

Running Head: BODY IMAGE AND ADOLESCENT BURN SURVIVORS

Shedding the layers: Exploring the impact of burn camp on  
adolescent campers' body image

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### Abstract

The purpose of this qualitative study is to explore the impact of the burn camp experience, as it relates to body image, on participating burn-injured adolescents. Focus groups were conducted with 52 burn-injured adolescents at three burn camps in geographically diverse regions of the US. Data revealed that burn camp is a place where they feel a sense of belonging and acceptance, a place where they don't have to hide their bodies, and a place where they can learn to integrate their scars into their overall body image in a positive way. Implications of this study include highlighting the contributions that burn camps may provide in helping burn-injured adolescents learn to cope with the devastating disfigurements that often accompany their injuries.

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Body image, already a very fragile concept for adolescents, can become increasingly salient and intensely negative for those who bear the physical scars of a disfiguring burn injury. Because adolescence is a time characterized by change, body images can be distorted even when disfigurement is not an issue (Cobb, 2001; Gullotta, Adams, & Markstrom, 2000). Body image is a part of the concept of self -- a concept formed from sensory and social experiences, which include others' reactions to one's body. These reactions often play a significant role in determining how an individual feels in relation to his or her body (Cobb, 2001; Gullotta et al., 2000; Jones & Bloomberg, 2000). Thus, a person's self-image is a reflection of a combination of one's own evaluation as well as one's perceptions of others' attitudes towards a particular trait or physical characteristic (Cobb, 2001; Gullotta et al, 2000). Cultural messages in society are clearly conveyed and reinforce that physical appearance is highly valued, even revered. Personality development, social relations, social perceptions, and social behavior are profoundly influenced by these messages and are especially noticeable when there are extremes in physical appearance (Brumberg, 1997). Adolescents, who are developmentally in the formative process of understanding who they are and how they relate and fit in to the world around them as their bodies undergo dramatic shifts, are particularly vulnerable to these influences. Adolescent burn survivors must face this process head-on as they are formulating their self-concept based in large part on the messages they receive from the external world as they reconcile their image of themselves. Both the perceived and actual context of an experience are important to adolescent development (Cobb, 2001).

It is reported that the emotional recovery process for burn-survivors, whose physical appearance may be irreparably altered, often involves depression, anxiety, and low self-esteem. (Williams, Davey & Klock, 2003). The situation is ripe for individuals with disfiguring injuries to develop a negative body image that acts as a schema with which they view the world and within which they operate. As Cash (1996) notes, social scrutiny and bodily exposure often serve as triggering events which activate this schema, leading to hyper-vigilance, negative interpretations of the behavior of others, attempts to conceal the body, avoidance, and other compensatory actions. Though there is a wide range of personal reactions to physical disfigurement, recent studies have identified common elements that are shared between individuals who have skin diseases, such as vitiligo and psoriasis, and people who are burn-injured or have disfigurement resulting from head and neck surgery (Dropkin, 1999; Kent, 2000; Kent & Keohane, 2001; Papadopolous, Bor, & Legg, 1999). Because of their injuries, they are challenged to restructure their self-concept and value systems by placing greater importance on characteristics other than physical appearance. In one of the few studies directly exploring the self-esteem in burn-injured adolescents in relation to their scars, the researchers interestingly found their sample to exhibit similar or even higher feelings of self-worth as compared to their peers in general. However, in the area of self-worth as it related to physical appearance, the burn-injured adolescents were significantly lower in self-esteem (Robert, Meyer, Bishop, Rosenburg, Murphy, & Blakenly, 1999).

The negative thoughts about disfiguring burn injuries can lead to what is known as “body image distress” (BID). These thoughts can be realistic (e.g., “People stare at me because of my burns”) or distorted (e.g., “Everyone finds me repulsive because of my burns”) (Heinberg, Fauerbach, & Kammerer, 2002). Pilot research on individuals with burn injuries suggests that

22% score in the severe range for BID, though none of the studies have measured BID directly. Normative data examining BID and burn survivors does not exist (Heinberg, Lawrence, & Fauerbach, 2002). Children with disfiguring conditions often try to protect the complete attrition of sense of self by holding on to the mental image of a “normal” body. They often fluctuate between their thoughts of their “old self” and the reality of the “new self” (Blakenly & Robert, 1998).

### *Social Support*

Researchers consistently report that social support is 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). Social support has been inter-related with the concept of hope, a positive psycho-social outcome that has been reported to be a powerful antidote among children who have received physical and psychological scars as a result of a burn injury (Barnum et al, 1998). Research indicates that burn-injured individuals who receive social support, especially from friends, have a more positive body image, as well as greater self-esteem and less depression (Jones & Bloomberg, 2000; Orr, Reznikoff, & Smith, 1989). Arenas that offer burn-injured youth opportunities to develop social supports in a safe environment are camps specifically designed for burn-injured children and adolescents.

The burn camp concept was born almost 20 years ago in response to the needs of burn-injured children who lacked appropriate mental health resources and support. The goal of these 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, 1992, p.71). Since that time, burn

camps have developed in countries around the world to provide a setting for burn-injured children to enjoy support and acceptance in a recreational setting. The camps appear to share a common goal: to provide burn-injured children a safe and accepting environment while providing challenges in a variety of activities and interactions that are designed to enhance self-esteem. Building self-esteem, and the concomitant process of improved body image, is embedded in the belief that success in one area will translate into success in other “everyday” areas of the burn-injured child’s life, such as home and school (Biggs, Heinrich, Jekel, & Cuono, 1997; Doctor, 1992).

A review of the literature revealed a scarcity of studies on the emotional and social aftermath of disfiguring conditions, such as dermatological diseases and craniofacial abnormalities, and disfigurements resulting from traumatic events, such as burns as it impacts adolescents. This study seeks to contribute to this gap by exploring the impact of the burn camp experience on the body image of adolescent burn survivors.

### Method

An exploratory, qualitative research design was utilized to examine body image issues among adolescents who attend burn camp. 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 the meaning that individuals attribute to their experience. This study employed a descriptive qualitative design to explore the perceptions of burn-injured adolescents in regard to their experiences at burn camp. This study, conducted by a team of two social work faculty members and two social work graduate students, was part of a larger research project that explored the impact of the burn camp experience on the adolescents who have attended multiple

years at camp. Three burn camps were investigated in different geographical areas of the US, one in the Southeast and two in the West. The research team actively engaged in the activities at all three camps in an effort to build rapport and develop a deeper understanding of campers' perspectives.

### *Participants*

The total nonrandom sample of 52 burn-injured adolescents (33 males; 19 females) included campers between the ages of 13-20 ( $M=16.3$ ). The participants were predominately Caucasian ( $n=37$ ), with six participants identifying as African-American, three as Hispanic, one as Asian, one as Caucasian/African-American, one as Caucasian/Hispanic, and one as African-American/Native American. Two participants did not identify their race/ethnicity. The age at which participants had been burned ranged from 2 months to 14 years of age. The number of years participants had been attending camp ranged from 1 to 12 years, with a mean of 6.14 years, indicating that the majority of campers were very familiar with the burn camp experience.

Information about the study, which was approved by the university with which the research team is affiliated, was included in camp registration packets. Parents who were willing for their child to participate signed a consent form describing the purpose of the study, a description of what their child's participation entailed, and the voluntary nature of participation. Upon arrival at camp, written assent was sought from campers whose parents agreed for them to participate in the study. Campers were assured that their parents' consent in no way obligated them to participate in the study, and they were informed that if they chose to participate, they could later change their mind and withdraw from the study without penalty. All campers whose parents gave permission to participate in the study elected to do so.

### *Data Collection*

Six focus groups (two at each camp) were conducted with adolescent campers ( $N = 52$ ). The size of the focus groups ranged from 8 to 10 participants.. Each group was facilitated by one faculty member and one graduate student. It should be noted that at one camp, the camp director was present during both focus groups, and at another camp, a counselor was present during one of the focus groups.

Focus groups were selected as the method of data collection for several reasons. First, focus groups permitted access to a greater number of adolescents, an important factor given the time limitations within the busy camp schedule. Second, focus groups promoted a level of interaction not be possible in individual interviews. Campers often elaborated on the ideas and feelings expressed by others in the group. Finally, it is likely that focus groups afforded some campers a greater degree of comfort in discussing matters of a sensitive nature (Royse, Thyer, Padgett, & Logan, 2001)

Assignment of participants to focus groups was based on natural camp designations (e.g., senior campers and counselors-in-training) as well as on the input of camp staff. Focus groups were conducted in the campers' cabins, staff housing, or the camp lodge and were scheduled at times that did not interfere with planned camp activities. Each focus group, which lasted approximately 60 to 90 minutes, began with an explanation of the purpose of the study and provided an opportunity for participants to ask questions. A semi-structured set of 15 open-ended questions that addressed the lived experience of being burn-injured and how camp facilitates the personal negotiation of this experience guided the discussion. Questions specifically related to body image addressed issues such as how the participants view their bodies and how camp has influenced this view, if at all. Focus group interviews were audio recorded and transcribed

verbatim by the graduate student members of the research team. Pseudonyms were used to ensure the confidentiality of participants.

### *Data Analysis*

Data were collected and analyzed inductively, using the constant comparative method (Glaser & Strauss, 1967), over a 10-month period. According to this method, data analysis proceeds simultaneously with data collection. As the focus group interviews were conducted and transcribed, each member of the four-person research team individually read, reread, and coded the transcripts for key points and tentative themes. By constantly moving between the data and the interpretations within the same transcript, and across different transcripts, a tighter structuring of the data emerged. This process resulted in findings that were sensitive to the data and that reflected our interpretation of the impact of the burn camp experience on the body image of adolescent burn survivors.

### *Limitations*

The findings of this study are limited by several factors. Given that the sample is small and non-random, it is not possible to generalize the findings in the statistical sense. Also, although participants came from geographically diverse regions, they may not be representative of the population of burn-injured adolescents in the US. Finally, despite expressed concerns by the research team that their participation might influence the willingness of the participants to be candid in their responses, a camp director at one of the camps and a counselor at another, participated in the focus groups.

### *Findings*

The purpose of this study was to explore the impact of the burn camp experience on the body image of adolescent burn survivors. Data analysis revealed four themes that describe the

camp experience and its effects on the body image of participants. Camp is a place where campers: (1) experience a sense of belonging and acceptance (2) are sheltered from stares and questions; (3) do not have to conceal their bodies; and (4) learn to integrate scars into their overall body image in a positive way.

*Campers Experience a Sense of Belonging and Acceptance*

Participants were quick to identify a sense of belonging and acceptance that they experience at camp, which is in stark contrast to the sense of isolation that is often the norm in their schools and communities. Repeatedly, they described burn camp as a place where campers “fit in,” feel “normal,” and find peers who understand the thoughts and feelings that burn-injured adolescents commonly experience. Homer, a burn camp veteran of nine years, expressed the sense of inclusion and identification that he experienced in this way:

‘Cause like when you first get burned, it’s like, I’m the only person this has happened to and it’s the worst thing that ever could have happened to me. But, when you go to camp, you realize that there’s so many people that it happens to.

Similarly, Cord, a counselor-in-training and a burn survivor, agreed, stating, “You know that you are just an ordinary person, just like everyone else and don’t worry about it.”

Caleb, a long-time camper, described the importance of having camp as a safe haven: “But, for me, I think I feel the most comfortable with other people that are burned. So, to me, camp is like my comfort zone, my most important place that I can go.” Leigh, a first-time camper, offered a fresh perspective in interpreting the acceptance she experienced, and witnessed others experience, as an authentic demonstration of caring:

And that’s one of the first things you learn here. That’s one of the first things I learned here. I don’t care what you look like, nobody’s going to think of you any less... nobody’s

gonna ignore you or anything. You'll have someone just come up and hug you and say, "I'm so glad you're here." And it don't matter what you look like or who you are or whatever, its just they care about you, not your scars.

Summer, one of the oldest campers, explained the contradiction between life at camp and life in the "real world" by sharing an interesting observation: "It's a reverse thing here because if I don't show my burns then I don't look like everybody else here. If I show 'em I look like everybody else I'm with...it makes me feel like...not left out." Many of the campers described camp as a place where they can forget about their burns and feel secure with themselves and others. Donna noted:

In the real world, I don't know – sometimes I don't feel like I'm a person. I don't fit in with the group, you know. I don't feel like I belong in the human species because, you know... it depends on where you go. And, here, it's different – I think the best thing about it is that you just forget it – and, and it's about fun. And we're also having fun, but we're also learning a lot. But we don't realize that we're learning, but we do learn.

Caleb, in echoing Donna's statements, also summed up the sentiment of the other participants: "To me, it seems like camp is like a retreat – somewhere you feel comfortable, somewhere you belong, somewhere... it helps you love yourself... get to know yourself."

*Campers are sheltered from stares and questions*

Horrible stares and a barrage of questions—even, at times, by individuals who would ordinarily consider themselves to be sensitive to the feelings of others, become a way of life for burn-injured individuals in the "real world." With relief and a profound sense of gratitude, the participants share that camp is significantly different in this respect. Leigh reflected:

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." You know all of the outside world is out there and we're all here and it's not...nobody's judging you. That goes for anybody. You don't get judged.

Barry also added that no one asked questions about his scars when he was at camp, "Nobody ever brings it up here at burn camp. In the world, people who aren't used to seeing people with scars and they're always asking. But, here, everybody knows you have scars and doesn't ask about it."

Terri, who has attended camp for nine years, attributed the absence of stares to the fact that having visible, sometimes disfiguring scars, is the norm at camp: "I mean, you know, you have, in the world people stare, but here they can't really stare cause everyone has the same thing, maybe not in the same place, but the same thing." Donna even found that being relieved of the everyday questions and stares bolstered her self-esteem:

You're not constantly thinking about, like, is anyone staring at me? Is anyone talking about me? Is anyone, like, pointing at me? And... I don't know – camp just helped me with my self-esteem with my confidence and, um, it just made me feel like I was normal – like I could do anything.

*Campers do not have to conceal their bodies*

Many of the campers expressed feeling a need to conceal their burn scars in their everyday lives and indicated the relief that they feel in being able to reveal them at camp. Terri observed that she feels safe from judgment at camp and can display her body—"scars and all," without feeling shameful. In fact, she indicated, that is a primary reason why she comes to camp, year after year:

I don't have to hide anything or cover anything up when you're at camp. Can't nobody criticize nobody about how they look, 'cause everybody got some type of scar on their body...so, that's another thing, you don't have to try to hide anything from nobody... or cover your scars... that's why I came back.

Some of the campers noted that determining what to wear, a decision most people make without much difficulty or thought, often presents agonizing choices for burn-injured individuals. Summer, one of the oldest campers, described it in this way:

And it's just so much easier here, because you know if you put, go put a swimsuit on you're not gonna have the questions. You're not gonna have the questions if you put shorts on. You're not gonna have the questions if you put the swimsuit on.

Many of the campers noted that they go to extremes to cover their scars in their everyday lives, even if it means wearing long sleeves and long pants in the heat of the summer. Jane, who has been attending camp since she was six, talks about her experience:

Me, I don't wear shorts when I go home. The only thing I wear is pants. And I got burned on my legs and my stomach and stuff. And, so, I wore shorts when I go to camp, I can just wear shorts or anything I want to wear. And I don't have to feel like someone is staring at me or what is this person thinkin' about me or... so conscious about how I look.

Eleanor similarly noted:

I wear clothing when I go to camp -- clothing that I don't wear, around at home. Cause I just wouldn't wear a tank top to school because everyone would be staring at me. They'd make comments and just be really mean about it. And, I just don't want to show that part of me. I'd rather go with long-sleeves or just like to here or something (indicates shirt

length to the elbow). And no bathing suits –well, I will when I really want to swim. But, I've changed. Like, coming to camp –I'm going to wear anything I want, and no one's going to stop me. If they want to look at me, they look at me, but it's not going to bother me. Just do my thing.

*Campers learn to integrate scars into their overall body image in a positive way.*

Campers come to appreciate that camp offers a “training ground” for behaviors that can transfer to life outside of camp. In offering a safe environment for learning, camp provides a foundation for integrating their burns into their body image Eleanor, in reflecting how camp facilitated growth in this regard, noted: “Yeah, it (being at camp) helped me kind of crossover – and coming in public and just wearing what I want. Not being all clothed up and sealed.” Terri expressed how camp benefits her at home and how that benefit is reinforced as she continues attending camp:

I used to wear a lot of pants, or jeans or whatever... the more I come back to camp the more comfortable I feel with showing my arms...or showing my legs and then when I get out there in ...the real world, I go back home, it makes me more comfortable there.

Campers described the process of integrating their scars into their body image as accepting oneself and understanding, finally, that the scars are a part of that self. Anthony, who after ten years at camp had much insight to offer younger campers, appreciated the role camp attendance played in gaining self-acceptance: “I think [this camp] helps associate the burn into your life. You realize...it's a part of you. You learn to accept it. It's just, it's a part of your life; you live with it.” Caleb, likewise, made a similar observation, and eloquently articulated this process of integration:

For me, my scars make me who I am. So even though it happened in the past and not everything that happens in the past is always good – but you have to live with it – you have to learn how to live with it. And, so, with my scars, it’s helped me... it’s made me feel stronger for myself; it’s made me a better person... And... and... the scar identifies me and it’s a part of me, but it also separates me from everyone else. It makes me who my individual person.

### Discussion

“It’s one week of the year when everyone actually feels comfortable with themselves.”

As Lorraine’s statement demonstrates, the burn camps in this study seemed to provide adolescent campers with a safe haven away from the stigma of their physical appearance. The campers’ insights highlighted the positive impact that they experienced at burn camp in relation to the legacy of their burn injuries. The findings of this study indicate that the participants overwhelmingly expressed that they experienced a socially supportive environment at burn camp, and that they perceived it to be a place where they acquire acceptance—particularly in relation to their bodies. As such, it appeared that camp has had a beneficial impact on their body image, supporting other studies that have found that burn-injured individuals who received social support had a more positive body image (Jones & Bloomberg, 2000).

It appears that one of the main factors that contributes to this positive impact is an environment absent of judgment and rich in acceptance. Being surrounded by others who are similar to oneself in terms of having had a burn injury experience and having scars from that experience, allowed the adolescent campers to feel a sense of “normalcy” about their bodies. At camp, they “fit in,” unlike in their home environment, in which they are often the only burn survivor in their social circle. An absence of unwanted attention, as well as an escape from the

pressure to explain their scars, provides a “comfort zone” for these adolescents. The participants in this study experienced a feeling of being accepted despite their “disfigured” appearance, which for some led to the realization that they are acceptable to others.

Burn camp offers adolescents a week in which they can experience bodily exposure as a positive rather than a negative experience. In individuals with a negative body image, this exposure often serves as a trigger for activation of a schema that calls for avoidance and attempts to conceal the body (Cash, 1996). As many of the campers stated, while in their home environments they wear clothing that covers their bodies; at camp they feel comfortable wearing shorts or swimsuits that expose their scars. In essence, camp serves as a testing ground for campers to explore and experience comfort in their own skin. While societal emphasis on physical attractiveness, as well as actual social reactions to their burns, may have led campers to believe that their bodies are physically offensive, camp seeks to deprogram this belief and alter the negative schema from which the campers may operate.

For many burn-injured adolescents, burn camp serves not only as a week of respite from the stresses of living with a disfiguring injury, it also, on a larger scale, serves as a vehicle for integrating their burns into their existing body image and definition of self. Burn camp offers adolescents a chance to feel successful about their bodies, which translates for some into bodily acceptance when faced with the challenges of the “real world.” For many, the positive impact of successive camp experiences in relation to their body image is cumulative.

### *Future Research*

As this was an exploratory study, further investigation of the specific impact that burn camp has on the body image of burn-injured adolescents is warranted, particularly in view of the dearth of studies in this area. It would be worthwhile to investigate the specific processes that

enable the internal shift that results in a more comfortable acceptance of one's body and scars. Furthermore, research involving burn-injured adolescents and body image, absent of the camp experience, would enhance understanding of how burn-injured adolescents cope and adapt when they do not have the support of a supportive burn camp environment. In order to better understand the factors that lead to the development of body image distress among burn-injured individuals, it would be beneficial to examine the potential relationship between BID and burns located on specific areas of the body, such as the face and head. In addition, an exploration of gender differences in this population could provide an enhanced understanding of the unique challenges of male and female burn survivors. Such research would be compelling in light of findings that indicate that accepting one's body is an adolescent task that is typically more difficult for girls to achieve than boys (Cobb, 2001; Gullotta et al., 2000; Johnson, Roberts, & Worrell, 1999).

Burn survivors, like many other trauma survivors, can provide valuable models for understanding the development of resiliency in the face of adverse challenges. This research, highlighting body image, represents only one area in which burn survivors demonstrate such resilience. As evidenced by the adolescents in this study, burn camp can play a vital role in determining how they perceive their bodies. Further research exploring the development of a model of resiliency specific to burn survivors would offer a greater understanding of the challenges and triumphs of this unique population.

### *Conclusion*

Given that body image is one aspect of self-concept that is formed in part from social experiences, which include others' reaction to one's body (Cobb, 2001; Gullotta et al., 2000; Jones & Bloomberg, 2000), it is likely that the positively reinforcing environment of burn camp

fosters a constructive change in the body image of burn survivors. Those adolescent campers who have positive self-perceptions about their bodies can serve as models of hope for others who have been burned and who face the challenges of body image development, an already delicate concept during adolescence. Leigh, after only having been at camp a few days, eloquently expressed the hope she felt at burn camp:

I've only been burned for seven months and, every time I look in the mirror, every time I take a shower, every time I look at myself, it's a constant...it's like a nightmare that I just can't wake up from. And, 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.' And I don't know it's just (that), it's good to see that there's an ending to everything. That maybe one day I will have a normal life and not 'Oh, God, is my face showing? My wig's not right and my arm' – thinking the burnt part sticking out of my shirt is not all that, And just think that maybe one day I can wear a tank top or a bathing suit or just anything.

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