children drew, this created a space for dialogue about the challenges of treatment adherence. Second, the drawings functioned as a tool for knowledge transfer; the drawings were used later as the illustrations in an educational storybook for other children.

The children clearly had common experiences with HIV&AIDS treatment. Through the role plays, they were able to express some of the difficulties they face with treatment adherence. When the children began drawing pictures of scenes from the role plays of their lived experiences, they began to express visually their challenges with treatment adherence. These drawings later precipitated ongoing formal discussions, initiated by the facilitator, about the challenges the children faced with treatment adherence and treatment literacy, and informal discussions about their drawings and lived experiences among the children after the workshop. One child shared with the group that he took all his pills everywhere in a Cal-C-Vita container. The immediate response of another child was to question how he knew which pills to take since they were all mixed together in one container.

The drawings were a significant tool to allow the children to go through a process of conscientisation and critical dialogue about their lived experiences. According to Brooks (2009), children can bring something into consciousness more clearly through drawing, and we saw this happening. Eventually, the children's drawings were pieced together by the children and the facilitators in order to begin to form a visual storyboard for a storybook. The children collectively decided that the storybook would be used as an educational tool to teach other children about the importance of treatment adherence. The book's storyline was derived from the transcribed role plays and the children's ongoing informal discussions about their drawings. The dialogue from both of these was recorded and later transcribed by the facilitators so that the children's own words could be used in the storybook. This made the entire process participatory since the children were active participants from the commencement to the end of the project, collectively designing an arts-based approach to addressing their issues, developing the creative content, and translating this content into an educational resource book for other children.

The drawings enabled the children to take the focus away from their own lived experiences and collectively reflect on their shared experiences of treatment literacy and treatment adherence. Through this process, the children collectively identified, in the group discussions, that their drawings reflected a common challenge, allowing them therefore to both problematise their issues as well as move on to discuss how they could address these. As is clear here, artistic activity is consistent with the tenets of PAR because it is, by definition, action-oriented. Drawing was used as the action component of the PAR process with the knowledge that art making lends itself to participation since it often involves people working collaboratively to identify issues and solutions (Spaniol, 2005).

The discussion in the next section reflects some of the theoretical considerations that emerged during the process of using art-based methodologies in working with the children. It is divided into two main sections. The first explores how drawings were used in the Hi Virus project to encourage dialogue and participation among the children in order to facilitate greater awareness and knowledge sharing regarding treatment literacy and treatment adherence. The second section discusses briefly how the drawings can be considered to be a participatory form of EE working towards knowledge transfer.

DRAWING TO PARTICIPATE: CATALYSING 'CRITICAL CONSCIOUSNESS'

The facilitators conceptualised and implemented the Hi Virus project with a participatory orientation clearly in mind. Hi Virus aimed to cater to the particular needs and interests of the children. This is, of course, one of the first pivotal components of participatory development (Bessette, 2004; Servaes, 1999). The process of participation was maintained since the children had ongoing opportunities, through informal discussions and group work, to describe some of their positive and negative experiences with treatment adherence. As these dialogues about challenges and problems developed, they assumed the

characteristics of Paulo Freire's participatory pedagogy. Freire (2002) criticised the conventional approach to education, the 'banking method', in which information is transmitted to so-called ignorant people by an external authority. In opposition to this, Freire advocated a 'problem-posing' approach in which people learn through active participation and dialogical exchange with others (see also Shor, 1987; Wallerstein, 1987).

Although Hi Virus created a useful resource for other children in the form of an educational storybook, the significance of the project process was the children's independent selection of drawing as a medium to explore their issues with treatment literacy and to share this knowledge. Once the children had discussed the problems and possible solutions to treatment adherence, they expressed these ideas by drawing pictures. For example, one of the children described how intimidated he felt by taking the ARVs each time he visits the doctor. This fear and intimidation was expressed when he drew his pill bottles as disproportionately big, in comparison to himself, possibly suggesting the overwhelming nature of treatment adherence. This suggests the power of art to help young people to express ideas, reflect on these ideas, and expand them—all in a manner that requires their active involvement (Brooks, 2009). The children also shared their experiences of the challenges of taking their pills since adherence to a cocktail of drugs is often very complex. As a result, they collectively decided that they needed more information about treatment adherence as well as a system that could help them adhere to their complex treatment. The picture illustrating the large medication bottles, drawn by one of the children, led to a discussion about better ways of adherence. The fact that the children identified their problems as a challenge common to HIV-positive children and that they selected drawing and other participatory means of learning was reflective of the power of the intervention to give voice to children through providing a space in which to make their own choices. This is often not a common experience for many children. The drawings, therefore, created a space for critical dialogue about the need for adherence and led later to the development of a pill box. This dialogical exchange occurred as the children collectively discussed the complexity of adhering to the cocktail of treatment while opening up some of the pill containers to show the facilitators and other children the number and variety of pills that had to be taken on different days of the week. Many of the children were not able to explain which pills should be taken at the appropriate times, thus identifying adherence as a problem common to many members of the group. All the children were excited about the possibility of having more discussions about better treatment adherence through a process of drawing. Knowledge sharing is a key characteristic of Freirean problem-posing education because it involves people learning through interaction with others. The children were able to generate suggestions for treatment adherence because they were able to work creatively with their facilitators and each other.

In addition to functioning as a means of dialogue and expression, the drawing also proved to be a method of empowerment for the children. After the children collectively expressed their anxieties with treatment adherence through the various

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drawings, they discussed possible ways of dealing with the complexities of adhering to treatment at different hours of the day. Many did not own watches or know how to read time. One of the children suggested he needed a 'pill diary', which later became known to the group as a 'pill schedule', and, sometimes, a 'pill box', which would 'remember' to take the pills. The others chuckled at the idea of a pill diary, indicating that they could not stick the pills into the book. With the help of facilitators, they individually developed and decorated pill boxes, with drawings of the sun to indicate the time for the morning treatment and drawings of the moon and stars to indicate the time for the evening treatment. Through drawings and sketches, the children were able to depict the times of the day when certain treatment had to be taken, thus demonstrating their ability to become empowered in taking ownership of their problems. From this, it is clear that drawing has the potential to bring children together so that they can share common experiences and problems and engage in joint learning: "Through expressive arts activities children learn how to solve problems with peers, negotiate and share" (Hutinger, Betz, Bosworth, Potter, & Schneider, 1997, p. 5).

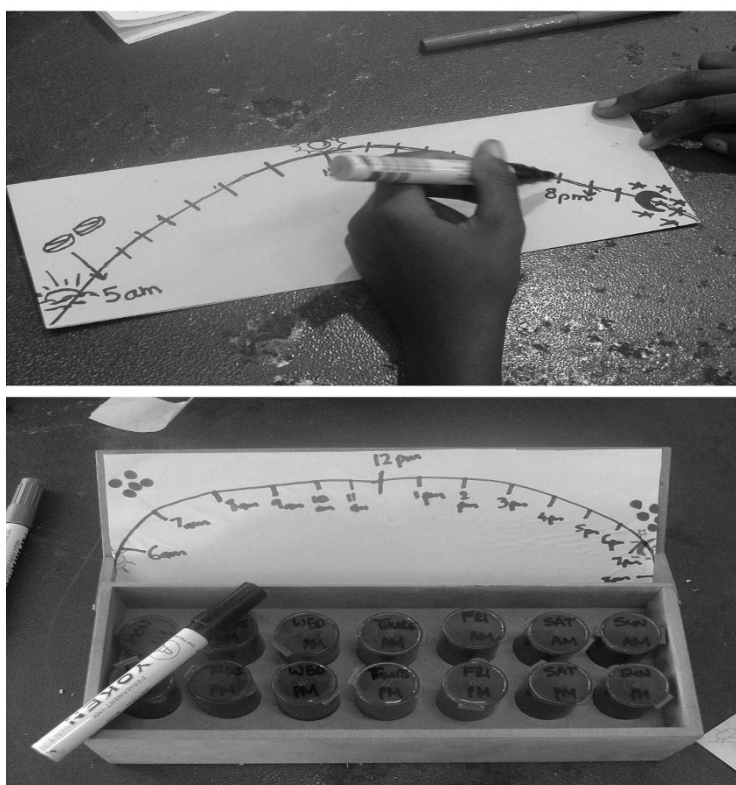


Figure 14.1. Children using drawings to depict sunrise and sunset as pill-taking times.

One of the key components of Freire's (2002) participatory pedagogy is the concept of 'critical consciousness', which involves people becoming more aware of their own abilities and competencies and actively using these to engage with the world around them (see also Nain, 2001; White, 1994). Such critical consciousness became evident when the participants of Hi Virus began to think independently and to develop a sense of self-confidence. The initial days of working with the children prior to the workshop were the most challenging because the children, clearly, were used to being passive learners and were hesitant to participate. During the workshop, however, the act of drawing dissolved the boundaries that existed between the children and the facilitators. As the children progressed in drawing images of themselves and of their lives, as they visually expressed their experiences with medication and doctors, they gained a greater sense of identity and self-esteem.

This new-found self-confidence became evident when the participants assumed control of how their drawings were to be used. The children initially thought that photographs of themselves at the workshop would be used for the images in the storybook. A few approached their facilitators since they were not comfortable with their photos being used in such a book. Here, they demonstrated that they were confident enough to challenge and question the development of the book project and the book's contents. The book development process was discussed and the children were thrilled to discover that their drawings, rather than photos of themselves, would be used in the book. By questioning and identifying their role in the book production, they were developing into activist artists. When Mitchell et al. (2005) conducted an innovative study using photographs to address HIV and AIDS, they realised that "the photos work best when the participants are engaged in selecting, commenting on and deciding on how their views can best be represented visually" (p. 265). Similarly, with the Hi Virus project the drawings worked best when the children felt in control of how their drawings would be used and represented. As they assumed control, they began to take ownership of the project, which is important since "the principle of participation and ownership acknowledges that change is more likely to be successful and permanent when the people it affects are involved in initiating and promoting it" (Thompson & Kinne, 1990, p. 46).

The Freirean concept of critical consciousness, however, extends beyond dialogical processes and problem-posing education to a sense of feeling competent and empowered to transform one's social reality and that of others. The process of drawing, as a result, extended beyond knowledge sharing between and among the children about their lived experiences to knowledge transfer: The knowledge gained through the 18-month intervention was transferred to other children through the production of the educational resource book. Central to this process of positive change was the use of drawings: "Visual images are particularly appropriate to drawing in [relation to] the participants themselves as central to the interpretive process" (Mitchell, 2008, p. 374). Hi Virus developed the children's capacity to the stage at which they were empowered enough to use their experiences and identities as HIV-positive individuals to educate others about treatment literacy. This critical

consciousness process was achieved through drawings that served as a vehicle for knowledge sharing and knowledge transfer.

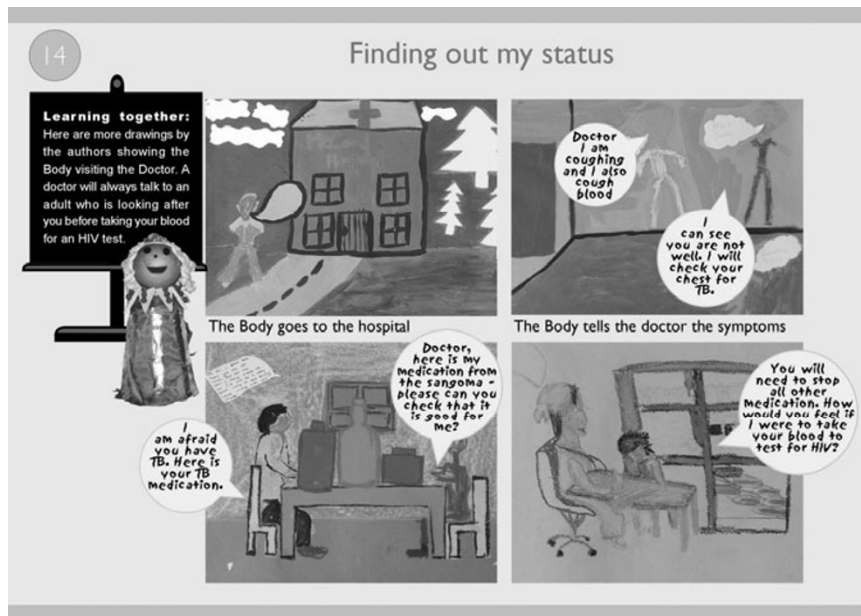


Figure 14.2. Through collective dialogue, the children drew pictures to represent their lived experiences.

EDUCATING THE ENTERTAINING WAY

Through the participatory process of art making, the Hi Virus workshops and the book development phase emerged as an interesting example of participatory Entertainment Education (EE) in practice. In recent years, EE has been used increasingly to communicate pro-social messages (Moyer-Gusé, 2008). As a communication strategy, EE combines both educational and entertainment aspects into communication messages based on the premise that people are more receptive to social messages and learn more effectively when they are enjoying themselves (Coleman, 1999; Singhal & Rogers, 1999). The entertainment aspect captures and maintains the audience's attention whereas the educational aspect focuses on conveying information about a particular social issue. EE has proven to be effective in public health communication, especially in the field of HIV and AIDS (Moyer-Gusé, 2008; Tufte, 2003).

Despite the potential power of EE, it has often been criticised for following a mass media approach, one in which television and radio were the predominant ways of presenting educational messages in an entertaining way. However, over time, EE has evolved to embrace more participatory, grassroots approaches (Tufte,

2005). Tufte divides the field of EE into three generations: the first generation focuses on the significance of social marketing for HIV prevention; the second on bridging paradigms originating in the modernisation-oriented paradigm with elements of the participatory paradigm; and the third focuses on empowerment and structural change (2005, p. 173). The third generation focuses on understanding the concerns of a community and empowering its members to identify their social issues and problems and then to address them in a participatory way. Similar to the way in which the field of development communication evolved from a mass media focus to a more participatory approach, the strategy of EE progressed to embracing grassroots activity and local involvement.

Whereas television programmes and radio dramas were considered to be the traditional forms of EE, drawing started to function as a more participatory form of EE during the Hi Virus project. The children were entertained while being educated about treatment literacy during the participatory art-based workshops. The way characters were depicted by the children often became a source of amusement and led to seemingly endless discussions among the group members. In particular, amusement arose when the children drew pictures of a *sangoma* (a traditional healer) and a Western doctor. Children often face challenges because they are given both traditional medicines by a *sangoma* as well as the ARVs prescribed by doctors. However, through the process of drawing, the children had educational discussions about the importance of taking only the ARVs and not mixing this treatment with any from a *sangoma*. Seemingly endless discussions occurred among the group members when the children drew pictures of *sangomas*.

These drawings expressed the reality of the children's lives; most of them have had treatment adherence experience dealing with both traditional and Western medicine. The entertainment component was evident when the children implemented their own competition to identify who could produce the best drawn *sangoma*. In many cases, the *sangoma* was drawn dressed in fashionable outfits, which contradicts the reality of their usual culturally appropriate attire and which perhaps demonstrates the thrill many children experienced in carrying out the drawing task. Many commented that drawing a *sangoma* is not a common experience (most of them had never drawn one before), and they found depicting the *sangoma* an entertaining process as they discussed the various images and identified the best drawings. Throughout the process, they also explained to each other, as they worked, why certain images were drawn in a particular way. The entertainment aspect of the drawing compelled even the most introverted children to share a smile and a laugh as they explained their drawings to each other.



Figure 14.3. Drawing of a sangoma as part of the depiction of the conflict between traditional and western medicine.

The potential for drawings to serve an educational function expanded from knowledge generation and knowledge sharing to knowledge transfer. The storybook created by the children during the Hi Virus workshops served as the vehicle for this transfer. At the final stages in the workshop process, the drawings were placed together to form a storyboard—a step towards creating a storybook for knowledge-transfer beyond the small group of children who participated in Hi Virus.

How much education took place relative to the amount of entertainment? Although the process can sometimes seem to be more entertaining than educational for children, the art-based methods provided them with a space in which to engage in both creative and entertaining artistic reflection and expression and to develop a critical consciousness of the possibilities of change regarding their treatment adherence behaviour.

EE initiatives often attribute their success to the entertainment aspect, capturing participants' attention first, so that they can then be educated. As Hutinger et al. (1997) observed, artistic activities have the ability to engage, amuse, and eventually educate those involved. The Hi Virus project, however, drew on the importance of active participatory engagement that the children suggested should be manifested through drawings. In the exploration of the educational and knowledge-sharing level of treatment literacy, entertainment became an explicit benefit of the intervention. Hi Virus drew on the power of art to gain and maintain the children's interest in the issues under discussion, and this led to their being entertained, as well.

CONCLUSION

The unique feature of Hi Virus is that it drew simultaneously on participation, Entertainment Education, and art to help children learn more about HIV and AIDS. By being part of participatory action research, the children engaged in Freirean critical thinking, dialogical knowledge sharing, and knowledge transfer. The PAR approach encouraged open, egalitarian learning, and the entertaining process furthered this enjoyable environment in which learning could occur.

Although EE is often thought of as having to do exclusively with mass media, the Hi Virus intervention suggests that drawing can function as an innovative form of participatory EE. The richness of the entertainment component of drawings can be effectively adapted to educate children about HIV issues, and we should be thinking about how to do this. Successful EE initiatives could be created by harnessing the effectiveness of drawings to encourage participation and dialogue and to stimulate greater awareness and critical thinking about a particular issue. In turn, these drawings could be developed further and used to develop participatory, child-friendly storybooks on a range of challenging topics. The significance of the Hi Virus initiative is not only that the drawings were used as educational tools among the participants but also that the participants became 'activist artists' by helping to form a book around their drawings in order to spread greater awareness of the importance of treatment literacy and treatment adherence.

Mitchell et al. (2005) argued that photographs can be used as a tool of inquiry, a tool of representation, and a tool for taking action, and, in arguing thus, they suggested the scope of possibility available to anyone working with visual methods. Hi Virus revealed the multiple functions of drawings as an art form, serving as a tool of expression, documentation, knowledge sharing, and, to a large extent, as an agent of change, or what we might call a catalyst for change. Drawing was a means of expression; the children were able to explore their lived experiences and feelings in a non-verbal context. Drawing was a tool for documentation; the children were able to record and reflect on the challenges of adhering to treatment. It worked as a tool for knowledge sharing; the children were able to use their drawings to discuss with other children some of the obstacles to proper and consistent treatment-adherence. It worked, too, as a tool to effect social change; the children created a storybook to educate other children about HIV and AIDS.

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NOTES

- ⁱ The first author has undertaken extensive research on Entertainment Education and participatory communication within an HIV context. Numerous workshops and interventions were developed as a result of this research. The second author has experience working with participatory arts-based methodologies with youth through her work with an NPO that uses art to educate and advocate for peace and reconciliation. Therefore, the past experience of both authors stimulated the interest in writing this chapter focusing on art and HIV/AIDS with children.
- ⁱⁱ The workshop was designed and facilitated by Eliza Govender, Lauren Cobham, and Bren Brophy.

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