

**Creating a Social Work Link to the Burn Community:  
A Research Team Goes to Burn Camp**

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### Abstract

Social work faculty and graduate students conducted focus groups with 52 burn-injured adolescents from three burn camps to explore perceptions of their camp experience. Three themes emerged from data analysis that suggest burn camps play an important role in participants' lives. Camp is a place where burn-injured adolescents: (1) feel "normal" and accepted; (2) acquire insight in regard to self and meaning in life; and (3) gain confidence, increase self-esteem, and develop empathy. This project highlights how the use of qualitative research methods with grassroots organizations such as burn camps can serve as a link to greater social work involvement with this community.

## Creating a Social Work Link to the Burn Community:

### A Research Team Goes to Burn Camp

The journey of recovery for burn-injured children is fraught with hurdles and challenges that would daunt the hardiest adult. Approximately one million children suffer burns each year, with 40% having injuries that require hospitalization (American Academy of Pediatrics, 2000). Additionally, 3% of all burn-injured children are affected by massive burns, defined as burns involving more than 70% of the body surface depth (American Academy of Pediatrics, 2000). The process of recovery often involves lengthy and multiple hospitalizations, severe physical pain and discomfort, and for many, the possibility of lifelong scarring and subsequent impairment. The families of burn-injured children simultaneously struggle with issues such as guilt, shame, anger and the competing demands of family life, in addition to massive financial burdens. Although there are charitable organizations that support the physical recovery needs of severely burn-injured children, these children and their families are often on their own when it comes to navigating through the harsh reality of returning to schools, neighborhoods, and communities. They are also on their own in coping with the emotional recovery process, a process that includes dealing with the impact of being physically altered.

One of the inevitable and distressing outcomes for survivors of deep thermal injuries is scarring of the body. The severity of a thermal injury is determined by the percentage of total body surface area burned (TBSA), depth of the burn, and the amount of time the skin was exposed to the burning agent (Patterson, Everett, Bombardier, Questad, Lee, & Marvin, 1993). Technological advances in medicine have insured that children spend a shorter time in the hospital, and thus the bulk of the recovery process occurs once they return to the home and community where they are forced to cope with the physical discomforts inherent in this process. However formidable this physical process is, the emotional pain is even greater (Williams, Davey, & Klock, in press) as survivors are subjected to curious stares and insensitive comments from friends, neighbors, and strangers. Children are especially vulnerable, given their exposure to the uncensored reactions of peers. Moreover, family members must struggle with their own reactions and stresses as they

attempt to support the survivor. Because of these circumstances, the burn-injured population is a particularly compelling one for social workers. Surprisingly, however, there is little evidence in the burn-injury literature of the social work profession's involvement with this particular population, specifically in after-care, despite the extraordinary needs of these vulnerable children and their families.

Aware of the difficult road to recovery that burn survivors face, researchers have explored factors that positively affect the recovery process. "Hope," a beneficial psychosocial outcome, seen as inter-related with social supports, is reported to be a powerful antidote among children who have received psychological as well as physical scars as a result of a burn injury (Barnum, Snyder, Rapoff, Mani, , & Thompson, 1998). Social support, defined as the care, support, and acceptance of others, has been cited as a strong predictor of emotional adjustment in children who have survived burn injuries (Barnum, Snyder, Rapoff, Mani, & Thompson, 1998; Blakeney & Robert, 1998; Holaday & McPhearson, 1997). Additionally, social support has been linked to a positive body image, greater self-esteem, and less depression in the burn-injured population (Orr, Reznikoff, & Smith, 1989). In fact, social support has been deemed critical to overall adjustment (Pruzinski & Doctor, 1994) as indicated in a recent study (Sheridan, 2000) of long-term outcomes of children treated for massive burns. Sheridan found that the quality of life of burn survivors was no different from that of other young people.

Among the programs that specifically address the isolation and emotional aftermath that burn-injured children face, are specialized camps run by burn foundations, hospitals, and other fire-related service professionals.

These camps have emerged over the past 20 years to meet the needs of burn-injured children in a safe, normalizing, and activity-focused environment. Over 40 camps exist in the USA today, with more in Canada, Europe, Australia, and New Zealand. Reputedly, the burn camp concept was initiated in response to the limited psychosocial care given to burn-injured children in rural areas. The primary goal of the first burn camps was, "to provide a therapeutic milieu away from the hospital environment where staff and patients could join together in fun and confidence-building activities that are geared toward facilitating a

higher level of adaptation” (Doctor, 1992b, p. 71). While burn camps presumably share the objective of creating a positive experience for children, they have different philosophies regarding how to achieve that goal (Doctor, 1992a). Camps with a rehabilitative focus (on positive psychosocial adjustment) provide children with an opportunity to “directly and symbolically address the issue of being burned and to deal with the consequences” (p. 72), whereas camps with a recreational focus offer children a reprieve from the ever-present realities of their burn injuries. Despite these two very different philosophies, with the former seemingly more compatible with social work theory and practice, Doctor (1992a) acknowledges that there is “no statistically proven ‘right’ or ‘only’ way to approach a camp program” (p. 72). In fact, there is no research that explores the impact of either approach.

For many of the camps, dedicated volunteers, such as firefighters and other fire-related personnel, raise funds so that children can attend free of charge. Firefighters often play a critical role in the development and implementation of the camps, some of which are run by state firefighter organizations. Regardless of the governing philosophy, camps for burn-injured children offer an opportunity to develop supportive relationships with adults who are comfortable with burn injuries. Because many of the adults are burn survivors themselves, they are uniquely positioned to provide supportive and role modeling opportunities for children. A culture of acceptance and support is encouraged among the campers and is demonstrated in the ways older campers influence and assist younger ones. It is little wonder that the metaphor, “we are family,” is a refrain at many of the camps, and that camp is viewed as an important, enduring source of social support. Given that burn camps are a haven of acceptance, it comes as no surprise that the return rate among campers is very high. Children often return to camp on an annual basis for years after their initial injury, even into adulthood.

Although there is anecdotal evidence that these camps are successful, the ethic of today’s workplace requires professional accountability through empirical documentation of success. Currently there exists only one study (Biggs, Heinrich, Jekel, & Cuono, 1997) in this regard, and it explores the short-term impact of a burn camp on the self-esteem of campers. Burn camps operate in a climate of limited resources, as do many charitable organizations and groups, which explains why funds are more

likely to be allocated to program development and implementation than to evaluation. The purpose of this evaluative study is to explore the impact of the burn camp experience on the campers themselves, most of whom are return campers. It is also intended to be an initial step in the establishment of an ongoing, collaborative relationship between the burn camp community and professional social workers.

### Methods

A qualitative design facilitates understanding of an experience or phenomenon from the perspectives of the individuals who have “lived” it. Participants’ words, rather than numbers, constitute the data in a qualitative study and are used to convey meaning. This study employed a descriptive qualitative design to explore the perceptions of burn-injured adolescents in regard to their experiences at burn camp. A secondary purpose of the study was to understand “what is it?” about the burn camp experience that attracts repeat campers. Approval for the conduct of this research was obtained from the appropriate human subjects review boards.

### *Sample*

Three burn camps were investigated in different geographical sections of the USA, from the Southeast to the West. They reflected both foci in underlying camp philosophy: psychosocial and recreational. While actual camp activities are similar, differences between the camps are most evident in the training and educational backgrounds of the volunteers and staff. The following are brief descriptions of the participating camps:

*Camp #1.* The first camp, located in a Southeastern state, is staffed completely by volunteers and is open to any child in the state who has suffered a severe burn and who has spent at least four days in either of the state’s two burn units. It was established in 1992 by a grassroots, non-profit, statewide organization comprised of firefighters who work year-round to raise money to fund the camp. As such, there are no specific cited goals and objectives other than the implicit goal of wanting to bring burn-injured children together for a week of fun. The firefighters, on a volunteer basis, also organize and facilitate camp activities. In its 10-year history, the camp has grown to serve over 100 children annually and is staffed by approximately 150 volunteers. Most of the volunteers, including the cabin counselors,

are connected with the fire service. Since 2000, volunteers have included social work students or recent graduates because of a service-learning course that is offered through the School of Social Work at the state university (Williams, King & Koob, 2001; Williams & Reeves, 2002). Training is comprised of a one-day orientation for new volunteers, and one and a half-day session for all volunteers and staff prior to the campers' arrival.

As reported in Table One, 19 campers from Camp #1 participated in a focus group for this study. Of these, 5 were female and 14 were male, and their ages ranged from 13 to 20 years of age. Almost 70% (13 campers) of the focus group participants identified as Caucasian and over 20% (4 campers) as African American. Age at burn injury varied from 1 to 18, with a mean of almost 7 years ( $M = 6.63$ ,  $SD = 5.47$ ). In addition, the participants had been attending burn camp for an average of almost six years ( $M = 5.94$ ,  $SD = 2.69$ ).

*Camp #2.* The second burn camp, located in the West, is one of the nation's first weeklong, summer camps (established in 1983), and is affiliated with a major children's hospital. The winter camp program is a mid-year complement to the summer program and, like the summer camp, their mission is "to provide a personal growth experience for kids who have had burn injuries, and for them to have a really great time doing it." Although funded primarily by individual and corporate donations, campers are charged a small fee (with financial assistance provided as needed). Unlike the summer camp, which hosts approximately 65 campers ages 8 to 18, the winter camp is limited to approximately 20 adolescents, ages 13 to 19, and is comprised of campers from all over the country. The overwhelming majority of the campers are male, as is the case with the other two camps in this study. Although this camp requires an extensive application process, there are no clearly defined eligibility requirements other than having experienced a burn severe enough to require hospitalization. In contrast to the other camps, most of the staff are paid, mostly professional social workers or professionals from other disciplines, and are selected through an extensive interview process. A few firefighters are selected as well. There were 16 campers from Camp #2 who volunteered to participate in a focus group, an overwhelming majority of whom were male (81%). Campers ranged in age from 13 to 19 years, and almost all (93.8%) identified themselves as

Caucasian. The age at which the participating campers were burned ranged from the age of 1 to 14, with an average of almost 9 years old ( $M = 8.56$ ,  $SD = 4.27$ ). Years of attendance at burn camp varied considerably, ranging from one to nine years ( $M = 4.63$ ,  $SD = 2.92$ ).

*Camp #3.* The third camp is funded and run by a non-profit burn foundation in a Pacific coast state. Their stated goal is to provide a supportive atmosphere in which a burn-injured child can feel at ease and have fun. The summer burn camp is staffed primarily by volunteers from the fire service and medical community. The paid staff does not include social workers. The camp is available free of charge to young burn survivors, both in the state and from surrounding states. The campers come from a diversity of ethnic backgrounds and walks of life. The first summer camp was held in 1987 and currently serves 200 children and adolescents. A young adult winter retreat was established in the mid-1990s to provide additional opportunities for interaction and personal growth for youth, ages 16 to 21. The focus of the winter retreat is purposely different than that of summer camp. While the goal of summer camp is growth through recreational activities, the focus of winter camp is on self-awareness and setting life goals.

Seventeen campers from Camp #3 voluntarily participated in a focus group for this study. Unlike in the other two camps' focus groups, a majority (64.7%) of the participants were female. The ages of the campers ranged from 15 to 19 years of age, and almost half (47%) identified as a Person of Color. Over  $\frac{3}{4}$  (76%) of these campers were burned prior to the age of five ( $M = 3.05$ ,  $SD = 2.64$ ), and the participants had been attending burn camp for an average of almost eight years ( $M = 7.88$ ,  $SD = 4.10$ ).

We were able to gain entry to these camps because of the personal and professional connections of the first author to key individuals in the burn community. Because it was essential that the sample be comprised of individuals who were at a sufficient level of cognitive functioning to reflect upon their experiences and articulate their viewpoints, participation was limited to adolescents, which we defined as being at least 13 years of age. Most of the participants were repeat campers.

Information about this study was included in the "camp registration packet" that was sent by each camp to prospective campers. Parents who were willing for their children to participate in the study were

asked to sign and return the consent form with the registration information. Upon arrival at camp, assent was sought from those campers whose parents had agreed for them to participate. Campers were told about the study and its purpose, and were asked if they would like to be a part of a small group that would talk for approximately one hour about experiences at burn camp. They were told that their participation was completely voluntary and that there would not be any negative consequences if they chose not to participate. They were also told that what they shared would be treated in a confidential manner; that is, they would be assigned a “fake name” (pseudonym) in the research report.

The final sample consisted of 52 participants (33 male, 19 female). They ranged in age from 14 to 20 years old, with a mean age of 16.3 years. A majority (39) of the participants self-identified as Caucasian. The racial/ethnic composition of the remainder of the sample was as follows: six African-American three Hispanic, one Asian, and three mixed-race/ethnicity. The age at which the participating campers were burned ranged from 2 months old to 18 years old, with an average age of about 6 years ( $M = 6.04$ ,  $SD = 4.80$ ). Participants had been coming to camp from 1 to 12 years, with a mean of 6.14 years of burn camp attendance. Demographic information for the three camps, including the average age as well as the mean years of burn camp attendance and mean age at burn injury, is provided in Table One.

#### *Data Collection and Analysis*

All three camps offer a weeklong summer camp as well as a shorter winter camp. Data were collected from one summer camp and two winter camps between July 2001 and February 2002. While it may have been preferable to conduct the focus groups in the same setting (e.g., summer camps), travel constraints did not render this feasible for the research team. Because the overwhelming majority of participants in the winter camps also attend summer camp, it was felt that camper attitudes and perspectives would be similar, regardless of the setting. Three members of our four-person research team (working in pairs) conducted a total of six focus groups (two at each camp). Each group had between 6-10 participants. Most of the participants in each group knew one another, some quite well. Additionally, groups were comprised of individuals similar in age: four included 14-17 year olds, one, 16-18 year olds, and another 18-20 year olds.

A semi-structured interview protocol was used to guide focus group discussions. A semi-structured format is recommended for investigating the “personal significance of what has transpired in the lives of respondents” (Coyne & Gottlieb, 1996, p. 985). Questions posed in the focus groups included campers’ perceptions of the value of camp, the influence camp has exerted on their lives as burn-injured adolescents, and the ways camp could be structured to better meet their needs. The focus group interviews were audio taped and transcribed verbatim.

Data were analyzed inductively using the constant comparative method (Glaser & Strauss, 1967), although the intent of the study was not to build grounded theory. Data were collected and analyzed concurrently, as is consistent with this method. Each member of our four-person team read, reread, and coded the transcripts for key points and possible themes, with the team meeting weekly for two to three hours. By moving between the data and the interpretations within the same transcript, and then across different transcripts, a rough classification scheme emerged. Further analysis transformed this initial classification into categories that were exhaustive, mutually exclusive, conceptually clear, and sensitizing (Merriam, 1998). This process resulted in findings that represent our interpretation of the camp experiences of burn-injured adolescents.

To insure the trustworthiness of the findings several strategies were employed. We used triangulation (both multiple investigators and multiple sources of data), data collection over time (nine months), and peer evaluation. We also used a multi-site design (three burn camps) that sought maximum diversity in regard to sample selection, and we clearly stated our positions as researchers (in regard to our professional identities, basis for selecting participants, and social contexts from which data were collected). Finally, we employed rich, thick description “so that readers will be able to determine how closely their situations match the research situation, and hence, whether findings can be transferred” (Merriam, 1998, p. 211).

### Findings

The purpose of this study was to explore the perceptions of burn-injured adolescents in regard to their experiences at burn camp. Three themes emerged from analysis. Camp is a place where burn-injured

adolescents: (1) feel “normal” and accepted; (2) acquire insight in regard to self and meaning in life; and (3) gain confidence, increase self-esteem, and develop empathy.

*Campers Feel “Normal” and Accepted*

Adolescent burn survivors struggle with the same developmental and cultural issues that many teenagers confront: a desire for peer acceptance, body image concerns, and the development of a sense of identity and autonomy. However, because of their unique situation, they often experience painful separation and stigmatization from peers, are identified as physically undesirable, and are continually reminded by a culture that worships beauty and conformity that they do not “fit in.”

Burn-injured adolescents often contend with their challenges in isolation, commonly reporting that they are the only burn-injured person of any age in their school or community. Lynn, 18, one of the older Southeastern camp participants, expresses it like this: “There’s nobody really around [in our community] that’s in the same situation we are. We all come here and everybody’s in the same situation. Everybody’s been through the same thing.” Participants’ perceptions that burn camp provides an environment where they can experience “sameness,” an ability to identify with others who share a common, profound experience (or, in the words of one participant, “be normal”), was particularly prominent. Sharon, a 19-year-old college sophomore, notes: “Around here [camp], I mean, I look around and everyone’s like me. At home, I look around and no one’s like me ... in any way.” Normalcy for these participants seemed to impart a sense of comfort and is captured in the words of 17-year-old Ellen, a veteran camper: “It’s so wonderful being with people that...have the same thing. They’re dealing with the same things in life, and you can kind of relate.” Maureen, a fellow long-time camper from the Pacific coast, similarly notes:

I was really scared to go to camp...then I got there and realized that, like, everyone is the same ... there are people with bad burns and there are people with not so bad burns. But everyone was still, like, the same. That’s what made me keep wanting to come back.

The sense of sameness that burn camp provides serves as a shield against the scrutiny and judgment that often accompanies difference. The differences that burn injuries present are likely to signal

stares, and hurtful comments as well. Many communities have never had a burn-injured resident, and community members may find themselves responding in inappropriate ways, even if not intentionally so. Jake, who has been burn injured for four years, describes the summer camp experience as a “week of safe haven from, you know, people staring.” Likewise, 19-year-old Lillian, who was burned in a car accident and is still recovering from her injuries, notes that at camp “people aren’t staring at you and you aren’t worried about people thinking, ‘Oh, God, look at her! Look at him!’ or ‘God, I’m glad I don’t look like that!’” She goes on to add, “All of the outside world is out there and we’re all here ... nobody’s judging you [at camp]. That goes for anybody. You don’t get judged.” Although participants described camp in many ways, from a “break from reality” to a “place where you get to fit in right away,” Chuck, who has been attending camp for 11 years, shares a particularly compelling description, “Camp is like my comfort zone, my most important place that I can go.”

Many of the participants also noted that at burn camp, unlike in the outside world, the presence of scars does not define who they are as human beings. Lillian, for example, states that it “doesn’t matter what you look like or who you are or whatever ... they [staff] care about you, not your scars.” At camp, the widely-held perception that scars are seen as only one of an individual’s many traits appears to free campers from defining *themselves* primarily in terms of their scars. Sharon, for example, comments:

Mine [scars] have become more a part of me. I don’t see them as separate from me anymore.

Now, it’s just one and the same and it’s all me and people either like it or they don’t. I can deal with them either way.

Similarly, Arthur, a 16-year-old who was burned at age 3, notes, “I think this camp helps associate the burn into your life. You realize...it’s [just] a part of you.”

That camp provides what Sharon calls a “heightened sense of belonging” was noted by all participants. Although many commented on the liberating effect of acceptance, Chuck’s words come closest to articulating the sentiment most commonly expressed: “Once you go to camp... you have that bond, you know, and with everyone you feel comfortable, you feel welcomed, feel like you can be your true self.”

*Campers Acquire Insight in Regard to Self and Meaning in Life*

A second theme revealed by participants is that the burn camp experience promotes learning about self and facilitates the process of making meaning of one's injury. Henry, a 17-year-old trade school student, notes that camp "is a chance of a lifetime, especially if you come real young ... it changes you, like a lot, like ... your outlook on a lot of stuff." Charles, who has been attending camp for nine years, captured the instructive value of the camp experience in his simple, yet earnest statement that camp "teaches me and helps me." Ellen, as well, emphasizes the role that camp plays in fostering personal growth, asserting that "you just come here and you have these amazing people ... you learn so much about yourself ... it's a really, really, great experience. I've grown in time ... through the years you just grow." Similarly, Chuck adds that camp "helps you love yourself ... [helps you] get to know yourself."

Although many campers spoke in general terms about the benefits of burn camp, others eagerly shared specific examples of how it had changed their lives for the better. Larry, who has participated in two different burn camps, reveals, "I used to be a really angry person. Every year I went to camp ... I would always meet someone new who would have a similar or different story than mine ... and I would actually learn something from them that I hadn't learned in the past." Sharon, who has attended camp for nine years, jokingly notes, "I'm not telling you to go out and get burnt so you can go to these cool places [camps] ... but I don't think I'd be the same person. I'm less judgmental now than I think I would have been. I'm more accepting of people with differences." Seventeen-year-old Ira, a camper who immigrated with his family to the USA following his burn injury at age 7, thoughtfully shares, "I think different [because of camp]. I give my positive side...and I show people that life is not ending when something [bad] happens to you." And, 15-year-old Amelia, a first-time winter camper, discloses a change in self that has influenced her personal value system: "My maturity level has expanded so much ... you don't look at somebody and go by the outside, by what you see, by the looks. You look for the inside, their personality."

In facilitating a deeper understanding of the self, the camp experience also provides a venue for campers to begin to "make sense" or "make meaning" of their injuries. One way this is accomplished is

by encouraging campers to situate their being burn-injured within the context of their entire lives. Ira, for example, comments that “even though it [burn injury] happened in the past ... you have to live with it and you have to learn *how* to live with it ... It [camp] helped me ... it’s made me feel stronger for myself.” Later in the discussion, Ira adds, “Sometimes you think that God made this happen because something good will happen out of this ... you get growth from the fact that you’re turned on to a bigger idea – what life is [about] and appreciate life for what it is.” Similarly, Billy, who has attended camp for four years, shares, “But when I come here [camp], it makes me think that there’s something more than just being burned to my life. Now, it’s something I have to learn to live with.” Jake underscores that camp has taught him “when you get burned it closes some doors, but it opens others.”

Many participants commented that until attending camp, the notion that their burn injuries could lead to anything even remotely positive would have been a “crazy idea,” as 17-year-old Michael put it. However, he goes on to share, “The first thing that I was taught when I came to camp was that I’m not a burn victim, I’m a burn survivor ... and that’s a key statement about the camp. We’re survivors.” Although a few campers reframed their burn injury in exclusively positive terms, as did Sharon in referring to it as a “blessing,” a more common understanding that participants had reached about their injury was reflected in a statement by 17-year-old Diane, a Western camp participant. In describing her burn injury and consequent life change as “really a bittersweet thing,” she eloquently captures the dual sentiment expressed by most participants: Though painful experiences can be a catalyst for enormous personal growth, they come at great cost nonetheless.

The majority of participants reveal that, over time, and with the support they receive at camp, they are able to successfully integrate being burn-injured into a more holistic view of themselves. An interesting paradox is that while many of the participants no longer define themselves primarily in terms of their burn injury (which they were inclined to do at an earlier point in life), they readily acknowledge that the injury has shaped their development in unique and distinctive ways. Kara, a first-time camper, believes that

It [burn injury] makes us better people even though sometimes we resent it, sometimes we wish we could just have, like, a normal arm or something normal. But it's who we are and it makes us what we are. And if we didn't have it, we just wouldn't be us.

Kara states that living without her scars at this point in life would be like "living in a new country and being unable to speak the language." That her scars are such an intrinsic part of the woman she has become is a realization that Kara says she is "shocked" to discover. Echoing a similar insight, Larry notes that he was offered this "new organic skin that they can grow in a lab so I could cover up everything on my back. And I just downright refused." He added, "I don't see how I could live, myself, without my scars. It has become a part of me, and it is me." Chuck, too, has discovered that the "scar identifies me and it's a part of me, but it also separates me from everyone else. It makes me the individual person that I am."

#### *Campers Gain Confidence, Increase Self Esteem, and Develop Empathy*

A third theme that resonated among the participants is that burn camp fosters a sense of self-confidence that endures well beyond the camp experience itself. Concomitant with the acquisition of a "can do" approach to life is an increase in self-esteem. According to Arthur, the "entire camp experience is basically a self-esteem builder. I know some kids have low self-esteem when they come to camp, but as you watch them, you can see their esteem go up." Linked to an increase in confidence and self-esteem is the development of empathy. As participants' thoughts and energies center less on themselves and their perceived inadequacies, they are able to understand and identify with the feelings of others to a much greater extent.

All three camps include numerous activities that are designed to challenge campers' perceptions of their capabilities. Many of the activities (e.g., snowboarding, skiing, rafting) are unfamiliar to the campers and are daunting initially. Arthur asserts:

The activities help kids realize that they aren't limited by their burn injury. They allow them to realize that they can do all the things they didn't think they could. I've seen kids with very, very limited abilities do very amazing things that they probably wouldn't have ever dreamed of doing

before they came to camp ... It's a really big confidence booster to say that they can do stuff that most people would say, "Oh, you're disabled. You can't do that."

Henry concurs, stating, "They [activities] loosen you up and let you know that just because you're injured, you're not limited in what you can do. You can do anything anybody else can."

Some activities, such as swimming, necessitate that campers expose parts of their bodies normally covered with clothing. Even if campers choose not to engage in these activities, being comfortable on the hot days of summer camp usually involves wearing fewer clothes. Campers consistently report going to extraordinary lengths and enduring great physical discomfort in order to conceal the burned areas of their bodies, even to others who have been burn injured. Exposing one's injuries to the scrutiny of others is among the greatest fears of a burn-injured individual. Fortunately, according to Chuck, "camp gives support and ways to conquer [this] fear." Jake similarly notes, "you come here year after year and it builds up your confidence ... you walk high." Tara, who has been attending the Southeastern camp since its inception, eloquently describes her experience:

I used to wear a lot of pants ... the more I come back to camp the more comfortable I feel with showing my legs and then when I get out there in the real world, it makes me more comfortable there ... I believe camp helped me to cope with that.

Burn camp also affords opportunities for campers who return year after year to serve as role models for other campers. Lynn comments, "I think sometimes it takes other people to get people motivated. They encourage them ... and show them that they can do it." Tim, who is in the 11<sup>th</sup> grade, likewise notes, "Every year, you get ... experience and you know that much more so you can help out others that don't have that much experience." Lillian shared a very moving illustration of how the confidence modeled by others has inspired her:

I've only been burned for seven months. Every time I look in the mirror, every time I take a shower, every time I look at myself, it's like a constant nightmare that I just can't wake up from. I come here and I see all these people that are burned so much worse than I am and they're out doing all this stuff and I'm like, "There's no way I can't do that."

Tim suggests that this phenomenon can be explained, in part, by the fact that “the more years you go to camp, the more you stop being a follower and start becoming a leader.”

The vast majority of participants note that serving as a role model for younger, less experienced campers bestows tremendous personal satisfaction. Sharon, for one, states, “I like helping people that have to go through the same thing I did.” Participants’ actions and comments also reveal that burn camp fosters the development of empathy, a characteristic closely linked to altruism. Mark, a 19 year-old college freshman notes, “for everything that I have gained from them [camp staff], I feel, like, a sense of obligation that I need to, you know, help out little kids like I got helped.” Henry similarly responds:

After coming [to camp] for a bunch of years, you see the kids get off that bus ... and they’re just dead quiet, shy ... You don’t want them to be shy anymore so you just go up to them and introduce yourself, find out everything you need to find out about that person, just so you can up their confidence while they’re there, the very first day. And that gets people off on the right track.

Ellen reiterates the desire to be of service to fellow campers as she states, “we just want to make those little kids feel extra special, just like we were treated.”

Implicit in the design of camp activities is the belief that the attitudes, skills, and knowledge acquired at burn camp will transfer to situations encountered outside of camp. The participants shared several incidents that confirmed this to be the case. Many, for example, noted that when they face challenges during the rest of the year, recalling a formidable situation that was successfully negotiated at burn camp provides an instant touchstone for confidence. Cliff, a long-standing camper from the Southeast, remarks: “If you wanna meet new friends or something, but you’re scared to approach them because you’re scared of rejection, you think back to [climbing] that wall and you think ‘Well, I thought I couldn’t do that wall either, but I did it.’” Underscoring this point, Diane notes:

The activities that we do at camp are like any other activities that people do. If you’re scared to do them [outside of camp] you take what you learned from camp ... and it’s like, “Hey, I *could* join a soccer team, or I *could* join a swimming team” ... It gives me self-confidence.

The empathy toward others demonstrated at camp also appears to “transfer” to society at large. Henry remarks: “When you see somebody else with like a different ... disability or something else that’s happened to them, you can kinda relate to where they’re coming from.” Affirming this experience, Kara adds:

Having my scars ... I think it’s made me more aware of other people ... I’m not, like, the friendliest person, but when I see someone teasing someone because of their race or their age or their gender or something, I get really offended. And I don’t want them to feel how I felt for a long time ... I think maybe if I hadn’t have gotten my scars, I would have been one of those people that tease people. But I think it’s [being burn injured] made me really more aware of how other people feel when they are getting teased. So, now, I have enough nerve to stick up for someone and just be like, “Hey, that’s not cool ... it’s just not cool” ... Maybe we can inspire someone to change someone’s life because of our misfortune.

#### *Limitations of the Study*

The findings of this study are limited by the fact that data were collected from only 52 participants at 3 of the 40 plus burn camps in the USA and Canada. Small sample size (in terms of both number of camps and number of participants) limits the ability to generalize the findings in a statistical sense. Despite the fact that the campers attribute some of their personal gains to their camp experience, many other outside factors may have also contributed to their progress. It should also be noted that the composition of the sample does not necessarily reflect the demographics of the burn-injured population in the USA.

In addition, the study may be limited by a lack of candor on the part of the participants, all of whom are burn-injured. None of the four researchers has experienced a burn injury. Although the three camps in the sample endorsed the study, participants’ feelings about our “right” to engage in research of this nature, or our ability to understand the perspectives of burn-injured individuals, may have influenced their willingness to be open with us. Moreover, at one of the three camps, an administrator insisted on

sitting in on both of the focus group interviews, despite expressed concerns by the researchers that this might influence participants' responses.

### Discussion

In the course of this study, 52 young people shared what their experiences at burn camp have meant to them, particularly in relation to the challenges they have faced in living with a severe burn injury. The themes that emerged reinforced the importance of establishing a place where “normalcy” can occur. For the participants, this means a place where they are not forced to contend with being defined by their appearance, by the issue of their scarring, or by the reactions of the outside world, however well intended those reactions may be.

Attending burn camp, according to participants, provides respite from the stresses they face in their everyday lives. Common refrains that were heard over and over across all three camps were that camp gives attendees an opportunity to “relax.” Study findings indicate that despite differences in programming, philosophy, staffing patterns, and/or location among the three camps, the mere fact that the campers were around other youth who shared and understood their experience afforded a much appreciated and sorely needed “break” from their regular lives. It is not surprising that camp provides a setting where burn-injured adolescents feel comfortable given the perception that like-minded individuals are apt to be more accepting, more capable of supporting the need to ventilate, and better equipped to provide accurate information and advice (Gutierrez, 1994). Similarly, the need for individuals to have a “respite from their regular lives” is supported by Reeves (2001), who notes, in a study of HIV-positive individuals, the importance of “escapism” in coping with chronic illness.

Universally, the participants perceived the staff/volunteers as proactively on their side, as concerned and caring at all three camps. Although philosophic differences undergird staffing patterns, the camper selection process, the choice of camp activities at each of the three camps, and the impact of the camp experience, as reported by the participants, was decidedly more similar than different. However, in the camp where staff was represented primarily by firefighters, the influence of staff appeared to be especially pronounced. Firefighters provide a critical link to the outside world since they are so closely

identified with rescue and safety. In fact, in at least one of the camps some of the firefighter volunteers were involved in the actual rescue of children attending the camp, further cementing the bond. Stories of the firefighters' displays of altruism, particularly at one of the camps, grew to almost mythic proportion, creating an image of the camp as a model of volunteerism and personal caring. The development of empathy for fellow campers that seems to be transferred to individuals outside of the camp milieu who are considered to be "different" appears to be an enduring legacy for all three burn camps. For youth in this study, the burn camp culture embodies an acceptance of diversity rarely reflected in their everyday lives, offering a powerful lesson in tolerance and compassion.

Some of the participants were able to express appreciation for the opportunities that their burn injuries had created for them. As they shared their stories, it appeared that they had been able to reframe adversity, giving their experience new meaning by constructing alternative ways of viewing the hardships they had endured and survived. Mezirow (1991) describes this process as one of "meaning-making" – a process that resides at the heart of transformative learning. "Normally, when we learn something, we attribute an old meaning to a new experience ... In transformative learning, however, we reinterpret an old experience (or a new one) from a new set of expectations" (p. 11). Participants described shifts in the way they view themselves and their outlook on life, noting that positive behavioral change often followed. This outcome is consistent with Clark's (1993) assertion that transformative learning "shapes people; they are different afterward, in ways both they and others can recognize" (p. 47). Janoff-Bulman (1992) notes a similar process for meaning-making and new learning, and suggests, "when trauma victims reinterpret their experience, they interrogate themselves about life's priorities and most often these lessons involve either a new found appreciation of life or a new found appreciation of oneself" (p. 135). In providing a climate of emotional safety that fosters personal reflection, burn camps provide a venue for learning that is life changing, and perhaps lifelong as well.

### *Implications for Social Work*

Given the potential contributions that social workers can make in working with burn-injured children and their families, it is surprising that the profession is so underrepresented in the burn literature.

The few articles linking social work with burn recovery focuses on the social worker as a case manager in the acute and rehabilitative stages of burn recovery (Horejjsi, 1987; Thornton & Battistel, 2001). This focus, however, overlooks the need to increase the quality of psychosocial care that accompanies the adjustment of burn-injured individuals and their families to a life-changing event. The need for improved psychosocial care, a mainstay of social work services, is supported by research that reports survivor benefits from interactions with peers who function as role models for positive social adjustment, as well as research that reveals the importance of family support in a positive recovery process (Armstrong, Gay, & Levy, 1994; Goodstein, 1985).

It should also be noted that among the helping professions, social workers are uniquely trained in a multi-level, systems approach to human behavior (Longres, 2000). They understand that “human behavior must be understood as a result of a multiplicity of factors, both internal and external, operating in transaction with one another” (p. 21). Consequently, they view burn camps within a larger eco-systemic framework that encompasses not only the campers and their families, but also the volunteers who make the camps possible, and they understand that “individuals both influence their environments and are influenced by them. Processes of mutual influence generate change and development” (p. 21). Thus, professional social workers can serve the burn community in their role as resource specialists with their expertise in the networking and collaborative processes that are critical to the development of (and access to) community services. They bring an invaluable perspective to these processes because of clinical sensitivity in working with traumatized populations, as well as an ability to appreciate the complex tasks and roles of non-profit and grassroots organizations – arenas that are comfortable domains for professional social workers.

Given the many contributions that the social work profession can make to the burn community, how can integration into this population be achieved? Education and advocacy within the burn recovery field in general, as well as specifically with the burn camp community can begin with social workers who are already working with this population. Substantive effort must be directed at expanding the image of social workers as professionals who are trained to work in areas other than social welfare. It is important

to remember that education and advocacy come in many forms, from making presentations at national, state, and local conferences and gatherings, to publishing research conducted with burn populations, to evidencing a willingness to step out of “office settings” and actually work with the volunteers who view their association with burns camps as acts of love, not work. What is abundantly clear is that greater integration of the social work profession into the burn community is dependent largely on the commitment of social workers to making this happen. They must be proactive in seeking out opportunities to work with this population, and their efforts must demonstrate a commitment to, as well as the promise of, a collaborative relationship between the social work profession and the burn community.

Individually, social workers will need to confront personal biases in regard to this population. Attitudes of professionals who are part of the recovery process for burn survivors are often based on their own projected feelings and thoughts as to what it would be like to be burn-injured. Holaday and Warren-Miller (1994), using predictions of Rorschach-responding, found that helping professionals often expected burned children to display more pathology than they actually did, and that they also demonstrated biased expectations of burned-injured children. If greater integration of the social work profession into the burn community is to occur, social workers must be open to confronting their perceptions of trauma and recovery, and they must evidence a willingness to act on these new ways of thinking.

#### *Future Directions for Research*

Burn camps appear to fill an expressed and important need for a population of children and adolescents who face enormous challenges over a lengthy period of time. As burn injuries continue to rise so, too, will the demands on burn camps as they strive to meet campers’ multiple and complex needs. Accountability of services is an important factor in developing quality camp programs. Given the philosophic divisions that exist within the burn camp community, an exploration of specific programmatic differences may inform future program development. There is also a need for the development and implementation of an evaluation plan to assist future program design, staff training, supervision, and program implementation efforts. Burn camps meet a critical need for burn-injured

individuals. Because they are heavily financed through public donations, a larger body of empirical data is needed to validate and substantiate the vitally important services burn camps provide.

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Table 1.

*Participant Demographics by Camp.*

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Camp	Camp	Camp	TOTAL
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	1 <sup>a</sup>	2 <sup>b</sup>	3 <sup>c</sup>	
No. of Participants	19	16	17	52
Gender				
Female	5	3	11	19
Male	14	13	6	33
Ethnicity/Race				
African American	4		2	6
Asian			1	1
Caucasian	13	15	9	37
Hispanic/Latino			3	3
Multiethnic		1	2	3
Did not respond	2			2
Mean participant age	16.31	15.80	16.82	16.33
Std. Deviation	1.96	1.86	0.88	1.64
Mean age at burn injury	6.63	8.56	3.05	6.04
Std. Deviation	5.47	4.27	2.64	4.80
Mean no. years at camp	5.94	4.63	7.88	6.14
Std. Deviation	2.69	2.92	4.10	3.46

<sup>a</sup>Southeastern USA. <sup>b</sup>Western USA. <sup>c</sup>Pacific Coast USA.