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Camp "Sababa" (awesome) — The world of children with burns

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ABSTRACT

Aims: Camp "Sababa" operates in Israel through the Burn Advocate Network of New Jersey, to help children with burn injuries cope with consequences of injury. The study assessed adolescents' perceptions of their participation in the camp, and its effect on their self-esteem and quality of life.

Methods: Ten adolescents from diverse cultural backgrounds attended Camp "Sababa" in 2017. All the participants and parents signed an informed consent form, responded to a demographics questionnaire, and participated in in-depth interviews and focus groups. Phenomenological analysis revealed three themes, reflecting the chronological sequence of rehabilitation: (1) coping with emotional and physical scars, (2) formulating coping strategies, (3) belonging to a group, and (4) implications of camp experience.

Results: Social participation engendered a feeling of safety and trust, enabling adolescents to share their burn experiences, and thus cope better with the physical and emotional challenges of their injuries. Participation in camp activities strengthened their confidence and social bonding; and their return to typical adolescent behaviour while at camp, and ultimately in the community.

Conclusions: The positive results suggest that burn camps should be part of the rehabilitation process of adolescents with burn injury, with emphasis on challenging, age-appropriate activities, and peer group participation.

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Abbreviation: TBSA%, percent total body surface area.

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1. Introduction

In Israel, an average of 676 persons are seriously burned annually; approximately 70% of these injuries occur at home. The main age group affected are children under 15 years (34%). The main causes for children's burns are scalding from hot water or flames, and contact with a hot object [1].

Injuries due to burns may cause physical disabilities, severe sensory deficit, loss of limbs, and limited range of movement [2]. Moreover, both the injury and traumatic experience widely affect physical, psychological, social, and functional aspects of wellbeing. Among children burn survivors, 25-30% were reported to suffer from post-traumatic stress disorder (PTSD) in the acute phase of the injury. Over the long term, 10-20% of school-age children burn survivors have been reported to develop PTDS [3].

Another difficulty that children experience as part of their rehabilitation process, is accepting their bodies, due to changes caused by the injury. Many injured report difficulty looking at their burns and exposing them in public. The social aspect is also a concern in regard to the use of pressure dressings, which patients need to wear during most of the day to treat scars [3]. All changes in appearance may affect the selfidentity and body image of burn survivors.

Body image is defined as a person's satisfaction with his/ her appearance, and is considered an important milestone in the development of self-esteem, particularly in adolescence. Therefore, teenagers are the most vulnerable age group regarding low body image. Among 361 adults, a direct correlation was found between severity of scars and selfesteem [4].

In reviewing the literature regarding the impact of injuries on adolescent burn patients, we found major implications at this age; these were related to the importance of the peer group [5], developing independence, leaving parents, making new friends, and self-identity [6]. Coping with burn injury and hospitalization places adolescents at particular risk.

Functional difficulty, prolonged coping, and slow return to routine are challenges for burn survivors [3]. Lack of normative activity for long periods of time may interfere with their proper course of development and lead to difficulties with various functional aspects, among them the abilities to maintain previously acquired academic levels, and to preserve friendships [7]. This may impair psychological wellbeing and lead to behavioural changes. These may include hypervigilance, repetitive thoughts about the injury, and physical symptoms such as abdominal pain without physiological explanation [8]. In contrast, the same researchers found that some of the children investigated had remarkable adaptive strength and described their injury as a life and personality-changing event, despite the difficult, painful, and traumatic experience [3].

Further to implications on the injured child, the family unit is also affected. Younger children and adolescents report the importance of family support in the rehabilitation process, mostly with regard to loneliness, sadness, and fear. Sometimes parents tend to become overprotective and more involved with the adolescent's medical care and everyday life [3].

During the rehabilitation process of the teenager burn survivor, continued emotional and social treatment are important to improve adaptive and appropriate functioning. Research from the psychological rehabilitation field found that the peer group has great strength in the healing process, by providing hope and shared destiny, by addressing emotional needs, and by affording burn survivors the opportunity to feel part of a group [2].

In 2007, through the support of the "Burn Advocate Network" association in New Jersey, the first burn camp for injured children, Camp Sababa, was established in Israel. Children from burn centers throughout the country are referred to the camp, which is managed by a health care professional team team from the Schneider Children's Medical Center of Israel, and supported by the "Our Children" foundation.

Approximately 50 children, aged 7-18 years, attend camp annually for four days. This is an inclusive enterprise that crosses population sectors and cultures, and is conducted in both Hebrew and Arabic.

Our literature review identified few qualitative and quantitative studies that addressed the effectiveness of burn camps for children. These studies mostly focused on quantitative parameters, and were not homogenous regarding the effectiveness and influence of participation in a camp [9]. However, qualitative research in this field consistently describes improvement in psychological parameters [10].

Therefore, our qualitative research aimed to expand and deepen results of previous quantitative studies, by answering the questions: (1) How do adolescent burn survivors perceive their experience in the burn camp? and (2) Which challenges, contributions, and meaning did adolescents attribute to participation at camp? Therefore, the research objectives

- To understand daily coping strategies of burn survivor adolescents.
- To obtain participants' perspectives on attending burn camps and their experiences.
- To document the reported social and emotional impact of participating in burn camps, and to attain insights for improving and modifying the project.

2. Materials and methods

The study was approved by Schneider Medical Center's ethical committee. Participating adolescents and their parents signed informed consent. Inclusion criteria were boys and girls aged 12-18 years who suffered burn injuries that underwent at least three days of hospitalization at a burn unit in Israel; and who participated in the camp for at least two years.

2.1. Research tools

2.1.1. Demographic questionnaire

Questions focused on demographic information, clinical characteristics of the injury, reported functional difficulty due to the disability, the use of assistive devices, participation in camp activities, and social participation in the community in their leisure time.

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2.1.2. Semi-structured interviews

Interviews were conducted in the participants' homes over a period of a few months, before and after camp. The topics of the interview included:

- Describing the adolescent's participation in daily leisure activities and community social life.
- Experiences from the camp and its meaning to the adolescent.
- Sharing the injury story and its meaning to the adolescent's life
- The adolescent's perception of the camp's contribution to his/her daily life.

2.1.3. Focus group (implemented after eight personnel interviews, and conducted during the camp)

The focus group facilitated in-depth investigation of phenomena that had been revealed in interviews; cross-examination and triangulation of the data enabled validating preliminary analyses of the results [12]. The following topics were addressed by participants: considerations regarding joining the camp, meanings of the social gatherings, participation in informal and formal camp activities, the contribution of staff to the participants' experiences, and experiences of separation — from families before camp, and from their friends, at the termination of camp.

2.1.4. Reflective study diary

Recording in a diary enabled the investigators to process their reactions and feelings during the observations and interviews, to help identify and mitigate study bias.

2.2. Trustworthiness

To ensure the accuracy and validity of the study, the following measures were taken:

- 1 A detailed description of the study participants and extensive use of interview quotes.
- 2 Data crossing (triangulation) of the findings from the interviews, focus group, investigator's dairy, and literature

- to obtain a broader and more comprehensive understanding.
- 3 Peer-reviewed process of data analysis of three investigators at all stages of the study.

2.2.1. Data analysis

All the interviews were audio recorded, transcribed, and identifying details were removed. The authors analyzed the data together, while extracting and interpretating text units. The researchers interpreted the findings in a reflective and critical manner to encompass both the personal and shared experiences of the participants. The interviews were analyzed according to 12 categories that were grouped into four main themes. Extraction and analysis continued until data saturation was achieved.

3. Theory/calculations

This is a phenomenological qualitative study that analyzed the rehabilitation process and the experience of adolescents who participated in a camp for burn survivors. This approach facilitated in characterizing the impact of participating in the camp on the adolescents' functioning and well-being in daily life. Moreover, the approach highlights subjective points of view and interactions with the environment, especially confrontation with harsh reactions [11]. Moreover, this approach addresses issues related to the rehabilitation process of adolescents, including self-identity and scar management years after burn injuries; the importance of informal interactions with other participants and staff; and the benefit of engaging with their peer group in and out of camp.

Results

Ten burn survivor adolescents were included. Demographic characteristics and burn characteristics of the study participants are presented in Table 1. The age range was 12–17 years, the mean was 15.4 years. The median number of years of

SN	Age (years)	Gender	Years attending camp	Burn characteristics	
				Years from injury	TBSA%
1	14	Female	2	3	15
2	17	Male	9	14	40
3	17	Female	9	16	20
4	17	Male	5	16	20
5	14	Male	2	3	25
6	16	Male	7	13	50
7	16	Male	7	10	30
8	12	Male	3	8	30
9	17	Male	8	13	20
10	14	Female	8	13	60
Mean	15.4		6	10.9	31
SD	1.68		2.64	4.57	13.92

Percent total body surface area=TBSA%.

participation in the camp was six (range 2-9) years. Most of the burn survivor adolescents had a percent total body surface area (TBSA%) of 20-50%. The mean time from the date of injury to study initiation was 10.9 years.

The main topics discussed in the interviews were emotional coping with the injury, dealing with others inside and outside the camp, the healing process, and social adjustment to living with burns.

Conceptualization of the findings of the study resulted in four main themes, presented in chronological flow of the rehabilitation process: (1) coping with emotional and physical scars, (2) formulating coping strategies, (3) the strength of belonging to a group, and (4) implications of participating in the camp (Fig. 1).

4.1. Emotional and physical scars

During the interviews, several issues were raised regarding the trauma of the injury, pain, physical changes that affect body image and emotional scars, and coping with loneliness.

4.1.1. Trauma

The emotional coping with an injury, such as a burn, continues throughout the rehabilitation process, from hospitalization to initial confrontation with society, and return to daily life. Although injured at a young age, nine of the 10 participants distinctly remember the hospitalization period, managing the pain that was part of the medical and para-medical treatment; and feeling anxiety, confusion, detachment, and isolation. The interviewees described difficulties they experienced, after the long and stressful rehabilitation, when returning to school and friends. These difficulties added emotional pain, mostly due to comments they received regarding the burns and the pressure dressing they had to wear.

4.1.2. Body image

Among teenagers, experiencing their body has special importance, as an effective parameter of self-esteem, which is part of the normative developmental process. One of the major difficulties described by the participants in the research was re-accepting their body and coping with the scars and the injured organs in terms of integrity, appearance, and function.

Sharing with the peer group in camp helped the teenagers accept the burns as part of who they are, and to learn how to cope with society's reactions. Both teenagers injured at a very young age and those injured during school-age stated that body image is an issue that occupies them greatly to.

4.2. Coping strategy

The long hospitalization after an injury such as a burn may lead to a firm and dramatic negative impact on social function.

Burn patients, pediatric and adult, report social isolation and declines in various aspects of social functioning. For young persons, and especially teenagers, social function and the feeling of being part of a peer group constitute major parameters in the development process, and are therefore of crucial importance in the rehabilitation process. During the research, two major strategies were noticed: concealment (hiding the injured organ), and abstaining from normative social activities of their peers. These strategies contrasted with a process of acceptance and adjusting, which led some teenagers to return to desired activities.

4.3. The power of participating in camp

4.3.1. Belonging to the peer group

Engaging with a peer group that also had severe burn injuries was experienced by many teenagers as a meaningful event that enabled them to view their bodies and life stories from other perspectives. The teenagers reported experiencing their scars in different ways, mostly by comparing them with those of other camp participants. This gave the participants the opportunity to look more objectively at their bodies, abilities, and skills. Eight of the 10 participants reported that after the first meeting with other burn survivor teenagers, they felt more self-acceptance, especially of their bodies, and felt more resolved regarding their limitations. Some described themselves as lucky compared to their camp friends.

Humans of all ages, especially teenagers, want to belong and resemble their peers. One of the main topics discussed in the interviews was reinforcement of the "feeling of belonging" during camp. Participants described camp as an opportunity to feel equal and part of a group again, compared to feeling different in the outside society. This also helped boost their self-confidence. Though not a therapeutic camp, it offered activities that encouraged participants to share their injury stories and accompanying trauma, and to reveal their scars, both physical and mental. The emphasis during the various activities was on coping and developing self-capability, through normative, age-appropriate activities, which take into account participants' limitations. Eight of the 10 interviewees mentioned that the peer group of teenagers who had experienced similar trauma helped them talk freely about subjects they found hard to share with most people, even those closest to them. This is why we find such encounters as essentials in the rehabilitation process, to help promote physical and mental healing.

4.3.2. Camp experience

The camp experience entails several important components, such as the characteristic of the activities (fun, interesting, age-appropriate, challenging), and staff with professional

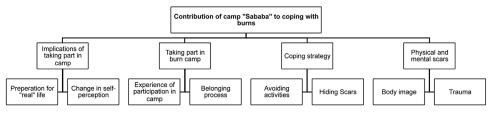


Fig. 1 - Research results - main themes.

expertise. We found the main reason campers returned year after year was the opportunity to meet their friends during activities and informal encounters.

We also found that initial connection with a personal tutor helped foster interpersonal connections with the peer group at the beginning of camp. When a first and positive connection with a supportive, encouraging adult was established, motivation increased to participate annually in camp.

4.4. The implications of participating in camp

The rehabilitation process after a burn is very complex, physically and mentally. The interviewees reported that attending camp helped them change their point of view and perspective on daily challenges, and led to changes in the way their parents treated them. The experience also helped them re-accept their body with improved self-confidence.

4.4.1. Change in self-perception

The functioning of pediatric burn patients is sometimes reduced. This is influenced by how family members and especially their parents relate to them. Due to the trauma, parents and teenagers are often overprotective regarding any type of outdoor activities. This can limit teenagers' social interactions and the way they view their abilities and identity. In camp, the adolescents have an opportunity to face physical challenges and improve skills in a challenging but safe environment. This may have implications on their life outside of camp. Attending camp changes participants' perspectives by improving their sense of capability, self-acceptance, and self-confidence, for months after camp.

4.4.2. Camp as preparation for life

The rehabilitation process after burn injury focuses on various aspects: plastic, physical, functional, and psychological. Group socializing treatment are rare; most patients and their families feel alone and helpless with regard to mental and social implications of the burn injury. Burn camp helps answer this need.

5. Discussion

The purpose of this study was to deepen the understanding of the experience of adolescents who attended a burn camp in Israel, through qualitative research. Since the emphasis was on understanding the subjective experience of this unique population of teenagers, this study was conducted as a phenomenology qualitative research, which is acceptable in this field. The choice of this exploratory research with qualitative research methodology was selected for three major reasons: 1. to deepen understanding of the complex life experienced by adolescents with burn injury, from their perspective [5,11]; 2. to collect examples, that will illustrate the recovery process that evolves following burn injury. 3. to examine a complex phenomenon, while emphasizing the participants' stories and connections with their environment. This is important in light of the harsh feedback from society, with effects far beyond the adolescent [11].

This study was conducted with adherence to a standardized process that fosters reliability and validity, and included processes such as triangulation and peer debriefing. Notably, the in-depth interviewing process was conducted in the participants' natural environment, thus promoting a sense of security and openness [11]; and was held until data saturation was reached, as customary with the phenomenological approach. To strengthen the findings that emerged in the personal interviews, a focus group was held and served as an additional source of information.

5.1. Rehabilitation of physical and mental scars

Previous studies reported effects of scar and trauma on body image and self-perspectives of burn survivors, and the significance of these aspects on child and adolescent development. The implication of the fragility of body image at this age was indicated in the fear of being bullied due to their appearance, reported by 51 percent of adolescents with burn injuries. Pediatric burn survivors were found to be prone to developing a low body image compared to the general population, due to their sudden change in appearance and to society's reactions [4].

In our study, difficulty coping with changes in appearance and with the traumatic impacts found expression in a number of domains of functioning; including motor, social, and emotional. Alongside the physical pain of the injury and the difficult medical procedures, patients had to cope with mental difficulties such as loneliness, anxiety, and difficulty participating in social activities. Some of the patients reported difficulty watching or exposing the scarred body parts, and embarrassment when exposing them to others. These difficulties, especially in teenage years, can lead to unfavorable coping strategies that impair social and academic skills, and that can impact the normal development path [7].

5.2. Coping strategy

Due to the associated traumatic experience and the difficulty adjusting to living with scars, burns cause behavioural and motional changes [3]. From the interviews we found that participants reported avoidance from age-appropriate activities, for various reasons: medical restrictions, physical limitations, parental overprotection, and psychological constraints. These restrictions result from coping with the trauma and physical changes, and long absence from routine life. Absences from normative activity may impair general wellbeing, and therefore can increase the risk for secondary insult, such as the development of psychological disorders. This correlates with the literature that reports the bidirectional connection between psychological wellbeing and psychological pathologies, and between social and academic functioning of teenagers [6].

Our study results indicate that the way burn survivor adolescents experience the healing process and adjust to their new situation can affect their selection of coping strategy, and implicate future function in different life contexts. Thus, avoiding normative activity can affect functioning level and self-welfare. Additionally, restrictions caused by the injury can amplify avoidance and loneliness during adolescence and over

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the long term. This emphasizes the significance of positive experiences with the peer group [10].

5.3. Participating in Camp Sababa

Several studies support the contributions of support groups for children with chronic illness such as diabetes and cancer [13]; few focus on pediatric burn patients. Our research helps elucidate, through in-depth interviews, the benefit of engaging with peers and staff to adolescent burn survivors, and the principals and characteristics of camp that helped the most. We found that the most predominant experience was meeting other adolescent burn survivors in a camp setting with normal, fun, and challenging activities (with the proper adjustment and support), and not merely therapeutic professional sessions. We conclude that changes in self-perception occurred due to the combination of participating in these activities with a peer group, accompanied by professional staff, and the encouragement to engage in activities that were adapted to compromised physical abilities. For the campers, this is an opportunity to practice interpersonal interactions in a supportive, non-critical environment. In the interviews, participants expressed the importance of the direct and indirect interpersonal relations with other teenagers.

In the pediatric population, being a part of the peer group can affect overall development and promote a feeling of self-capability [14]. As reported by the interviewees, participation in camp imparted tools for coping with social situations in their age group, and helped foster a feeling of belonging. This helped the participants return to normal social life in their natural environment. Their experience in social situations in a controlled and protective environment may have helped them adopt strategies and gain self-confidence to deal with life outside of camp [15].

5.4. Outcomes of taking part in camp

An important aspect of the rehabilitation process for a burn victim is mental rehabilitation [15]. Considering the process in a holistic way, aimed to promote returning to full functioning and sociability, mental healing is integral to involving the burn survivor in meaningful activity. This is evident from the interviewees' description of an avoidance pattern. The interviews demonstrated that taking part in camp directly entailed a meaningful contribution to the healing process, and indirectly to everyday functioning. Participating in formal and informal activities, and coping with physical and mental challenges within a peer group of equals, helped the participants improve their self-perception and confidence, and accept their new body and identity.

Moreover, obviously camps may be generally beneficial for all children, especially adolescents; however, as we described in the paper, children with burns tend to avoid attending regular camps, and sometimes avoid socializing at all. The environment of burn camp promotes engagement in normative activity by improving self-identity and body image.

This study found that taking part in burn camp helped improve social skills and self-advocacy, both in camp encounters and outside the camp. The adolescents reported that camp time was an opportunity to exercise confrontations

in social situations in a controlled and safe environment. This enhances openness and trust to share injury stories and everyday coping.

6. Conclusions

This is a unique study that demonstrated the importance of operating a burn camp for children, and especially adolescents. The benefit was mostly derived from social involvement, as a promoter of health and welfare. The findings of this study highlight the need to encourage open discussions with adolescent burn survivors. The main conclusions are the importance of such projects for pediatric burn survivors, as an integral part of the rehabilitation process, with multi-year participation after the injury. The findings emphasize the importance of burn camp as a safe environment, with ageappropriate, fun, and challenging activities; with mutual support in the peer group, in a supportive atmosphere. Furthermore, participants requested that the project be expanded to include additional activities throughout the year. We also found that participants' families benefitted substantially, as they generally experience guilt feelings and loneliness in confronting the situation. Although the methodology was precise and profound, due to the small sample we have to be caution and modest when project the conclusions on the general population. This exploratory research can become a base for building and choosing research tools and can be used as a sequential research, which will be used to further deepen and develop a quantitative research.

Declarations of interest

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Yehiel Hayun: Project administration, Methodology, Writing original draft, Writing - review & editing. Anat Ben-Dror: Project administration, Methodology, Investigation, Formal analysis, Writing - original draft. Naomi Schreuer: Project administration, Methodology, Investigation, Formal analysis, Writing - original draft. Yuliana Eshel: Project administration. Dean Ad-El: . Asaf Olshinka: Methodology, Writing - original draft, Writing - review & editing.

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