

Remembering Camp Dreamcatcher: Art Therapy with Children Whose Lives Have Been Touched by HIV/AIDS

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Abstract

Society calls upon art therapists to meet the needs of troubled community members. This article describes one art therapist's experience of "giving back" to the community by volunteering to provide art therapy at a therapeutic camp for children whose lives have been touched by HIV/AIDS. Some of the medical, social, and psychological issues affecting this population are addressed. The development of specific art therapy goals and techniques designed to meet the needs of the campers is explored. This report demonstrates the value of art therapy in a therapeutic camp setting, as well as some of the benefits volunteerism can hold for art therapists who wish to contribute more to their communities.

Introduction

In the wake of 9/11, along with most Americans, I found myself struck by a sense of utter powerlessness. As I watched and read how Americans rose to the occasion by offering whatever supplies, services, and skills they could provide to help the country recover, I was amazed at the power in each of us. I read the articles in this journal's "Special Issue on 9/11." I was proud of how my colleagues had risen to the challenge and provided invaluable services to those in need. As Lani Gerity (2002), guest editor for the issue, wrote in her editorial, "Reading how these authors helped others rebuild their hearts and communities, you may find your own heart made whole. You may find you are in a community of generous, brave, and humane art therapists" (p. 99). The American Art Therapy Association's (2003) *Ethical Principles for Art Therapists* states, "Art therapists value participation in activities that contribute to a better community and society" (p. 8). Giving back to our communities is not only a nice idea but also a responsibility of our profession. I was inspired to find a way that I, as an art therapist, could make a contribution to my community—the community that keeps my family and me safe and nurtured each and every day.

An idea was sparked by a small item in the local paper, a request for counselors and medical staff to volunteer at a camp for children infected with or affected by HIV/AIDS. I visited the website. The camp was open to children (ages

5-15) whose lives had been touched by HIV/AIDS. While camping for a week, children could enjoy hiking, boating, swimming, go-carts, basketball, arts and crafts, music, Native-American ceremonies, a dance, and a talent show. In addition, teens could receive education on puberty, HIV/AIDS, relationships, teen depression, drugs and alcohol, body image, and sexual assault training. Camp Dreamcatcher provided a safe, therapeutic environment with groups in art, music, and movement therapies, as well as guided imagery, yoga, and massage therapy (Hillkirk, 2001). I spoke with the director and agreed to be the art therapist for camp. I felt privileged to be invited to participate in one of only three therapeutic camps in the country, and the only one located on the East Coast.

The idea of working pro bono brought forth positive feelings of excitement and altruism for me, but also presented financial and personal childcare challenges. Therapists may be altruistic people by nature—which is what may lead us to choose art therapy as a career. As Kottler (2003) writes about therapists,

Altruism is certainly a driving force behind our motives and actions as helpers. There is nothing like that feeling of elation that we sometimes experience when we know beyond a shadow of a doubt that our efforts have helped redeem a human life. (p. 49)

However, devoting time without pay had a whole different feel to it because I was choosing to use personal time to spend with others rather than with my own children. Working at camp would be no less clinical or therapeutic than paid art therapy experiences, but it would be perhaps more meaningful because I made the choice to give up personal time to help others. That is how I imagined the art therapists who volunteered during 9/11 must have felt.

When the date for camp to begin was still months away, I decided to do some research to prepare myself. Although I had years of experience in psychiatry (adult and adolescent inpatient), including treating an occasional HIV-positive adult, I had never treated children with HIV or AIDS. As a group facilitator, I felt I needed a stronger understanding of the AIDS virus, as well as the medical, social, and psychological issues that affect this population. Also, I had to explore my feelings about working with medically ill children and death. According to Elkinson-Griff (1995), "Work with this population forces all involved to face the issue of death and to individually find resolution" (p. 69). In choosing to step out of my normal realm as an art therapist, I felt like a student again. This was both excit-

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ing and intimidating. I was naive in my understanding of the AIDS virus and how it impacts children. The United States Agency for Internal Development (2001) projects, "Forty-four million children in 34 countries hardest hit by HIV/AIDS will have lost one or both parents from all causes, but primarily AIDS by 2010" (para. 2). And WebMD (2002) states, "Even if a cure were found today, AIDS will be the most deadly disease to ever plague mankind" (WebMD, 2003, What is AIDS? section, para. 5). I knew I had much to learn before I set out for camp.

Understanding the Effects of HIV/AIDS

Camp Dreamcatcher is open to children whose lives have been touched by HIV/AIDS. Some campers are HIV positive whereas others may have lost one or both parents to the disease. According to Kelly (1997), "HIV affects not only the person who is infected but everyone who loves and cares for that person" (p. 31). Many factors affect this population. There may be multiple medical issues requiring many medications even when the person is asymptomatic. For some there may be a constant fear of germs or of contracting an illness. Some children may need IVs, oxygen, or other medical interventions. They may be weak and unable to walk, setting them apart from other children. Alienation and isolation often are felt by these children.

The social issues facing anyone who is HIV positive are many. Despite educational efforts and media coverage of the facts, some people still fear that they or their children can get AIDS from casual contact. People may be afraid to touch, play, swim, or eat with or even go to school with children who are HIV positive. This can create feelings of isolation, anger, shame, guilt, and depression for these children. Even if a child is healthy but has a family member who is HIV positive, the child may face the same forms of social judgment. Because transmission can involve sex and drug use, people are quick to judge the behavior of others. Kelly (1997) states that discrimination is a way of life for those who are HIV positive. When individuals are first diagnosed and share the results, they may face immediate rejection and loss of social or family support.

The psychological factors affecting those with HIV/AIDS are many. Feelings can include isolation, abandonment, alienation, helplessness, hopelessness, depression, and even suicidal feelings. Many people who are HIV positive live in a world of fear—fear of becoming ill, passing the illness on to another, suffering, losing friends and family, and dying. Children can be especially vulnerable when so many feelings bombard them. A young person may not have the maturity or coping mechanisms to understand and manage these feelings.

Developing Art Therapy Goals and Tasks

Armed with a basic knowledge of HIV/AIDS and its effects on people, I selected art therapy goals, tasks, and media that would best serve the needs of the campers. A review of art therapy literature revealed limited information about art therapy with children who are HIV positive

or have AIDS and almost nothing about art therapy in a therapeutic camp setting. Piccirillo (1995) writes of the many benefits art therapy offers for persons living with AIDS. She suggests that experimenting with change and unknowns through the artwork can help people to learn new behaviors and coping skills, as well as safe ways to manage the unpredictable features of life with AIDS. Patients can use art therapy to share wishes, fantasies, and worries, and "some exercises can be interactive and playful, spontaneously providing relief from the sobering reality. Simply having fun is a significant benefit for everyone" (p. 65). Art therapy also provides patients with a forum to explore existential issues and to create artistic products that may serve as "their final mark in the world" (p. 66). In specifically addressing children, Piccirillo (1999) writes, "Art therapy has the comprehensive capacity to provide for the five central needs of children living with HIV/AIDS: mastery, communication, enjoyment, belonging, and legacy" (p. 122).

The art therapy goals for the children at Camp Dreamcatcher were fairly simple and straightforward. I planned to meet with each cabin of children (ages 8-12) two times during the week. I wanted to provide a safe, therapeutic environment in which the children could share their feelings both verbally and through their artwork. My hope was that each camper would participate as best he or she could during the group. My aim was to provide a nurturing environment and art opportunities to promote self-expression and supportive group interactions.

I selected three art therapy projects I thought might be valuable for the campers. The first was a memory-box project I had used in an afterschool program with middle school students. The students had enjoyed decorating a white box (similar to an old-fashioned cigar box) with a lid that flips up. Piccirillo (1999) suggests that memory boxes can be used to preserve the memory of someone lost to AIDS. Farrell-Kirk (2001) explores the role of the box as "protector" of secrets, precious memories, and emotionally valuable material (p. 90). Further, an Internet search turned up information about a memory-box project in Uganda. Memory boxes and books were created by HIV-positive women to leave to their children. Morgan (2000), a clinical psychologist who worked with this project, wrote, "It seems that the art of focusing special attention on the containers for the memories represents an opportunity to protect, make space for and attach value to the processes of storytelling and art therapy" (The Box section, para. 1). The first box for the project in Uganda was completed by Maki Lufhugu. She passed away on April 27, 2000. Her box was presented to her family and two children at a memorial service. It contained her *skaf-tin* (lunchbox), her handwritten life story, her favorite hat, a scrapbook of certificates, photos, and press clippings describing her public disclosure of her HIV-positive status in 1984, along with other artifacts. Morgan added that while he thought the memory box project was all about death, he found otherwise:

The memory box process is able to help a great deal in relation to changing negative self-image, as well as in relation to

shifting self-blame and shame. It is about finding, naming, documenting and stepping into our preferred versions of ourselves. (Morgan, 2000, HIV Affected section, para. 2)

I felt the memory box could serve a dual purpose for the campers. It could be used to contain personal items of remembrance, as well as things to help the campers remember those they may have lost. According to Malchiodi (1992), "Art has often been made in memory of someone who is lost or departed. In some sense, all art expression may serve as an act of remembrance" (p. 117). She cites the AIDS Quilt as a powerful example of the need for individuals to creatively express their grief and immortalize someone who has died. Fry (1995) writes of a 4-year-old who lost her mother to AIDS and then her father to suicide. Her creative participation in making a quilt panel helped in her healing process. "Connecting her family tragedy to a larger cultural problem gave her pain more meaning, and helped her symbolically join with other grieving children" (p. 155). Cook and Dworkin (1992), in their work with bereaved children, suggest, "Artistic creations can serve as concrete reminders of more abstract ideas, values, or emotions. These creative works often seem to encapsulate the essence of what the bereaved shared with the deceased" (p. 85). They also suggest that concrete symbols of remembrance can bring comfort to those left behind, and for those who are chronically grieving, it helps to put some of their grief "outside of themselves" (p. 90).

My plan for the second art therapy project was to draw a favorite memory. It was my intention that this image could also be placed in the memory box. According to Farrell-Kirk (2001), "Placing something in a box can not only signify the inherent value of the thing, but can actually imbue a mundane object with newfound importance" (p. 89). The third art therapy task was to complete a group mural. Two of the main goals of the camp were to share a week with others affected by HIV/AIDS and to be supported by counselors who have been trained to deal with these issues. I wanted an art therapy task that would promote group interaction so the children could feel more socially connected and supported by their peers. I chose an amusement park theme with which I had worked extensively in the past (Hrenko, 1996). I felt the theme would lend itself well to summer camp and the children's interests. Also, Piccirillo (1995) reports, "Use of the metaphor of a roller coaster is commonplace [for clients with AIDS]." She adds, "It is helpful to keep in mind that if you do not like the unpredictable experience of being on one, you will be especially challenged working with HIV+ individuals" (p. 62).

Art Therapy at Camp

Camp began for me on a beautiful August morning. I entered the lodge to find 141 campers laughing and talking as they enjoyed breakfast. It brought back memories of when I had once been a camper. I met my first cabin—a group of boys who greeted me with waves and smiles. What struck me initially was how healthy and happy every-

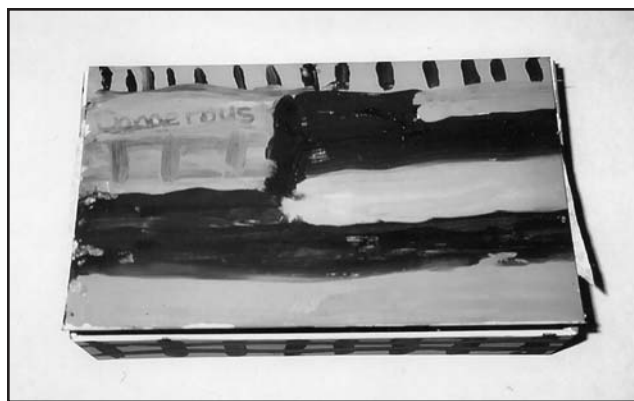


Figure 1

one appeared. Then as children received their morning meds, the truth was evident in the form of individual plastic bags filled with many pills of various shapes and sizes.

I held art therapy groups with five different cabins (four cabins of girls and one of boys), working with a total of 35 campers. Each camper was given a memory box and instructed to decorate the box in a way that represented him or her. Emphasis was placed on each person being special and unique, as each box would be. A variety of supplies were provided (pencils, markers, tempera paints and brushes, sequins, buttons, tacky glue, and scraps of material). The response to the task was overwhelmingly positive.

Figure 1 shows the outside of a box created by an 11-year-old female who was born HIV positive and whose mother had passed away from AIDS. This box was painted in orange and black stripes because the camper's nickname was "Tiger." She stated, "Tigers are tough." She also wrote "Dangerous," which she said was the name of her group. Whereas the exterior of the box seemed designed for protection, inside were scraps of material chosen to represent her interests (football and basketball), her friends, and her boyfriend. Willemsen and Anscombe (2001), in their work with preschool children infected and affected by HIV/AIDS, found that children often chose to be lions and tigers during art or play therapy. The children would request that their faces be painted like these animals. Willemsen and Anscombe believed that the wild animals represented many aspects of being a "sick" child and that perhaps the animal was a symbol of the illness inside them (p. 348).

Figure 2 was created by a 10-year-old female whose foster siblings were HIV positive. The inside of her box was designed like a quilt to express a view of herself as "colorful." She decorated the outside of her box with the names of her friends, counselors, and favorite musical groups. Avril was her favorite singer.

At the end of the first day, I was relieved that the day had gone so well. I felt that stepping out of my niche was helping me to gain new perspectives that could improve my therapeutic skills. The other camp volunteers, many of whom had volunteered for years, were inspiring. They helped me to understand the issues the campers were addressing. I was impressed by their genuine concern for the campers and their utter lack of pretense. They saw a job



Figure 2

that needed to be done, and they did it. Perhaps that came from giving of their time and talents for free. As a volunteer, it was clear to me that I had made a wise choice to spend this week at Camp Dreamcatcher. I had found children who really needed art therapy, and I was able to help fulfill that need.

At the end of the first session, the campers were given a “homework” assignment to find or create something that would help them remember camp. The second session began with the campers sharing their items of remembrance. These included rocks, pinecones, dreamcatchers made in arts and crafts, photos, notebooks, diaries, and nametags. The counselors from one cabin wrote individual notes for each camper to put in the boxes. Another counselor created mini wish-logs as souvenirs. Each year the camp held a wish-log ceremony and bonfire. The campers were encouraged to find a log or stick and decorate it. Each camper was given a chance to come before the group, make a wish, and then toss the log on the fire, sending the wish up to the heavens or spirits. The campfire created a special environment in which to share thoughts and dreams. It also provided the group with a time to acknowledge campers who had died or who were too ill to attend camp that year. This Native-American-based ceremony was very moving for both campers and counselors.

For some cabins, the second-session art therapy task was to draw a favorite memory. For others, a group mural was assigned. I based my choice of task on how the groups had functioned at the first session. The cabins of older campers who collectively seemed more cohesive and cooperative were given the group task. The cabins with younger members who seemed to need more individualized attention were given the favorite-memory assignment. The responses to both tasks were positive. However, the favorite-memory drawing seemed more intimidating. Asking the campers to think of their lives at home was difficult for them. This stimulated feelings of both homesickness and sadness for some. The mood was quickly elevated when the children, as a way to defend against painful thoughts, picked camp memories like swimming, driving go-carts, playing basketball, catching butterflies, arriving at

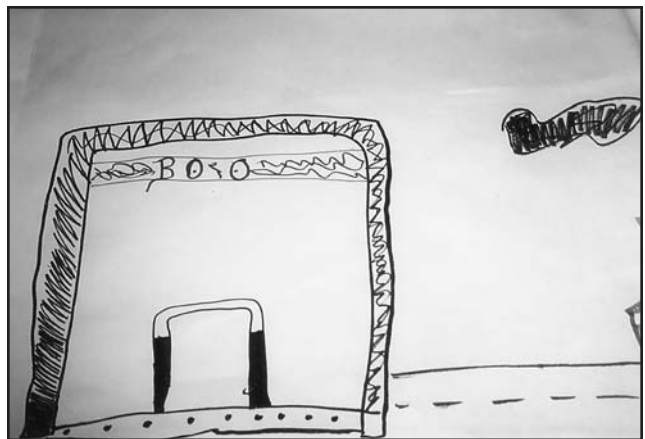


Figure 3

camp, and so on. I chose not to explore deep personal issues at that time since my contact with the campers was so brief.

My style was purposely aimed at development of healthy defenses rather than psychological uncovering. Many times I reserved my inclination to ask questions and delve deeper into the artwork. I constantly had to keep my goals in mind. I was forced to rethink my traditional therapeutic approach. It was refreshing to experience a new population in a different setting and to adjust my interventions accordingly. There were certain themes I specifically emphasized, including expressing thoughts and feelings creatively, accepting oneself and others, and cherishing life memories. Just as there were topics I emphasized, there were important HIV/AIDS topics I specifically did not address because I was seeing the campers only twice. I knew that issues of depression, death, sexuality, drugs and alcohol, and so on were being addressed appropriately in the psychoeducational groups and one-to-one sessions with camp counselors.

The amusement park murals from the second session produced laughter, cooperation, and sharing of memories. Figure 3 was created by the 11-year-old camper previously discussed. She drew a “Boo” mall at the amusement park. She described it as looking “scary” on the outside like a haunted house, but on the inside it was just like a regular mall including food places, games, and bathrooms. The path on the right connects her mall to her friend’s booth. In group we discussed the importance of connecting with others and developing a support system in life. Figure 3 seems reminiscent of the camper’s previous work in which she portrayed herself as “tough” or “dangerous” on the outside and nurturing on the inside. This may reflect her way of protecting herself and her feelings while dealing with the difficulties associated with being HIV positive. Following each task, campers were given the chance to share their artwork and feelings with the group. This seemed an easy task for many, perhaps because they had been to camp for several years and felt comfortable with their cabin mates. Upon leaving art therapy, the children waved, hugged me, and smiled while asking, “You’ll be back next year, right?”

Conclusion

Art therapy was a successful addition to Camp Dreamcatcher. The campers were given an opportunity for creative self-expression. They were able to share a personal symbol in an environment where they were supported by their peers. The memory boxes and favorite-memory drawings gave the children concrete reminders of good times in their lives. The boxes also provided them with special containers in which to gather additional important items and happy memories that could serve to nurture and comfort them during difficult times in the future. The amusement park murals promoted cooperation and group cohesiveness. They also provided forums for discussion on finding positive support systems in life. The murals empowered the children to create an environment where they could make choices about what they wanted or needed to have fun. As a person who still cherishes fond camp memories from my past, my hope is that these campers will remember the lessons they learned in art therapy and throughout their week at Camp Dreamcatcher.

My experience as an art therapist at Camp Dreamcatcher was extremely rewarding. I would encourage all art therapists to consider volunteering a portion of their time in service to their community. I learned much about HIV/AIDS and how it affects children in so many ways. My skills as a therapist were strengthened and refreshed by exploring a new population and by adapting my approach to the specific needs of the campers. I was once again reminded how valuable art therapy is in providing creative and powerful outlets for feelings that need to be expressed. My week at camp renewed my faith in the power of the human spirit to fight on against all odds. It also touched my heart to see how the many unpaid doctors, nurses, and counselors, through simple acts of kindness and caring, were able to give much to children who often have so little. At the wish-log ceremony, I watched the flames and smoke rise to the heavens. I listened to the wishes of children affected by HIV/AIDS and thought, "It's the least I could do as an art therapist to reach out to my community." And the campers were right, I did return the following year.

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