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*Journal of Contemporary Ethnography* 2002; 31; 548

DOI: 10.1177/089124102236542

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“  
*Whether or not  
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settings.*”

## **MEMORY CIRCLES**

The Implications of (Not)  
Grieving at Cancer Camps

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*Journal of Contemporary Ethnography*, Vol. 31 No. 5, October 2002 548-581

DOI: 10.1177/089124102236542

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*Each summer, Camp Anuenue is in session. Billed as an opportunity for young people with cancer to have a “normal” camping experience, this camp provides a sense of community and a needed break from hospital stays. Despite increasing survival rates for young people with cancer, a number of children and teenagers die each year. However, because Camp Anuenue is designed as a place to have fun, discussions of death and dying are often marginalized. Following a social drama and outpouring of communal grief in 1992, camp administrators implemented a grieving ritual. During the next four years, there was a struggle regarding where and how grief should be enacted. As the objective of the ritual gradually shifted from communal grieving to sharing favorite moments from camp, young people found more informal and individual ways of processing grief.*

Those who learn to know death rather than to fear and fight it, become our teachers about life. There are thousands of children who know death, far beyond the knowledge adults have.

—Kübler-Ross (1983, xvii)

Camp Anuenue is located on the northwest shore of Oahu, between Ka’ena Point and Waialua. To get to camp, you take the H-1 freeway out of busy Honolulu and drive forty-five minutes until you connect with H-2 in Wahiawa. As you go farther west, the landscape begins to change dramatically; the buildings and houses give way to mountains and pineapple fields. Driving north past Kemoo, you come to the Waialua-Haleiwa junction and see one of the most picturesque spots on all of the Hawaiian Islands. Rolling sugarcane fields seem to drop off into the aqua-blue ocean, and mountains with deep trenches and jagged cliffs line both sides of the road and stretch toward the horizon. Turn left at the junction and drive along the coast until you see a sign for Mokuleia. Four miles on, past Waialua High School, you will see Camp Anuenue on the *makai* (ocean) side of the road.

Walking along the campgrounds, the small stretch of sand is warm and soft under your feet. You notice that coconuts and seaweed dot the coastline. Facing north, you see rolling sugarcane fields where the annual burning of cane leaves a sweet smell permeating the air. Shaped

*AUTHOR’S NOTE: The author wishes to thank James VanOosting, Subrina Robinson, Rob Benford, and the anonymous reviewers for their helpful comments on earlier drafts of this article. He is especially grateful to the campers and volunteers at Camp Anuenue who made this research possible.*

by volcanic eruptions and covered by dense vegetation, the Waianae Mountains serve as a backbone to the camp. From the cabins, you can hear the soft summer waves that roll onto the shore. Geographically, Camp Anuenue is a liminal zone. Situated between cane fields, mountains, and ocean, its borders are constantly in flux. This location seems fitting for young people with cancer who are suspended between health and illness, life and death. These campers represent what Kaminsky (1992) referred to as people who fit into a "categoryless category" (p. 31).

In 1982, the American Cancer Society (ACS) implemented the first cancer camps (Back to School). Established in 1985, Camp Anuenue is the first and only camp in Hawaii for young people with cancer (Camp Anuenue 1995). Today, there are more than seventy-five summer locations for children and teens with cancer. Camp Anuenue, established and funded by the ACS, accepts campers from seven to seventeen years of age who are healthy enough to enjoy the camp experience (Camp Anuenue 1995). The purpose of this camp, according to the *1995 Camp Volunteer Staff Manual*, is "to offer the child who has, or has had, cancer an enjoyable, stimulating, supporting, and happy-away-from-home summer experience, similar to the typical summer camps enjoyed by 'normal children' of the same age" (Camp Anuenue 1995, 10).

As recently as fifty years ago, there was little perceived need for cancer camps because only 5 percent of young people could expect to survive cancer (Charlton, Pearson, and Morris-Jones 1986). Today, there is a 50 percent to 70 percent survival rate for the most common childhood cancers (Charlton, Pearson, and Morris-Jones 1986; Katz et al. 1992; Treiber, Schramm, and Mabe 1986; Young Cancer Survivors 1993) and a cure rate of 80 percent for acute lymphoblastic leukemia, the predominant cancer among youths (Lanier 2001). Cancer camps provide an opportunity for young people to be surrounded by peers who have shared similar experiences. The friendships formed at cancer camps are strong and lasting (Bluebond-Langner, Perkel, and Goertzel 1991).

Despite increasing survival rates for this population, cancer is the second most frequent cause of death for young people in the Western world (Tonnesson 1990). Because death is more prevalent at cancer camps than in the general population, one might expect that this subject is openly discussed with campers. However, for a variety of reasons, this is not usually the case. To date, there has been only one published study on issues related to grieving at cancer camps. Spirito et al. (1992) contacted nine cancer camps to learn if any form of remembrance

programs was used at their facilities. These researchers learned that only two out of nine camps implemented a grieving session despite the fact that the majority of campers wanted to have a remembrance program.

Even with the recent advances in pediatric oncology, some young people die in the months that follow camp. As Spirito et al. (1992) noted, "When children return to camp after another year of treatment, the possibility exists that a camper from the previous summer has died. Consequently, developing ways of addressing the death of campers is important" (p. 104). In 1992, during my first year of fieldwork, two popular campers died prior to the start of camp. Although some campers privately discussed the deaths of their friends, there were no public displays of grief until midweek, when a social drama erupted during a camp talent show. In response to the social drama, a performative ritual known as a Memory Circle was implemented. During the next four years, I studied how the enactment of grief was negotiated in communal and private settings. This article aims to contribute to research in the fields of performance studies and health communication by focusing on communal grieving rituals and more everyday, less institutionalized private practices. In addition, I feel that this study may be valuable for individuals in a variety of disciplines who work with pediatric oncology patients and survivors. I believe that Anuenue campers compose a "Speech Community," a term that Carlin (1992) used to describe a group that is not formed necessarily along geographic lines but rather "economic, social, and psychological contexts" (p. 137). By listening to the voices of these community members, it becomes possible to hear a new story about death and dying.

## METHOD

This article is part of a larger study on the lives of young people who have cancer. The methodology for this study combines audio-recorded interviews, open-ended questionnaires, and participant observations at Camp Anuenue, an overnight, eight-day camping experience for children and teenagers who have cancer. The data were collected over a five-year period. I was able to participate in and observe Memory Circles during each year of fieldwork. Approximately fifty-five campers ranging in age from seven to seventeen attend each session. The

majority of campers are from the Hawaiian Islands, with a small percentage of campers from the Marshal Islands and Samoa. My procedure for selecting interviewees was informal. Each year, I explained that I was collecting data for research purposes and encouraged campers, counselors, and medical personnel to share their experiences with me. Interviews usually began with the question, "What is your experience with cancer?" Follow-up questions were contingent on the response to the first question. Interviews, which lasted from thirty minutes to ninety minutes, were recorded on a hand-held tape recorder and later transcribed. I formally interviewed twenty campers, five counselors, two parents who lost children to cancer, and three health care professionals. In addition, I had numerous informal discussions with children and adults throughout my tenure at Camp Anuenue. I also used focus groups with teenagers on three separate occasions when campers were asked to discuss their feelings about cancer pain (Rich 2001) and death and dying. Each focus group consisted of three campers, and the meetings took place over a one-hour period.

Cancer camps represent close-knit communities in which many of the counselors are survivors of childhood cancer. In addition, some of the counselors have lost children to this disease. A volunteer staff of counselors and health care professionals, many of whom return each year because they find the experience to be rewarding, run the camp. Bombeck's (1989) assertion that volunteers at cancer camp "are the first to admit this job rewards them in a way few jobs ever can" (p. 108) certainly rings true here. As an outsider, I felt it was important to establish a barterlike relationship. In his fieldwork with Hmong refugees, Conquergood (1988) explained, "One of the things that worked well for me as a health worker was to barter recommendations and health practices with traditional healers. This kept the program from being too one-sided" (p. 182).

In my case, I worked as a volunteer counselor and a drama specialist. This position required that I attend all camp activities, follow general camp rules, and reside in the cabin with a group of children or teenagers. My willingness to volunteer at camp over a five-year period and make additional visits to the pediatric oncology unit of the local hospital helped remove some of the barriers to open communication. In addition, I established interpersonal relationships with many of the campers and their families. Once I established the trust of community members, I found that many of the campers and adults had experiences that they

wanted to share with me. I also came to understand how the voices of young people with cancer must be added to the dialogue on death and dying.

## SOCIAL DRAMA

Before camp begins, a two-day orientation is held for volunteers. During orientation camp, leaders stress that Anuenue's mission is to provide a fun and safe environment for campers. Since many campers spend time in hospitals or under the protective watch of parents, camp is designed to create an atmosphere where young people can have a normal experience. Hence, volunteers are asked to treat campers like "regular" kids while recognizing that some children and teens may have limitations. Since the primary goal of camp is to provide a fun atmosphere, counselors are expected not to discuss or dwell on subjects such as death and dying. Unfortunately, at least one camper (usually more) will die during the year. Although many campers hear bad news by word of mouth, some children and teenagers do not learn of their friends' deaths until they arrive at camp. When this occurs, there is an undercurrent of pain and grief that stands in contrast to the mission of camp. In 1992, the discrepancy between camp mores and the campers' feelings of grief created a ripe environment for the enactment of a social drama.

Since all communities experience conflict, Turner and Bruner (1986) argued that social dramas are a "fact of everyone's experience in every day human society" (p. 65). When social dramas occur, they unfold in four observable stages: (1) breach, (2) crisis, (3) redress, and (4) reintegration or spatial separation (Schechner 1977, 1985, 1988; Turner 1985; Turner and Bruner 1986). Turner (1982) explained,

A social drama is initiated when the peaceful tenor of regular, norm governed social life is interrupted by the breach of a rule controlling one of its salient relationships. This leads swiftly or slowly to a state of crisis which, if not sealed off, may split the community into contending factions and coalitions. To prevent this, redressive means are taken by those who consider themselves or who are considered the most legitimate or authoritative representatives of the relevant community. . . . The next phase of social drama . . . involves alternative solutions for the problem.

The first is reconciliation of the conflicting parties . . . the second, consensual recognition of irremediable breach. (p. 92)

When campers arrived in 1992, they learned that two popular young people had died during the year. Since the deceased were adolescents, the deaths seemed to have the most profound impact on teenagers. Although some counselors felt the recent deaths should be discussed immediately, others believed that camp activities should go on as planned. Midweek, however, death-related issues came to the surface during a talent show.

Each year, a talent show is held at Anuenue. Usually, it is a night of upbeat songs, skits, and dance numbers. In contrast, during the 1992 talent show, two counselors decided to dedicate a song to one of the campers who had died. The song title was the name of one of the deceased campers.

In the middle of the song, there was a disturbance in the auditorium. I recorded the event in my field notes:

During the song, I heard muffled noises from around the room. At first, I thought it was some of the younger children laughing because it was a slow song. But then the sounds grew louder and I realized that some of the older kids were crying, wailing—crying like I've never heard before—deep moans and sobs. Suddenly, some campers stormed out crying. . . . The counselors chose to finish the song and the ACS director leaned over to me and said, "This was not the time or place for this." It set up a kind of camp controversy . . . because some people felt we shouldn't do this kind of stuff while others felt it needed to be done to release the emotions.

According to Turner's model, breach occurred when the counselors broke camp rules by singing an emotional song and dedicating it to deceased campers. The ACS director's comment, "this was not the time or place for this," indicates that the counselors performed an inappropriate act. The crisis stage was initiated when campers ran out of the room and could not immediately be located. In addition, factions were formed when counselors argued about whether the song should have been done at the talent show. Redressive means for the counselors took place later in the evening when an "emergency" meeting was held to provide an opportunity to vent feelings and discuss the talent show. It is interesting to note, however, that no redressive activity was undertaken

for campers until later in the week when a Memory Circle was scheduled to help the campers grieve. Campers were given as much time and space as they needed before rejoining activities. Particular attention was paid to younger children who may have been frightened when teenagers ran out of the talent show.

In response to the social drama, and in an attempt to contain expressions of grief to a specific time and location, a Memory Circle was used at camp. A Memory Circle is a performative ritual designed to foster communal grieving. To date, there have been no comprehensive studies conducted on the prevalence of grieving sessions at cancer camps. At Camp Anuenue, Memory Circles serve numerous, often contradictory functions. Designed to provide a safe space for campers and counselors to grieve, these rituals can be best understood as complex cultural performances.

## MEMORY CIRCLES

For the first time in nearly a week, there is silence at Camp Anuenue. All of the counselors and campers move in a procession from their cabins to a wooded area where a campfire is illuminating an otherwise dark sky. In the distance, the rhythmic sound of waves can be heard rolling onto the shore. Once the campers and counselors reach the campfire, they sit in a tight circle and wait for the director to speak. There is tension in the air as she slowly rises from the circle and begins to address the camp. Young children crawl into counselors' laps, and teenagers put their arms around one another.

"I'll start the circle by sharing my memories," she explains,

and after that, anyone who wants to share a memory is free to do so. After the last person has spoken, we'll walk down to the beach and drop the leis we have made into the ocean to symbolize the circle of life.

She also explains that Anuenue is Hawaiian for rainbow and that each child who dies becomes part of the rainbows that are seen during camp.

The director shares her memories, returns to the circle, and sits down. After a few moments of silence, a counselor who has lost his daughter to cancer stands and shares a poem he has written in her memory. While reading the poem, he becomes overcome by emotion and

struggles to finish the last few lines. Many campers and counselors begin to sob. Friends hold a teenager as she shares memories of a camper from the previous summer. A number of people choose to share stories, poems, and songs. Most of the memories occur spontaneously; a few have been prepared in advance for this occasion.

The previous paragraphs describe the 1992 Memory Circle. I believe that Memory Circles are representative of cultural performances, which many contemporary researchers have studied to gain a better appreciation of specific communities. Although broadly defined, cultural performances may include ritual, legends, myths, stories, narratives, and social dramas (Manning 1983; Speer 1986). For Turner and Bruner (1986),

Every type of cultural performance including ritual, ceremony, carnival, theatre and poetry, is explanation and explication of life itself. . . . Through the performance process itself, what is commonly sealed up or inaccessible to everyday observation and reasoning . . . is drawn forth. (p. 13)

Scholars are paying close attention to what cultural performances can reveal about a community. For example, in *The Celebration of Society: Perspectives on Contemporary Cultural Performance* (Manning 1983), contributors from a variety of disciplines examine community festivals, sporting events, masquerade shows, and carnival to learn “how cultural performances reflect, interpret, and influence their society” (Manning 1983, viii). Similarly, in *Text, Play, and Story: The Construction and Reconstruction of Self and Society* (Bruner 1984), researchers analyze kayak festivals, Puerto Rican sports, Christmas mumming, and other cultural performances. According to Bruner, cultural performances are “the community members’ representations and interpretations of their own experiences, a first-order interpretation” (p. 9). An analysis of Memory Circles can help illuminate the culture of Camp Anuenue.

Drawing on his fieldwork experiences, Turner (1985) has concluded that rituals “make visible specific structural aspects of the situation to which they refer, as, for example, the local or tribal hierarchy of authority” (p. 20). I believe that Memory Circles are ritualistic in nature. In my discussion of Memory Circles, I am using the term *ritual* to describe an event that has three characteristics: (1) rituals are liminal, (2) rituals

eliminate the space between performer and audience, and (3) rituals are goal directed.

Turner (1977) and Schechner (1985) explained that a ritual is a liminal event that creates

a state or process which is betwixt and between the normal, day to day cultural and social states and processes of getting and spending, preserving law and order. . . . It is a time of enchantment when anything might, even should, happen. (Turner 1977, 35)

Rituals create a liminal space in which participants are transformed to a new status or state of being. Hence, participation in rituals can result in an emotional, physical, or social change for participants. Memory Circles are ritual events that occur outside of normal day-to-day happenings at camp. In addition, Memory Circles take place in a sacred space delineated for remembering loved ones. It is not my intention to argue that Memory Circles necessarily result in permanent transformations. Rosaldo (1989) reminded us "rituals are often but points along a number of longer processual trajectories" (p. 20). Memory Circles do, however, create a space where transformations are possible.

A second component of ritual is the breakdown of the wall between audience and performer. That is, everyone who is present at a ritual participates at some level in the unfolding of events. Memory Circles create a space where campers and counselors share equal status. Everyone is encouraged to speak. This stands in contrast to traditional theatre where an imaginary fourth wall separates actors from spectators. The absence of a fourth wall in ritualistic performances fosters communal participation. Turner and Bruner (1986) explained,

The whole community goes through the entire ritual round, whether in terms of total or representative participation. . . . The whole ritual round adds up to the total participation of the whole community. Sooner or later, no one is exempt from ritual duty. (p. 31)

From 1992 through 1994, Memory Circles were obligatory for all campers and counselors. Conversely, in 1995 the Memory Circle was optional. I will consider the implications of this change later.

Third, rituals are goal-directed activities used to accomplish some objective. The primary reason a Memory Circle was used in 1992 was to help campers and counselors grieve the loss of loved ones. Often, grief

is experienced in isolation: "The end of public mourning only seems to make the bereavement process a more individualized, subjective, and private experience" (Dickinson, Leming, and Mermann 1993, 204). Like funerals, Memory Circles can provide an opportunity for communal mourning. Schechner (1977) explained that rituals should provide a "link to an absent other," help bring "the other here," and foster audience participation (p. 75).

Although it is possible to describe some basic components of ritual, it is more difficult to ascertain whether a ritual has been successful. Defining rituals as a success or failure creates a binary distinction and raises a number of questions, such as who is the ritual serving, who has the authority to define a ritual as successful, and what criteria should be used to determine the success of a ritual (Myerhoff 1992)? As a performance studies researcher, I am most interested in looking at ritual from a more theatrical perspective. Hence, I will discuss Memory Circles in regard to their ability to be persuasive. Myerhoff argued, "Above all rituals are dramas of persuasion. . . . [They] may be judged like any drama—they must be convincing. . . . The appearance of attention is essential, and everyone is in it together" (p. 156). Persuasive rituals foster a sense of "One People," participants "connect with those of their kind who have gone before and those who are yet to come" (p. 151). The ability of a ritual to be persuasive, to convince the audience that they are witnessing and participating in an important, collective drama, is the criterion I will use in assessing the Memory Circles at Camp Anuenue.

### **CHRONOLOGY OF MEMORY CIRCLES: 1992-96**

Although some campers were able to release feelings of grief during the 1992 talent show, the Memory Circle was still very emotional. Many campers and counselors elected to share memories and stories during this ritual. Parents used the Memory Circle to remember their children, while campers dedicated songs or poems to friends who had died. One young woman made a dedication to the children she could never have due to cancer treatment. I shared memories of my grandfather and close childhood friend, both of whom died from cancer. After the last memory was shared, everyone walked down to the beach and released leis into the ocean. Campers and counselors hugged, cried, and laughed. Everyone stayed on the beach for an extended period of time, watching the leis float out to sea and enjoying the feeling of unity and

heightened sense of belonging. There was an intense outpouring of emotions consistent with Smith's (1993) description of embodied grief:

When there is an understanding that someone is dead, the body responds with feelings. Our bodies are self-healing organisms. A look at the healing of a physical wound shows us how our body protects, cleanses, flushes, and rebuilds itself. . . . The cleansing and the flushing of our psychological wounds are accomplished through the expression of our feelings. Our bodies sweat, shake, become hot, cold, cry, yell, and sleep. It is a full-bodied experience. (p. 215)

The 1992 Memory Circle was a persuasive ritual. The entire camp participated in the ritual to some capacity, and it seemed to foster a heightened sense of belonging. Many campers and counselors were able to express feelings of intense pain in a safe environment, surrounded by people who understood what they were feeling. While the opening and closing of the Memory Circle were scripted, it was the stories from the participants that created the most dramatic aspects of the evening. It is the "open or improvised" components of a ritual, according to Myerhoff (1992), that create "a sense of accuracy and authenticity" (p. 132). The dramatic staging of the 1992 Memory Circle—outside, around a campfire with the invocation of the "children of the rainbow"—helped create a sacred space for the enactment of a ritual: "Ritual dramas must be fully staged, abounding in vocabulary and props to flesh them out, conceptually and sensually" (p. 133).

After the social drama of 1992, the Memory Circle was changed to reflect different goals. Instead of remembering deceased campers, the Memory Circle was used to share favorite moments from camp. This change was implemented because the director felt that the 1992 Memory Circle was too emotional. Campers who wanted to share memories of loved ones still could; however, everyone was encouraged to keep the Memory Circle lighter than it had been in the past. As Gray (2000) noted, "Rituals not only express feelings but mold them and tame them" (p. 9). I recorded my feelings after the 1993 Memory Circle:

This year's Memory Circle was more about giving a memory of the best thing that happened at camp. People talking about the happy things. Although people still cry because some emotional things come up, it was more of, I guess, a happy crying this year, whereas last year it was a real outpouring of emotions. What troubled me in some ways is that some of

the ACS people . . . said the teenagers had worked through this stuff already at the [teen] weekend. And I'm not sure about that. . . . It's really tough to know. But to say that these teens got it all out of their system a couple months ago, I would just, I would have to disagree with that.

Although the 1993 Memory Circle was held outside around a campfire, there was no mention of the "children of the rainbow." In addition, during the introduction to the Memory Circle, the director emphasized that the purpose was to share favorite memories from camp. By doing so, she framed the event as a place to share fond memories rather than narratives of grief. Hence, the campers were asked to share specific stories, stories that were in line with the camp's philosophy of having fun and skirting serious issues. According to Smith and Watson (1996), "Recitations of our personal narratives . . . are embedded in specific organizational settings and in the midst of specific institutional routines or operations. . . . Each location manages a specific piece of our lives and calls for specific kinds of personal recitations" (p. 10). In 1993, the institutional goals of Camp Anuenue dictated the kinds of narratives that were available to the campers during the Memory Circle.

In 1994, the Memory Circle placed even less emphasis on grieving. As goal-directed activities, the 1993 and 1994 circles were quite different from the 1992 circle. Although all three circles had obligatory attendance, the latter circles were designed to celebrate the best moments of camp. Furthermore, the performance behaviors changed during these Memory Circles. For example, only a selected group of volunteers placed a lei in the ocean in 1993 and 1994. Also, the image of the "children of the rainbow" was not invoked during the 1993 or 1994 Memory Circles. Although some campers became emotional in 1993 when they shared memories of deceased friends, by 1994 the participants no longer made any references to the deceased. In fact, in 1994 it would have been out of place for a camper or counselor to use the Memory Circle as a place to grieve. The ritual had been altered to focus entirely on happy moments from camp. In essence, there was no longer an opportunity for communal grieving to occur at camp. Still, the 1993 and 1994 Memory Circles were, in a sense, persuasive. The entire community participated in the circles, and many campers and counselors shared favorite moments from camp. In addition, the Memory Circles of 1993 and 1994 did present a convincing portrayal of camp life as a week devoid of sadness or grief. Rituals create the belief "that things are as they have been

portrayed—proper, true, inevitable, natural” (Myerhoff 1992, 129). If I had only visited camp in 1993 and 1994, I might not have recognized the extent to which campers experience grief.

Although some counselors expressed concern in 1993 and 1994 that the essence of Memory Circles had been lost, there was no unified dissenting voice until 1995, when a new director decided to cancel the Memory Circle. This individual felt it was unnecessary because the only campers who needed a Memory Circle (teenagers) were talking about death and dying at a camp-sponsored teen weekend. In an interview with Ikaika, one of the teens in my cabin, I asked him about opportunities to grieve at the teen weekend:

Marc: I heard that the teenagers had a chance to deal with these feelings [grief] at the teen weekend.

Ikaika: I didn't think we dealt with it at the teen weekend. It wasn't there either.

The director also argued that Memory Circles frightened younger campers. The director was ultimately persuaded to hold a Memory Circle so long as it was optional for campers and counselors and held at the beginning of the week so that the campers could “get the sad stuff out of the way.”

When the 1995 Memory Circle was held at the beginning of camp, there was a very low turnout among campers. One reason for the poor attendance could be that campers did not feel the need to grieve for loved ones in a formal, communal setting. Perhaps they chose to process their grief privately. Another possibility, however, is that the director planned a popular activity during the same time as the Memory Circle that attracted the vast majority of campers. Either way, the Memory Circle no longer had communal participation or obligatory attendance.

When new directors assumed leadership positions in 1996, they decided to reintroduce an obligatory Memory Circle. Modeled after the 1992 remembrance program, its function would be to help campers grieve. I am not sure why a grieving session was reimplemented. To my knowledge, campers and parents were not consulted during the decision-making process. The night the 1996 Memory Circle was scheduled, it rained. Hence, we were unable to go outside or start a campfire. Rather than postpone the grieving ritual, the directors decided to have it

inside. The 1996 Memory Circle helps illustrate how important a setting is for ritual.

“Ritual dramas,” argued Myerhoff (1992), “are elaborately staged . . . so that our senses are aroused and flood us with phenomenological proof of the symbolic reality which the ritual is portraying” (p. 161). When Memory Circles were held under the stars and around a campfire, a dramatic space was created for the enactment of a ritual. In addition, by holding the rituals in a designated space outside the normal confines of camp, the audience was made aware that something out of the ordinary was occurring. Finally, being seated in a large circle enabled everyone to see one another, limited the space between observers and participants, and increased the likelihood of communal participation. In 1996, we were in an enclosed, stuffy room with no sense of a sacred ritual space. The room, too small to accommodate all the participants and well lit, was on the campgrounds and frequently used for more mundane activities.

Perhaps it is not surprising that no campers or counselors shared memories during this event. There were a few moments of awkward silence, and then it was over. All of the campers and counselors immediately returned to their cabins. As Smith and Watson (1996) noted, “In specific situations, people may choose not to narrate the stories that are prescribed for them” (p. 13). Although all the Anuenue participants were present at the 1996 circle, there was no communal participation. It is fair to say that the 1996 circle was not a persuasive ritual. Myerhoff (1992) explained, “A ritual fails when it is seen through, not properly attended, or experienced as arbitrary invention” (p. 183). By designating a time and place for communal grieving but failing to consider the important dramatic tools necessary to implement a persuasive ritual, the directors were unable to create a Memory Circle that fostered communal participation. One might wonder if, perhaps, there was no need for campers to grieve in a communal setting. My subsequent interviews with campers following the 1996 circle, however, demonstrate that at least some of the children and teenagers were longing for a place to mourn.

Immediately following the 1996 circle, some male teenagers in my cabin remarked that they wished there would have been a “real Memory Circle.” I believed some of them had issues to work through because a teen from the previous year had died. I sat down with some of the campers in my cabin and asked what they thought about Memory Circles.

Ikaika, a sixteen-year-old who had just completed a bone marrow transplant, said, "I miss them [Memory Circles]. . . . I really need that. . . . I think they should still be a part of camp." Keoni, a camper who was a close friend with the teenager who died, explained, "They should really get into that [Memory Circles]. . . . It's really important. It's our bond here at camp." Makamae was at camp for the first time in 1996. He had been diagnosed with cancer in 1995 camp and had several close calls with death. Makamae believes that "it helps to talk about it. We probably should have a session or two to talk about our feelings. It's really therapeutic." The rest of the teenagers agreed that there should be time set aside to grieve. After consulting the other counselors in my cabin and the directors, the decision was made to hold a private Memory Circle for the male teenagers. Although it was suggested that a program be held for all the adolescents, the guys in my cabin said they would feel more comfortable if it was a private circle. We respected their wishes.

During the last night of camp in 1996, a private Memory Circle was held. We sat on the beach in a tight circle and watched the sun slowly set behind the mountains. We chose to hold the circle in a private area of the beach where other camp participants would not disturb us. In addition to the teenagers and counselors from our cabin, three other adults were in attendance. The teenagers asked that Marsi, an adult survivor of cancer and close friend to many of the guys, be invited. In addition, a pediatric nurse who was close to the boys and their parents was present. After consulting the teenagers, I also asked Irving, a veteran camp counselor and social worker, to attend. I felt it was important to have a trained professional at the Memory Circle. The teenagers respected Irving and knew he had lost a five-year-old daughter to cancer.

Although the teenagers had remained silent during the Memory Circle held inside, it was clear these young men had grief to work through in a safe, communal setting. The private circle helped create a sacred space in which grieving stories could be told and heard. Many of the teenagers wanted to remember the camper who had been in our cabin the year before. This death was particularly difficult for Keoni for a number of reasons. First, he had lost one of his best friends. In addition, Keoni had the same type of cancer (osteosarcoma) in the same leg as the young man who died. They went through treatment together and forged a close friendship. Jacob also had osteosarcoma. During the Memory Circle, Jacob explained that he was also close to the camper who died and never saw him again after camp. Many of the teenagers chose to

remember friends they had lost. Ikaika became very emotional when he remembered a pen pal who had recently died. One of the most touching moments occurred when Keoni spoke of Irving's daughter. Although Keoni never met her, he said that he could feel her presence and love through Irving. By the conclusion of the ritual, all of the participants had shared a memory, and everyone was in tears. This emotional grieving session helps substantiate Doka and Martin's (1998) claim that young men grieve in different, albeit not deficient ways.

The 1996 adolescent experience fostered a feeling of love and solidarity. We exchanged hugs and stayed on the beach long after the sun had set. The private teen circle of 1996 was a persuasive ritual in that it enabled campers and counselors to grieve in a communal setting. By framing the event as a time to remember loved ones, narratives became available to the participants that had been rendered obsolete since the 1992 Memory Circle. Furthermore, there was no wall between audience and performer. Instead, the ritual was cocreated by all who were present. Finally, the staging of the event—outside in a tight circle—helped foster disclosure and communal grieving. It is worth noting that all of the counselors who were present at the private Memory Circle, including the author, were chastised by the directors for taking too long at the grieving session and being late to the next camp activity.

From 1993 through 1996, there was no designated place for grieving at camp. In addition, the 1996 remembrance program had the full attendance of campers, but nobody chose to share their memories. During the programs of 1994 and 1995, campers were expected to share stories of a certain ilk—joyful moments from camp—and not dwell on serious subjects such as death and dying. "In telling their stories," Smith and Watson (1996) argued, "narrators take up models of identity that are culturally available. And by adopting ready-made narrative templates to structure experiential history, they take up culturally designated subjectivities" (p. 9).

In 1993 and 1994, only certain kinds of narratives were available for the participants at Memory Circles. The campers, by telling narratives about favorite moments from camp, took the role that was expected of them by the institution. Despite the fact that there were no opportunities for communal grieving at camp for a number of years, I learned that individual campers, and campers in small groups, did share grief narratives outside of institutionalized settings. Rosaldo (1989) reminded us

that “human beings mourn both in ritual settings and in the informal settings of everyday life” (pp. 13-14). Whereas Memory Circles generate immediate, emotional narratives, in one-on-one interviews and small focus groups the campers were more reflexive, and their responses illustrate that grief “is processed over time: a storied view of life proposes that human development is continual and that loss and grief are likewise processed over time and often across the life span” (O’Toole 1995, 28). A camper named Michael told me that he was comfortable with the thought of his own death but grieved a young man who “was like a brother” to him:

There was one friend in particular that really touched my life. He was a very funny guy and full of energy. He was somebody that could share my feelings of cancer with and would actually understand. . . . One day he got really sick, his cancer had relapsed and the doctor could not do anything. He passed away in his mother’s arms in the bedroom. . . . I was so hurt inside because he was so close to me like a brother. . . . I think about him all the time and it still hurts. But I know that he will always be in my thoughts and I will meet him again someday.

I have never spoken with a camper who has not lost a friend to cancer. At times, the pain associated with losing friends can be overwhelming. Ikaika explains, “There was one little boy. His half sister matched him perfectly and he went in to his transplant. And he went back to school . . . and to find out he just got sick . . . that he died. That hit me hard.” During his time as a camper, Keoni has seen a number of young people die: “Seeing other guys die, that was the hardest part. They suffered through everything, all the treatment.” Kris, an adult survivor of cancer, explains how difficult it is to lose friends: “Although I accept the thought of my own demise, the death of friends, and the young campers of Camp Anuenue is still painful. . . . The death of a classmate at a school was the most painful memory for me.” Makamae, only sixteen, said,

It’s just really sad to see these kids that are so much younger than you and there’s so much they can look forward to and they just pass away. You know, it’s hard to deal with, especially if you know them.

William explains how he felt when one of his fellow campers died:

When I was first diagnosed I heard that he had died. My second chemo treatment. That's difficult. I'd walk in the hall and all of the nurses and doctors are running to his room. I was like, oh, what's going on? I went back to my room to stay with my mom. One of the nurses came in said oh, he passed away. And I just didn't know how to react to it. I still don't know how to react to it.

Of the five summers I conducted research at Camp Anuenue, three were spent rooming with the teenagers. I watched some of the guys in my cabin become increasingly sicker and ultimately die. Fortunately, some of the teens, such as Jacob and Keoni, got stronger and healthier each year. Both young men are remembering a close friend, and one of our cabin mates, in the following statements:

Jacob: Everybody's close and like last year he was just like so funny in his wheelchair and stuff, and I, I didn't get to see him after camp. I never saw him again.

Keoni: That was like the hardest one for me. 'Cause the way we met, me and him had the exact same thing in the same leg and we just clicked like that and from then on we were like tight and we were getting closer and closer. And [he] just couldn't take it anymore and the treatments were getting too hard and his lungs were just dying. And I guess after you get that tight bond, it's just hard to let go.

Whether or not remembrance programs are used at cancer camps and designed as the place to grieve, young people will find other outlets to process their feelings and speak about death-related issues. Smith and Watson (1996) explained, "Even if the story remains unspeakable in the larger community, narrators can find ways to convey the unspeakable to a community of secret knowers" (p. 15). Hence, directors are mistaken if they believe that canceling Memory Circles will ensure a camping experience that is void of grieving. As with the 1992 social drama, failing to provide a space for communal grieving can have dramatic implications for the campers and staff. From my own interviews, it appears that many of the campers would like to have some type of remembrance program. There are, however, significant issues that directors consider when they decide whether to hold a remembrance program. I consider these issues in the final section of this article.

## PHILOSOPHICAL AND ETHICAL CONSIDERATIONS

Why are directors hesitant to include remembrance programs at camp? Furthermore, why would the subject of death be marginalized at a cancer camp? My preliminary research, supported by Spirito et al. (1992), suggests that campers would like an opportunity to process grief in a communal setting. Camp directors may elect not to have remembrance programs for three primary reasons. First, they may feel that it is necessary to shield young people from issues related to death and dying. Second, camp leaders may believe that remembrance programs foster feelings of grief, an emotion that is incongruent with camp philosophy. Third, directors may assume that young people with cancer are frightened by the notion of death.

In the not-so-distant past, health care professionals believed that young people should not be given information about serious illnesses such as cancer (Slavin 1981). Unfortunately, hiding information from children and teenagers can have negative consequences. Young people know when they are seriously ill. Hence, when information is hidden from them, they may create terrible scenarios in their minds or feel that they are to blame for their illnesses. Although it is much more common for young people to be informed of their diagnoses today, there is still a prevailing attitude that young people need to be shielded from death-related issues.

Even in books supposedly written for young people with cancer, such as *What Happened to You, Happened to Me*, a booklet distributed by the ACS (1984), the subject of death is usually glossed over or totally ignored. Although this book includes some isolated negative experiences, the overwhelming majority of teenagers treat cancer as a nuisance that will go away. For example, the following statements conclude the narratives in the "How I Felt in the Beginning" section: "I'm now just fine!" "Now I'm off drugs and doing great!" and "I knew I would be better soon." These statements are consistent with what Frank (1995) called the restitution narrative: "The plot of the restitution has the basic storyline; 'Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again' " (p. 77). This book fails to account for teenagers who feel terrible or have to face death.

When a young person loses her or his hair, has chronic fevers or stomach problems, and spends numerous days in the hospital, she or he

recognizes that something is seriously wrong. In fact, a number of campers I interviewed told me they knew they had cancer even before diagnosis. For example, Michael stated, "I already knew I had cancer and wasn't surprised at all." Chris, who began experiencing intense headaches and vomiting as a result of a brain tumor, told me,

I remember that the doctor left and I remember hearing my parents start walking down the stairs and dreading every step because I knew what they were going to say. I think that there is a lot to say about human intuition and I think our kind of science-oriented culture really has pushed that away. But I think you just really know when something is wrong. And we kind of want to deny it.

Kübler-Ross (1983) explained, "All children know (not consciously, but intuitively) about the outcome of their illness. All little ones are aware (not on an intellectual, but on a spiritual level) if they are close to death" (p. 1). In a study of spontaneous drawings by dying children, Bach (1999) found that their pictures sometimes indicated the growth of disease prior to diagnosis or symptoms. If directors choose not to hold grieving sessions in an attempt to shield children from thoughts about death and dying, they may be making an assumption that is incongruent with the experiences of young people and contemporary research.

A second reason directors may choose not to hold a grieving session is because they are incongruent with camp philosophy. For example, if a director believes that cancer camps should provide a respite from the world of cancer and provide campers an opportunity to feel like "normal kids," then a Memory Circle is viewed as a reminder of cancer and death. Maher (1995) challenged this philosophical stance:

Given the traumatic demands of living with cancer, I find it surprising that some camp philosophies insist that these children be treated as "normal" all of the time. . . . It would seem better to view them as normal children with special needs. (p. 105)

Perhaps some directors feel that discussing death and dying may threaten the upbeat atmosphere of camp. This way of thinking is definitely prevalent in Western culture. Aries (1993) noted that there exists a "moral duty and social obligation to contribute to the collective happiness by avoiding any cause for sadness or boredom, by appearing to be

always happy, even if in the depths of despair” (p. 12). Perhaps there is no more taboo topic in Western culture than childhood death (Benson 1988). Many adults find it difficult to speak openly about death and dying with young people. In addition, when a young person dies, most adults consider it a tragedy. Dickinson, Leming, and Mermann (1993) explained,

Adapting to the death of a loved one is always difficult. The death of a child, however, is typically regarded as the most difficult of all deaths. The death of a child violates what most believe is the natural order—parents are supposed to die before their children. (p. 204)

Camp directors and counselors who are uncomfortable speaking about death and dying may try to ensure that these subjects are not discussed at camp. As I explained earlier, however, young people will find places to grieve outside of institutionalized settings. It is not an easy task to speak with young people about dying. Some adults who run cancer camps may avoid the subject of death because it provides them with an opportunity to have control over childhood cancer. Because cancer is such a random disease, adults often feel powerless during diagnosis and treatment. When a young person with cancer dies, adults have no control.

The third and perhaps most compelling reason not to hold remembrance programs is the widely held belief that young people with cancer are scared of death and dying. As one counselor stated, “I do not feel that camp is a proper forum to discuss this very difficult issue, the ultimate fear.” There is evidence to suggest, however, that campers may be comfortable with the thought of death. In his 1999 study of bereaved children for example, Howell learned that children who experience a loss are more aware of death but do not have greater danger concern or defensiveness. Although many adults believe that campers are terrified of the subject, I have found that members of this population speak freely about death and dying. In their study of remembrance programs at cancer camps, Spirito et al. (1992) concluded, “Some staff members may need help in overcoming the tendency to attribute to campers what could be their own uneasiness or even fear of discussions and reminders of death” (p. 111). Adults may be uncomfortable discussing issues related to death and dying because such issues force them to confront their own mortality. Furthermore, if the adults are parents, discussing

childhood death could force them to consider the mortality of their own children.

For a number of years, researchers have claimed that young people live in constant fear of death. Koocher and O'Malley's (1981) *The Damocles Syndrome: Psychosocial Consequences of Surviving Childhood Cancer* is consistent with studies that represent this position. Damocles Syndrome is used in reference to Cicero's story about a man who tries to enjoy a large feast while a huge sword is suspended over his head by a single horsehair. Koocher and O'Malley explained that young people with cancer experience this syndrome because they live in constant fear of relapse or death. The Damocles Syndrome label became a lens through which other researchers viewed young persons with cancer. For example, according to Van Dongen-Melman and Sanders-Woudstra (1986), "As remission lengthens, there tends to be a continued movement towards health and life. However, this change is accomplished within the shaky context of ever-present doom" (p. 149). The Damocles Syndrome label used to describe young people with cancer is problematic for a number of reasons. First, studies conducted in the past focused on individuals who were almost certain to die. Therefore, it seems logical that a person with a nominal chance of survival would be preoccupied with thoughts of death. Second, there were fewer treatment facilities for young people twenty years ago. Hence, most young people were treated in adult facilities and isolated from children and teenagers. Third, since survival rates were so low for this population, some children and teenagers received experimental, often painful, treatments. Invasive treatments were often worse than the cancer itself. Hence, it is not surprising that young people lived in fear.

Unfortunately, contemporary researchers still argue that a diagnosis of cancer is a death sentence. Allan and Hall (1993) claimed, "For most cancers, treatment just postpones the inevitable from the disease. Even those cancers that respond the best to chemotherapy and radiation . . . usually return to kill the patient unless something else intervenes to cause death first" (p. 74). This mentality stands in contrast to the feelings of many young people with cancer, including Jason Gae (1987), author of *My Book for Kids with Cansur*. As a six-year-old, Jason was diagnosed with Burkitt's lymphoma, a very rare cancer where tumors double in size every 48 hours. While receiving heavy doses of chemotherapy and radiation, Jason wrote an unedited book about his experi-

ences. Jason stated, "The reason I wanted to write a book about having cancer is because every book I read about kids with cancer they always die. I want to tell you kids don't always die" (p. 12). Today, approximately 70 percent of young people with cancer will be long-term survivors. Even though survival rates continue to rise, people's perceptions about childhood cancer and death are slow to change.

When I asked campers how they felt about death and dying, I found that their responses stood in contrast to published texts and contradicted the opinions of "experts." In his discussion of sociology and ethnographic fieldwork, Karp (1999) noted, "At its best, qualitative sociology often subverts the status quo by challenging mythologies about the way that disenfranchised groups organize their worlds" (p. 601). LeCompte (1993) has suggested, "Researchers seek out the silenced because their perspectives often are counter-hegemonic. Their voices serve to critique the canon of existing social structure, relationships of production, aesthetics, and even scientific theories" (p. 10). In interviews with campers, I learned that their relationship to death and dying was far more complex than anything I had read prior to fieldwork. In discussions with children and teenagers, I came to see that their responses to my questions about death, dying, and fear clustered around three primary themes: (1) the presence of fear at diagnosis, (2) non-debilitating fear, and (3) lack of fear. It is my hope that the campers' responses to these issues may help directors make an informed decision about Memory Circles and help to deconstruct the victor-victim binary so prevalent in cancer research (Park-Fuller 1995).

## FEAR AT DIAGNOSIS

Many interviewees told me that they were fearful of death when they were first diagnosed. William notes, "When I was first diagnosed, I thought I was going to die. There was no way I could be cured. The percentage of living was only like a 29 percent chance of living." Waipiolani explains, "When I was first diagnosed I did think I was going to die." After Chris was diagnosed with brain cancer, he had to choose between chemotherapy, radiation, or surgery. Although the surgery, if successful, offered him the best chance for survival, he was forced to face his own mortality because of the precarious position of the tumor:

I went in for the surgery and that was terrifying. I mean, everything else was this kind of day-to-day dread, but the surgery was this terrifying, traumatic one time, you know, it wasn't drawn out, it was coming and it was just bam, there, and it just scared the living shit out of me. I honestly didn't know whether I was ever going to wake up again.

After Keoni was diagnosed with osteosarcoma, a cancer that can spread to vital organs, he faced death for the first time. According to Keoni,

Just having cancer just woke me up because, you know, it could happen to anybody anytime. Death can just come like out of the blue. You might not even expect it. When I first got diagnosed, that's what really spooked me out. I just had this thing in my mind that I was gonna die.

### **NONDEBILITATING FEAR**

After initial diagnosis, some of the campers still feared death. However, the fear was not necessarily overwhelming or debilitating. Although the children and teenagers recognized that they could die, they found ways to manage their fear. Keoni explains,

As treatment went on and I started to understand more and it just gives you like a whole new perspective on life and that you just see how everybody else just deals with it and I mean, just being diagnosed I think that was a scary part about death. . . . But then as treatment went on, you get to understanding and you kinda get to understand how it goes and how to deal with it and you get stronger in the mind and body.

Makamae, who experienced fevers of 106 degrees and strokelike symptoms, spoke about death in a matter-of-fact tone:

It has probably made me think about it more because I've come so close to death like many times during the past year. And, actually, you know, it hasn't, I'm still scared of it and all, but you know it just goes to show you that, you know, anything can happen. It helps to keep a positive outlook even though you know you might be really close to dying. Just a positive attitude because I made it through and I was really close a lot of times.

Ikaika was diagnosed with cancer at thirteen. After relapsing, he underwent a bone marrow transplant, a brutal procedure with a less than 50 percent survival rate. At the time of the interview, Ikaika was quite

weakened by the transplant. Because bone marrow transplants are used as a final, dramatic attempt to cure cancer, Ikaika knew that his life was hanging in the balance. According to Ikaika,

The question of death was always there. You cry yourself to sleep some nights wondering am I going to die or not. But you know you have enough mental and physical power to get through it and I think that is what drives you on knowing that you can get through it.

Although Jacob was in remission during our interview, when I first met him he was in the middle of intense treatment. At that time, his physicians were unsure of his chances for long-term survival. Jacob listens carefully to Ikaika's answer and adds,

I knew there was a risk of dying, but the way things were going I knew that I wouldn't. I felt strong enough that I could fight it . . . so I didn't really worry about it 'cause I kinda figured that I was strong enough to pull through. . . . It didn't scare me big time.

The campers I have interviewed have been surprisingly open and comfortable discussing issues related to death and dying. It appears that having childhood cancer may actually make some of the campers at Anuenue more comfortable with a topic that is taboo in Western culture.

### **LACK OF FEAR**

Considering the Damocles Syndrome label often applied to young people with cancer, perhaps the most enlightening responses to death and dying came from campers who appear to have little or no fear of death. In fact, having cancer and facing the possibility of death actually reduced their fears. Joshua, diagnosed with brain cancer at thirteen, said, "I had a fear of dying before I got cancer, but now I am not afraid to die." According to Michael, "Having cancer has changed my views about death. I realize that death is not something horrible but just another chapter in one's life." Kris, an adult survivor of childhood cancer, explains that she can accept the thought of dying but realizes that others are uneasy talking about this subject:

From this experience [cancer] I learned that I am comfortable with the thought of my own death; however, this is a topic I am not able to discuss

with many people . . . due to their discomfort. . . . I wouldn't even try to discuss [it] with members of my family.

Harris, diagnosed with leukemia at eight years old, made a statement that seems particularly interesting in light of Koocher and O'Malley's (1981) study: "I don't remember ever thinking I was going to die."

One of the most interesting interviews I conducted at Camp Anuenue was with Marsi, a survivor of leukemia. Although Marsi has a tough exterior, I came to see her as a caring and sensitive individual. When Marsi's cancer was resistant to treatment, her physicians decided she needed a bone marrow transplant. During this process, the patient's immune system is also destroyed, and survival is dependent on the successful transplant of a donor's (or his or her own) bone marrow. Marsi became so ill during this procedure that her body began shutting down, and death seemed imminent. Lying in the hospital bed, oblivious to the outside world, Marsi had a near-death experience (NDE):

Marsi: I just went, all of a sudden, I ended up in a big grassy meadow. It was really bright white. It was like flowers everywhere. There was singing. It was so peaceful. That's the most I can say. It was so peaceful because it was more than just what it looked like. It was just the feeling. It was really peaceful. It was so calm. It was like I didn't want to go back. I felt really warm. Just like there was sun but there was no sun. It was just white. Bright white. And it had a tree on the left, I know that. And I went and I stood by that tree. But now I'm getting too involved [Marsi begins to cry]. But I swear I stood by that tree and I was just like I can do this. And there was singing. Choruses, chorus like singing. I remember saying I want to stay. I remember a voice telling me no you can't stay.

Marc: Do you remember what the voice was that said that?

Marsi: It was a guy. I believe it was God. I really believe because I kept saying I want to stay. "No, you have to go back." That's when I kind of sort of, I guess, came back because then the next thing I know my dad is trying to wake me up. Going "Marsi, Marsi." And I'm like, "What?" You know, I wake up and he is like, "What are you doing? What song is that?" And I'm like, "What song?" I didn't even know I was singing it.

Marc: So, in the hospital bed you were singing the same song that you were hearing?

Marsi: Mmm hmm, probably. But it was, but I didn't even know I was singing anything. I didn't know. That's all I remember. The next thing I know

my dad is waking me up telling me what are you singing? So he was tripping out.

Marc: So at that point you think that you were ready to die?

Marsi: Oh, yeah. 'Cause I kept . . . saying, God, I'm ready. I can't take this anymore. I can't take this pain. It just hurts too much. I wanna go. . . . I was right there knocking on the door going let me in.

Marsi's out-of-body experience is not uncommon for persons on the brink of death. In fact, a 1982 Gallup poll found that eight million Americans have had an NDE. With Raymond Moody's (1976) publication of *Life After Life*, NDEs became the focus of much attention. In 1979, the International Association for Near Death Studies was created for the purposes of studying NDEs (Dougherty 1993). In recent years, a number of articles and books have been devoted to the study of NDEs. NDEs are defined as

the transcendent or mystical-type experiences that occur among many people who have come close to death or have ever suffered an apparent clinical death during a severe illness or accident, but who then recover, are resuscitated, or escape serious injury. (Stevenson, Cook, and McClean-Rice 1993, 87)

Researchers have learned that persons who experience NDEs usually develop a positive attitude toward death and dying (Dougherty 1993). Marsi's NDE has had a profound impact on the way she views life and death. In fact, she told me that she would forgo further cancer treatment if she were to relapse:

If it did come back, I would just say no [to treatment]. I had enough. I'm not gonna do this again. It was a onetime deal and stuff. . . . That's just too hard to take for a couple months longer. I'd rather die with my hair on.

Although most campers I interviewed were never clinically dead, almost all of them contemplated death because of cancer, and many of them were near death at some point of their treatments. These "brushes with death" appear to give some campers a healthy attitude toward dying.

## CONCLUSIONS

Historically, individuals who hold leadership positions have shaped Memory Circles at Camp Anuenue. Since these positions are filled every two years, there is little consistency regarding how death and dying are treated at camp. Furthermore, because camp is positioned as a place to have fun and not focus on anything negative, only certain types of narratives are available to campers in communal settings. As Smith and Watson (1996) noted, "When we interact with . . . institutions we engage their already provided narratives" (p. 11). My own research indicates that campers would prefer to have some venue in which they could talk about friends who have died. Many campers value a formal Memory Circle because it allows them to work through grief together. Future studies might consider the use of remembrance programs at cancer camps on a national or international level.

By examining the evolution of Memory Circles at Camp Anuenue, it becomes possible to conceptualize how grieving occurs in communal settings as well as in less institutionalized everyday communications. In 1992, after the enactment of a social drama and an emotional Memory Circle, directors altered the Memory Circle to reflect new goals. Instead of remembering deceased campers, the Memory Circles were used to share memories from the week. These circles proved to be less emotional than the 1992 ritual. In 1996, after a Memory Circle failed to be persuasive, the male teenagers held a private circle to grieve loved ones. Whether or not remembrance programs are used, young people will experience and talk about grief in informal, less structured settings. Although cancer camps do provide an excellent opportunity for children and teens to enjoy "normal" summer camp experiences, it is not possible for campers to ignore feelings of grief or forget that they constitute a unique community. If cancer camps as institutions do not allow grief narratives to be shared, it is possible that events such as the 1992 social drama will continue to occur.

In the future, researchers will need to consider whether young people with cancer are fearful of death and dying. In this preliminary study, the evidence suggests that children and teenagers who experience cancer have a healthy attitude toward these subjects. What is missing from this study, however, are interviews from young people who are in the later stages of cancer. This is a population that needs to be heard. Unfortunately, dying from cancer is often equated with a slow, painful death. Hence, the individual fighting cancer is reduced to a victim in the

literature. Park-Fuller (1995) was correct when she asserted that “to be a victim is to suffer, to die. There’s nothing active about it. Certainly there is nothing to ‘tell’ ” (p. 62).

I have discovered that there are stories to share about young people who have taken an active role in their lives and deaths. For example, one teenager who relapsed after a number of cancer-free years decided not to undergo further treatment. Instead, she lived every day to the fullest and even planned her own funeral. She got the last laugh when “Another One Bites the Dust” was played during her funeral! One counselor shared a narrative with me about the last few days of his daughter’s life. When his daughter, who was thirteen, realized she was not going to recover, she asked to leave the hospital and die at home. The girl’s physician explained that he could be summoned at any time to perform a life-saving procedure. She replied, “I don’t want any of that. If I go bad, just let me go.” Although this counselor was informed his daughter would live for only twenty-four to forty-eight hours, she survived for two weeks surrounded by loved ones. Rather than dying in a hospital full of tubes and painkillers, she made the decision to control when and how she would die. Ultimately, she slipped into a coma and died at home in her own bed and on her own terms.

Stories that are particularly poignant to me involve campers who gain control of their deaths during the last days or hours of life. After enduring months of painful and invasive treatments, some children and teenagers decide that they are ready to die. Often, they make this decision despite an attempt by adults to prolong the inevitable. Whittam (1993) explained why some physicians continue treatment in the face of certain death:

Unfortunately, even in the end stages of life, the motivation of some health care professionals continues to be investigation, diagnosis, prolonging life, and cure. This is due, in part, to the death denying aspects of our society and the view that death is avoidable. (p. 3450)

I am convinced that young people with cancer have much to teach us about dying and living. Watching a child or teenager who is near death enjoying swimming, hiking, or laughing with a friend speaks volumes about how to live one’s life. The memories of campers who have died have been present in my body while writing this article. Every paragraph, each word, brings back vivid memories. I am reminded of

Conquergood's (1991) assertion that "ethnography is an embodied practice: it is an intensely sensuous way of knowing" (p. 181). These memories, however, are not of poor, suffering children. I do not recollect ever meeting a victim at Camp Anuenue. Instead, I remember a camper in a wheelchair playing basketball with his friends. I see a young boy's smiling face covered with ice cream. I recall an adolescent girl dancing the hula. I believe that similar images are forever ingrained in the minds of adults who are fortunate enough to work with this population.

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