

THE ROLE OF BURNS CAMP IN THE RECOVERY OF YOUNG PEOPLE FROM BURN INJURY:

A qualitative study using long-term follow-up interviews with
parents and participants.



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The role of burn camp in the recovery of young people from burn injury: A qualitative study using long-term follow-up interviews with parents and participants.

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Abstract

Background: Children and adolescents recovering from burn injury are at heightened risk of psychosocial problems. An integrative form of psychosocial intervention is burn camp. However, evidence about burn camp effectiveness is equivocal.

Objectives: This study examined the role of therapeutic camp experiences in the recovery journeys of children and adolescents who had experienced burn injury and been treated in a tertiary pediatric hospital in Brisbane, Australia.

Methods: Retrospective semi-structured interviews were conducted with youths and parents. Inductive reflexive thematic analysis was used with pooled interview data.

Results: The participants were eight youths who attended at least one burns camp (between 2009 and 2019) and 15 parents of youth campers. An overwhelming majority (96%) reported a positive experience of camp, that they would return, and that they recommended the camp to other youth with burns. The four strengths of the camp experience were fun, adventurous activities; social relatedness (friendships, socializing); camp setting and experience; and acceptance. The four impacts of the camp on youth campers were normalizing (“I’m not the only one”, shared experience); social support (making new friendships, social confidence, mentoring others); psychological recovery (happier, mentally stronger, more resilient, independence building); and confidence (increased self-confidence, increased social confidence, leadership development).

Conclusions: Although this is the first known research about burn camp in Australia, the findings are similar to a handful of other qualitative studies about burn camp experiences and impacts.

Recommendations include future research on aspects of camp experiences that contribute to targeted outcomes, the role of staff and previous camp participants as mentors, and comparisons with other psychosocial interventions for youth burn survivors.

Keywords

burns, camping, child, social adjustment, self concept, emotional adjustment

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1. Introduction

Children face the greatest risk of burn injury [1,2]. Furthermore, children's burn recovery journeys involve navigating both physical development and psychosocial challenges during adolescence [3-5]. As a result, children and adolescents with burn injuries are at greater risk of psychological and social problems than healthy controls [3,6-8].

Recovery from traumatic burn injury is influenced by a complex interplay of pre-burn (e.g., age, gender, and personality), burn (e.g., severity, location, and event), and post-burn factors (e.g., quality of life, self-confidence, social support, body image, mood, and hope) [3,7,9]. Children and adolescents are particularly vulnerable as they are already undergoing significant developmental changes. For example, time away from school and extracurricular activities can result in fewer opportunities to develop social skills and to deal with peer rejection and bullying [7,10,11].

One form of psychosocial intervention for youth who experience injury, disability, and/or chronic illness is adventure- or camp-based programs. These programs use diverse approaches, but draw on foundations in positive youth development [12], therapeutic camping [13], and adventure therapy [14]. It has been estimated that there are over 400 medical speciality camps, servicing approximately 30,000 pediatric clients, annually in the USA [15]. In Australia, camp programs have been conducted for those recovering from cancer [16], HIV [17], and acquired brain injury [18]. Such programs typically aim to foster psychosocial development, particularly self-esteem and social confidence, through residential, multi-day, "place apart" experiences. These experiences involve fun and challenging outdoor activities and social interaction with others who are experiencing similar health problems, under the guidance of supportive staff, including health professionals [19].

Evidence about the impact of medical speciality camps on psychosocial functioning is promising, but far from comprehensive [20]. For example, oncology camps can improve physical activity and fatigue [21], cancer knowledge [19], psychological well-being (such as mood, self-concept, quality of life, self-esteem, hope, and emotional well-being) [19,21-23], and social well-being (such as empathy, social acceptance, and friendship) [19,22,24]. There is also evidence of positive effects of camps for

children with diabetes [25], kidney disease [23], congenital heart disease, epilepsy, juvenile rheumatoid arthritis, obesity, and other chronic illnesses [24,26]. However, evidence about the psychosocial processes and outcomes of camp programs for youth who have experienced burn injury is more limited and equivocal.

Residential camps for youth who have experienced burn injury have been conducted since at least the 1980s [27-29]. In 2010, it was estimated that there were approximately 60 camps worldwide [29]. Currently there are 31 member camps of the International Association of Burn Camps [30]. A recent systematic review of 11 English-language articles about 10 studies published prior to May 2018 of the effect of therapeutic camps on the psychosocial functioning of 711 burn survivors reported contrasting findings: quantitative studies showed little to no long-term positive impacts whereas qualitative studies were overwhelmingly positive [28]¹. The quantitative evidence shows minimal impact of burn camps on measured outcomes, most commonly self-esteem and body image [28]. Two of the seven quantitative studies reported short-term benefits. For example, self-esteem improvements were maintained at a one-year follow-up in 49 USA children who returned for a second burn camp [11]. However, self-esteem and body image improvements were not maintained at a 16-week follow-up in a study of 52 Dutch children who attended a burn camp [32]. Armstrong-James et al. [33] reported mixed pre-post survey results for 23 children who attended a UK burn camp. There were positive changes in self-perceived stigmatisation and body image based three months following burn camp. However, there were no changes for social comfort and parents reported poorer behavioural conduct by their child following camp.

The qualitative research about youth experiences of burn camp has been more positive, identifying several psychosocial benefits from the perspectives of campers, parents, and staff. These benefits include enhanced self-confidence, body image, social competence, coping skills and independence [27-29, 32, 34-37]. The inconsistency between quantitative and qualitative findings is not readily explained. Kornhaber et al. [28] suggest that it may result from a lack of comparability between the constructs measured in quantitative and qualitative designs, the relatively short duration of burn camp interventions, overly complex quantitative measures for young people, low small sample sizes, and/or

inclination towards socially desirable responding to interview questions. Regardless, this supports the view that more work is needed to develop evidence-based interventions to assist young people recovering from burn injuries [3].

In the Australian context, there is no known research about the psychosocial processes and impacts of camp experiences for youth who are adapting to burn injury. The current study sought to help address this gap by investigating a well-established camp program (Camp Oz) for youth with burn injury in Australia. The aim was to retrospectively explore the camp experiences and longer-term psychosocial impacts of burn camps on child and adolescent burn survivors from the perspectives of youths and parents.

2. Methodology

2.1 Study Design

A qualitative research design was used, with all data collected during follow-up interviews.

The project team had research and clinical backgrounds in pediatric burns care (MS), outdoor adventure interventions (AS, JN), occupational therapy (MS), and psychology (IG, JN). JN and MS have led the design and analyses of peer-reviewed qualitative and mixed method studies. MS worked clinically in the setting at the time of the current study and was CHQ program lead for all burn camps during the study period except one (2012) due to leave arrangements.

This study received human research ethics approval from the University of Canberra (20181556) and the Children's Health Queensland Hospital and Health Service Human Research Ethics Committee (HREC/18/QCHQ/48922). Administrative ethical approval was also obtained through Children's Health Queensland (SSA/2019/QCHQ/48922). The Consolidated Criteria for Reporting Qualitative Research (COREQ) [38] was used to guide the reporting and preparation of this manuscript.

2.2 Study population and setting

All youths who attended at least one burn camp between 2009 and 2019 were eligible to participate in the current study, as were their parent/guardians. Youths who attended the camp had received burns treatment at the Stuart Pegg Paediatric Burns Centre (Queensland Children's Hospital, Australia).

This is a statewide service, with the most common patient profile being male (60%), aged below two years at time of injury, with scald or contact burns [39]. The majority of burn injuries were below 5% total body surface area (TBSA).

Participation in the study was voluntary. The consent process ensured that participants were informed that any information they provided would be confidential and that they could choose to withdraw at any time.

The burns clinical staff team, including music therapists, nurses, occupational therapists, physiotherapists, psychologists, and social workers, collectively identified young people with burns who could potentially benefit from participating in the annual burn camp. This approach was supported more broadly by the Children's Health Queensland Hospital and Health Service holistic integrated care strategy [40].

2.3 Camp Oz intervention

Camp Oz is a three-day residential camp conducted annually since 2008 through the Pegg Leditschke Children's Burns Centre at Queensland Children's Hospital (previously Stuart Pegg Paediatric Burns Centre, Royal Children's Hospital, Brisbane) in collaboration with the Bornhoffen branch of the Police-Citizens Youth Club (PCYC Bornhoffen), Queensland. A key rationale for this program is that children who are admitted to hospital with burn injury often also have heightened developmental risk profiles in other areas, such as with family, schooling, and psychosocial skills. Thus, the burn camp program aims to provide early intervention to enhance personal coping resources for adapting not only to the burn injury, but also to other challenging life circumstances, using a learner-centred approach [41].

The annual camps are typically attended by 20 to 30 youth participants aged 8 to 16 years and approximately 6 to 10 hospital staff and/or volunteers (including occupational therapists, physiotherapists, nurses, social workers, music therapist, and burn researchers) and 3 to 5 Bornhoffen Leadership Development Facilitators. The Children's Hospital Foundation has financially supported Camp Oz with approximate costs of \$15,000 to \$21,000 (AUD) per year. The camp drop-off point was at the hospital, which allowed for annual clinical check-ups to be conducted on the first morning of the first day. This was beneficial as some families had to travel for several hours from regional and rural locations and were therefore able to access financial support for travel.

The main camp location since 2008 was the Police Citizens Youth Club Bornhoffen Leadership Development Centre, located in sub-tropical hinterland. An alternate, coastal location (Point Lookout Surf Lifesaving Club, Stradbroke Island) was used for three programs (2012, 2016, 2018). Camps

were two nights and three days in length. Participants were divided into three age groups (8 to 10 years, 11 to 13 years, and 14 to 16 years). From 2015, selected former camp participants (16 to 18 year old) were invited to return for leadership training and participate in camps as a mentor. Each group was accompanied by a PCYC leader and a clinical or research staff member (e.g., PhD students) working in the burns centre, as well as a peer mentor where available. The main accommodation was in dormitories, with communal meals. Each program was designed and matched to the profile of the young people attending, with consideration to their readiness and the capability of the adult leaders accompanying them. The main camp activities were designed to be progressively more challenging for each age group, and included ropes challenge courses, abseiling, creeking, orienteering, hiking, camping, group games, raft building, and canoeing. A constant connection to the choice and challenge are reinforced to participants through a challenge by choice philosophy. Challenge by choice helps young people to be generous about their assumption of themselves and others, reduce judgements and dispel concerns about self-image, acceptance, and the perceived safety of the program experience [41]. An example program has been included, as well as further information about the culture and approach taken in the design, delivery, and supervision of the program (Supplemental File 1).

Since 2014, a service level agreement has been negotiated annually between Children's Health Queensland (CHQ) and Police Citizens Youth Club - Bornhoffen. The CHQ program lead was responsible for initiating a risk assessment management plan, informed by Bornhoffen Leadership Development, CHQ internal Procurements and Legal department representatives, and endorsed by the CHQ Executive sponsor.

2.4 Procedures

PCYC Bornhoffen sent a SMS message to the contact parent/guardian of the 83 youths who attended the burn camp between 2009 and 2019 to ascertain whether they were willing for their details to be passed on to the researchers for the current study. There were 45 (54%) affirmative responses, 29 (35%) non-responses, 7 (8%) negative responses, and 2 (2%) indicated that they were no longer the

custodial parent/guardian. Affirmative respondents were then contacted by the University of Canberra research team to request their participation and/or their child's participation in a telephone interview. Up to two SMS reminder messages were sent to these contacts if they didn't reply.

2.5 Data collection

A semi-structured interview protocol was developed for caregivers and young people for the current study (see Supplemental File 2 and 3). The protocol included mostly open-ended questions about the camp experience and camp impacts with some close-ended rating questions about the nature of the burn injury (age, location, and mechanism, recovery) and overall ratings of the camp experience using a 5-point or 10-point Likert scale.

Brief semi-structured interviews were conducted by a team of five third year undergraduate psychology students who each completed 120 hours as research assistants as part of work-integrated learning internship experiences for academic credit. Interviewers were trained by JN in how to conduct, record, and transcribe phone interviews. The 15 to 20 hour research interviewer training program, adapted from the phases suggested by Goodell et al. [42], was completed by the interns before they conducted their first interview for the current study.

Interviews varied in length, ranging between 7 to 34 minutes ($M = 14.4$ minutes). Where a parent and a youth from a single family (dyad) participated, the interviews were conducted separately. Interviews were audio recorded, transcribed, checked, and de-identified by the University of Canberra research team.

2.6 Data analyses

An inductive reflexive thematic analysis approach (identifying patterns of meaning using the content of the interview data) [43,44] was used to analyze the open-ended responses by deriving codes, then themes, about camp experiences, the psychosocial processes, and program impacts of young people's participation. A consensus approach was used whereby IG and JN (who had not been directly involved in facilitating the camps) familiarised themselves with the interview transcripts and co-

developed a codebook. Each transcript was independently read and coded by the two coders (IG and JN). In the small number of instances where there were coding discrepancies, these were discussed between the two coders and a consensus was reached. Multiple response analyses were used to statistically summarise the extent to which each theme was expressed by participants. Responses to closed-ended interview questions were entered into a spreadsheet for descriptive statistical analysis.

3. Results

Twenty-three interviews were conducted. A third of the interviews were with youths ($n = 8$; 35%) who attended Camp Oz and two-thirds were with parents of youths who attended these camps ($n = 15$; 65%) were completed. Six (26%) of the interviews were from matched youth-parent dyads. The interviews were treated as a single group for analytical purposes due to the small sample size.

The median age of the 23 youths referred to in the interviews (i.e., self or child) at the time of their first camp was 11.2 years (ranging from 8.1 to 14.9 years). Interviews took place between 0.6 and 9.6 years after youths attended their first Camp Oz ($Mdn = 1.6$ years). The idea for attending the camp, in almost all cases, had been presented to the youth and their parents by clinical staff at the hospital burns unit, usually during regular check-ups. The age when the burn injury occurred ranged from birth to 13 years ($Mdn = 4.75$ years). Burn mechanisms were reported as direct contact with a heat source (e.g., muffler, coals, stove top; $n = 6$), scalding (e.g., boiling water, super-heated food; $n = 6$), flames ($n = 5$), friction (e.g., road surface, exercise equipment; $n = 4$), chemical burn ($n = 1$), and unidentified ($n = 1$). Almost all youths attended more than one camp ($n = 21$; 92%), whilst two (8%) had attended only one camp (in 2017 and 2019 respectively) at the time of interview.

Eight youths (35%) experienced burns to their head, neck, and upper limbs, of whom six also experienced a burn to their torso and four to their lower limbs. Four youths (17%) experienced burns to their torso, of whom three also experienced a burn to their upper limb, while one was also burned on their lower limbs. Six (26%) of the youth participants experienced burns to their upper limbs, of whom three also experienced burns to their lower limbs. Five (22%) youths experienced burns only to their lower limb. Visibility of the burn scar(s) was perceived as moderate (i.e., between “somewhat” and “pretty” visible) on a subjective 5-point Likert scale (ranging from 1 = Not visible at all to 5 = Very visible); ($M = 3.54$, $Mo = 5$; $n = 20$; dyad scores were averaged to create a single visibility score). However, there was considerable variability, with 40% of participants reporting maximum visibility. Participants rated recovery from the burn injury as very high (between “pretty well” and “very well”) at the time of interview on a 5-point Likert scale (ranging from 1 = Very poorly to 5 = Very well; ($M = 4.50$; $Mo = 5$; $n = 19$; dyad scores were averaged to create a single recovery score).

3.1 Program context

Almost all participants reported positive experiences of camp ($n = 22$; 96%). One youth respondent had a mixed response because, being unable to recall their burn experience as an infant, they reported difficulty relating to the traumatic burn experiences of other camp participants. Four themes about the strengths of the camp experience were derived (in order of descending frequency): fun, adventurous activities (especially abseiling, creeking, high ropes, hiking, kayaking, swimming), social relatedness (friendships, socialising), camp setting and experience (fun and enjoyment, locations, staff, time away), and acceptance (confidence, sense of community). These themes are described further in Table 1.

Activities were the standout strength, mentioned by 83% ($n = 19$) of respondents and constituting a third (32%) of all comments. Social relatedness was also very prevalent, mentioned by 74% of respondents ($n = 17$), the general camp experience (56% of cases; $n = 13$) and experience of acceptance (48%; $n = 11$) were each also reported by approximately half of the respondents (see Table 2).

Participants were also asked about the low points, or worst aspects, of the young person's camp experiences. The majority did not report negative experiences of camp (61%; $n = 14$). The remainder ($n = 9$) reported a total of 11 varied responses which differed from the themes about strengths of program experiences. Food for dietary requirements (pescatarians and vegetarian) and the weather (raining and cold) each received two responses, while insects, homesickness, being exposed to the recent serious burns of another camper, transport, repetitiveness of camp activities, and the camp being too short each received one response. Due to the limited number and pragmatic nature of these responses, they will be discussed further in the program improvements section.

3.2 Program outcomes

Interview participants were asked about what effects Camp Oz had on campers. Of those who responded ($n = 20$), it was clear that the camps had a positive experience on youth ($n = 19$; 95%). One respondee indicated a neutral effect from the camp, arising from a very positive experience at the first camp followed by a less positive experience at the second camp due to boredom arising from the repeated nature of the experience. Thematic analysis of interview responses derived four themes about the impacts of the burn camps on youth campers (in order of descending frequency): normalising (“I’m not the only one”, shared experience), social support (making new friendships, social confidence, mentoring others), psychological recovery (happier, mentally stronger, more resilient, independence building), and confidence (increased self-confidence, increased social confidence, leadership development). These themes are described further in Table 3. The number of participants endorsing each theme is provided in Table 4. The normalising experiences of camp were noted by 91% ($n = 21$) of the respondents, constituting 30% of all comments. The availability of social support through camp was also strongly endorsed, mentioned by 78% of respondents ($n = 18$; 25% of responses), while psychological recovery from being at camp (74% of cases; $n = 17$, and increased confidence arising from being at camp (65%; $n = 15$) were reported by approximately three-quarters and two-thirds of respondents respectively.

Participants were also asked to rate how worthwhile the camps had been for the youth camper on a 10-point scale (from 1 = “Not very worthwhile” to 10 = “Very worthwhile”). The results again reflected highly positive experiences, with 19 (83%) participants rating worthwhileness 10 out 10 ($M = 9.61$).

Participants were asked whether the youth camper would return to Camp Oz, based on their experiences. Of those who responded ($n = 16$), the majority indicated they would return ($n = 14$; 88%), while one indicated that they would “maybe” return (due to exceeding the upper age limit), and one responded that they would not return (due to perceived repetitiveness of the camp experience). Participants were also asked whether they would recommend the camp to others. All respondees ($n = 21$) reported that they would recommend the camp to other youth with burns.

3.3 Improvements

Most respondents indicated that there was nothing that required improvement ($n = 14$; 61%).

Suggestions for improvements were quite idiosyncratic and did not tend to cluster into themes. The most common requests were for different camp locations, a greater variety of activities, and more obvious support around the mental impact of suffering burns and how to cope with the sequelae of burns (e.g., one-on-one counselling, group “chat” sessions, older participants sharing coping strategies), which each received two responses. There were single responses about food, access to camp photos, availability of preliminary information about the camp, and making the camp longer. Participants were also given the opportunity to make any other comments about their, or their young person’s, experiences of camp. Most respondents ($n = 16$; 70%) made additional comments. Of the 27 additional comments, 19% ($n = 5$) indicated that the camp was well organised, 19% ($n = 5$) noted that the program was well structured, 15% ($n = 4$) were about staff, mentors and volunteers being positive and helpful, and 11% ($n = 3$) were grateful for the camp. Less frequent responses indicated that camp participants appreciated the food ($n = 2$), activities ($n = 1$), and low-cost nature of the camp ($n = 1$).

4. Discussion

This study contributes to the small, heterogenous body of research about psychosocial interventions for youth with burn injury and is the first study of experiences and outcomes of burn camps in Australia. The method used long-term follow-up interviews with youth participants and parents from a well-established camp by Children's Health Queensland. Youths and parents almost universally reported positive experiences arising from the burn camps. Clearly, well designed and supported speciality camp experiences are enjoyable for youth with burns, many of whom participate annually over several years.

The salient aspects of these burn camps according to parents and youths were: fun, adventurous activities, social relatedness, the camp setting and experiences, and a sense of acceptance. Four themes about the impacts of the camp on participating youth were identified: normalising, social support, recovery, and confidence. Previous qualitative research using focus groups with burn camp attendees ($N = 52$) from three USA burn camp programs identified that camp is a place where campers experience a sense of belonging and acceptance, are sheltered from stares and questions, do not have to conceal their bodies, and learn to integrate scars into their overall body image in a positive way [34].

Adventure-based activities provide an opportunity for developing a sense of autonomous achievement by overcoming the physical and mental difficulties that these challenges present. The camps foster a social environment which is conducive to building friendships and normalizing social engagement regardless of individuals' burn or scars [35]. The camp setting and experience is a place apart from everyday social norms and an opportunity to interact with positive staff and older burn patients who role model an optimistic view of the future. The camp also develops an environment of belonging and acceptance through a sense of community and shared experiences [34, 35]. The management of, and the response to, burn scar symptoms (including appearance) by the individual, their peer group, and wider community are considered integral to burn scar health-related quality of life [45].

These key camp processes likely influenced the longer-term outcomes of attending camp. Shared experiences of achievement through the adventurous activities, coping with burns, and the associated sense of community contributed to normalising camp participants' experience of their long-term adjustment to burn injury. The camp increased confidence in social relationships by reducing and removing the sense of difference and otherness in being a burn patient. This led to long-term friendships for some camp participants and provided a model for developing enduring social connections outside of the camp or burn treatment setting. The increase in self-confidence, acceptance of the group, modelling from other campers, and mature burn patients (mentors) provided opportunities for psychological growth and increased resilience. There were indications that the camp experiences led to long-term improvements in self-efficacy and -agency in the form of self-confidence for camp participants.

The themes identified through thematic analysis of camp strengths and outcomes reflect highly positive camp experiences consistent with other qualitative analyses of burn camps for young people [28]. A review of five burn camp studies across Europe showed a similar range of outcomes that participants gained from attending camps [27]. In that study, themes from parent reports of their young person's attendance at burn camp (in order of descending frequency) were increased confidence, friendships and social skills, support through shared experiences, new skills, increased independence, increased ability to cope with their burn, and happiness. The consistency of these results across different locations reinforces the types of benefits that youth typically derive from burn camps.

The themes in the current study are also consistent with those identified for the National Burn Camp in Belgium [37] which found that camp participants learned social skills in a relatively unstructured manner, without specific skills-based interventions. There were also similarities in the participants' ability to put their burns into perspective after socialising with others who were perceived as having worse burn injuries.

The positive changes arising from Camp Oz appeared to generalize to the everyday lives of the camp participants, based on the consistently positive reports up to 10 years later. The high return rate of participants (92%), strong ratings of camp worthwhileness, and high willingness to recommend the camp to others also support the positive impact of the burns camp experience.

The themes identified in the current investigation of the Camp Oz program reflect the therapeutic nature of the camp based on shared experiences in a residential environment and intentional sequencing of outdoor activities. The camp process and activities were aimed at developing social and emotional capability in participants through physical challenges and social networking, with the goal of enhancing participants' ability to manage their everyday challenges and thrive post-injury. The themes demonstrate that the burn camp participants experienced positive impacts through the normalising effect of shared experience with other campers, social confidence throughout the camp, increased psychological resilience from overcoming challenges, and an overall increase in self-confidence.

The heterogeneous nature of the population of burn patients means that a one size-fits-all approach is unlikely to achieve benefits for a broad range of individuals. Thus, the Camp Oz model used a tailored approach which allowed individual participants to engage according to their level of readiness. This was consistent with participant feedback about potential areas for improvement of the camp; for the majority, no obvious improvements were suggested. Some responses suggested a greater variety of locations for the camp and a more structured approach to facilitating the psychosocial aspects of burn recovery. Given the low response rates for these issues it seems unlikely that they would have a notable impact on overall outcomes. There is a risk that more direct therapeutic approach may even detract from the integrated and holistic approach facilitated by Camp Oz through the natural appeal of outdoor challenges and the normalising social environment cultivated at the camp [46].

4.1 Limitations

Two limitations about the current study are worth noting. First, although the whole target population was invited to participate, those with the most positive experiences of the camp were probably more likely to engage, potentially biasing the results. Thus, a more traditional pre- and post-test survey format across camp years, ideally with a control group (e.g., no camp intervention) and long-term follow-up, could provide a more representative research evaluation. Second, the parent and camper interviews were treated as a single group for analytical purposes due to the small sample size and limited number of dyads. This prevented comparison between perspectives of campers and their parents. Future studies could compare perspectives of camp participants and their parents which could provide richer information about the short- and longer-term impacts of the camp experience on youth. Both these limitations appear to be reflected in the inconsistencies identified in the recent systematic review of the effect of burn camps on the psychosocial well-being of youth with burns [28]. This review noted that there was a tendency for quantitative responses to show limited improvements in participant well-being, while qualitative responses showed marked improvements in participant confidence, social skills, and coping skills.

The positive outcomes following attending burn camps and the long-term maintenance of benefits is consistent with the broader adventure therapy approach [47]. The mechanisms of change, however, remain ambiguous and there are questions about whether similar positive developmental outcomes could be achieved via other psychosocial support approaches [48]. Further research to operationalize the change process activated by the camp experience is indicated. This may allow for a more consistent, tailored approach to assisting youth with burn injuries to generalize positive camp experiences to their day-to-day lives. The involvement of hospital staff in conducting the burn camps is a unique feature of the Camp Oz approach. Research into the impact of this involvement on youth attitudes to regular treatment, staff responses to youth with burn injuries, and the overall impact on treatment outcomes would be valuable in understanding the use of an integrated healthcare model in the camp context.

5. Conclusion

This study makes a unique contribution to burn care research by presenting the first evaluation of burn camp experiences in Australia, based on a well-established program. This is also the first known long-term retrospective study of burn camp participants. The results could inform the design and delivery of future burn camp programs in Australasia and beyond and may be relevant to the development of other interventions to support the psychosocial recovery of youth with other health conditions that affect life trajectory.

¹ Kornhaber et al.'s [28] systematic review updates (and is consistent with) an earlier narrative review of the impact of burn camps on self-esteem [29]. Jenkinson et al [31] reviewed five of the same studies as Kornhaber et al. [28] as part of a systematic review of psychosocial interventions for young people with visible differences and came to similar conclusions.

Declarations

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Table 1. Themes, Codes, Definitions, and Representative Interview Extracts for Program Experience Strengths

Theme	Codes	Description	Interview extracts*
Activities	General, abseiling, bushwalking, campfire, camping, canoeing, climbing, creeking, flying fox, glow worms, high ropes, hiking, kayaking, new, swimming, water	Engagement in adventurous activities that enhance self-confidence, involve working with others, and have natural consequences of actions.	"I think the physical activities, the fun activities, and the friendships probably were the highlights" [5P]; "The first year she came back and told me she was really proud of herself with the ropes" [52P]; "Brilliant activities, he looked forward to it every year" [57P].
Relatedness	Socialising, friendships, belonging	Building trusting relationships with similar others and providing an opportunity for feedback and shared experience in social interactions.	"It was especially good when I went back again the following year because I had friends" [58Y]; "I really enjoy Camp Oz, the social side of it ... just group bonding. It was something that I always looked forward to" [60Y]; "She loves all the people that go to it [camp]" [9P].
Camp setting and experience	Fun/enjoyment, staff, locations, food, time away	The "place apart" camp milieu, including natural environment location, friendly/supportive staff, affording new/unencumbered perspectives.	"One of the top three things of my childhood" [57Y]; "He said they were looked after very nicely, a lot of supervision which we were happy with" [7P];

			"People there ... from the hospital were good" [15Y]
Acceptance	Confidence building, sense of community, mentoring others	Normalising experiences of burn recovery through focus on self- and other-acceptance, successful encounters with challenging activities, and typical, age-consistent friendships.	"Knowing that I'm not alone ... I'm not the only one that's gotten burned and I know that other kids have gotten burned" [47Y]; "With his scars, he's not the only one, there's other people out there and they do get better over time" [40P]; "They're all here because of the burns so ... nobody would say anything [negative]" [9P].

Abbreviations: P = parent; Y = youth

* Transcripts are numbered according to the random allocation of the 83 youths who had attended Camp Oz between 2009 and 2019

Table 2. Multiple Responses Analysis of Program Experience Strengths

Theme	<i>n</i>	% responses	% cases
Activities	19	32	83
Relatedness	17	28	74
Camp Setting and Experience	13	22	56
Acceptance	11	18	48
Total	60	100	261

Table 3. Themes, Codes, Descriptions, and Representative Interview Extracts for Program Outcomes

Theme	Codes	Description	Interview extracts*
Normalising	Broader perspective, sense of community, confidence in visible difference	Normalising impact of attending camp on participants' perceptions of their injuries and scar(s), leading to improved self and social confidence about their visible difference(s).	"Helped her realise that she's just like everybody else still" [6P]; "They don't feel like they are alone, it's not an exclusive experience, they're all dealing with their injury" [7P]; "Showed her that even though she's got these injuries she can still do whatever she wants to ... it's not going to stop her" [18P]; "He returned to being a more able person mentally and physically because he got over anyone wanting to see his leg [40P]"
Social Support	Compassion/empathy, friendships, acceptance of others	Positive impact of attending camp on participants' psychosocial development and peer relationships	"Doing things and meeting people - it definitely helped with making me happy" [57Y]; "I sort of felt really isolated after I got burnt and now I'm going to Camp Oz, hanging out with other burn kids and it just shows you that it's all good and it's not a big deal" [46Y]; "I would get bullied about it but when I went to Camp Oz I found [burns] worse than mine ... it really helped me [9P]"

Psychological recovery	More resilient, mentally stronger, happier, independence building	Positive impact of attending camp on psychological resilience and well-being.	"Because she's gone to camp and they talk about lots of mental health things as well as doing the stuff, she's really good at verbalising how she's feeling" [6P]; "Once you come back, you're definitely in a better mind-frame" [57Y]; "She was having less anxiety attacks in the mornings in the months post camp" [6P; 1g]; "He wasn't as withdrawn or as angry" [7P];
Confidence	Increased self-confidence, increased social confidence, leadership development	Positive impact of attending camp on participants' self-confidence and independence.	"She's just finding that confidence in herself again from the camp" [6P]; "He's more independent and confident" [7P]; "It has helped me be more confident, more outgoing" [55Y]

Abbreviations: P = parent; Y = youth

* Transcripts are numbered according to the random allocation of the 83 youths who had attended Camp Oz between 2009 and 2019

Table 4. Multiple Responses Analysis of Program Outcomes

Theme	<i>n</i>	% responses	% cases
Normalising	21	30	91
Social support	18	25	78
Recovery	17	24	74
Confidence	15	21	65
Total	71	100	308

Supplemental File 1 Program design and intent and example timetabling for Camp OZ and OZ
Mentor

The culture or approach of a service and the program design and supervision can be invisible to the inexperienced practitioner. It is included here because of its influence on the intent of the program and how the service is delivered. We hope that other agencies may choose to duplicate the program in therapeutic settings. The following key elements are the non-negotiables in effective program delivery and supervision for PCYC Leadership Development in providing a collaborative service with the Children Health Queensland. They apply specifically to the Burns program as well as other programs with special needs populations.

Alignment - The program is designed and matched deliberately to the profile of the young people attending with consideration to their readiness and the capability of the adult leaders accompanying them. Readiness is “a state where learning can be accomplished given the appropriate environment” [49, p. 63]. Readiness of all people is determined by considering mental, physical and emotional ability and prior experience. There is a direct alignment between the learning outcomes that drive the rationale for the program and the experiences offered as part of the program timetable. Many experiences have natural learning characteristics that evoke reflection, and these can be further enhanced through intentional and guided reflection that is free from illustrative approaches to learning. We like to ask people what they have learnt rather than tell them what we think they should have learnt.

Assessment of Risk – An experience or program or the sequence of experiences form the risk profile of the program. Consideration is given to the profile and the level of challenge required to help young people to shift their thinking in line with the intended outcomes. Too much challenge and people feel disengaged or feel failure, too little challenge and they can be bored or easily distracted. Effective programming balances the risk and benefit for all people.

Personal Choice - A constant connection to the choice and challenge are reinforced to participants through a challenge by choice philosophy. Being able to choose your engagement is paramount for safety. Saying no to an experience is just as powerful as saying yes for any person. The benefit and agency this brings for a young person is important due to the risky nature of program participation with an injury. Also, additional variables exist during the program experience through simple environmental changes like the weather, participants energy levels and group cohesion. It is also important to foster a recognition of the difference we feel/experience in each other. Challenge by choice helps young people to be generous about their assumption of themselves and others, reducing judgements and dispelling concerns about self-image, acceptance, and the perceived safety of the program experience.

Positive Environment - Scaffolding around the group's interaction provides a positive group environment and interaction. Interpreting and leading the group dynamic with goal setting and agreements on the important positive behaviours help to establish a trust building environment which in turn empowers participants to reconsider respect for self and others and re affirms their value.

Small group ratios and consistency of leadership - A ratio of 1 x Facilitator and 1-2 adult leaders and 6-8 young people who are grouped in a similar age for activity groups enables age-appropriate conversation and in terms of their readiness and maturity. Small groups of like-minded young people coupled with a consistent facilitator and adult leader link learning safety and trust between the group. When the environment is safe young people can experiment with alternate ideas of who they are and the possible choice of responses thinking and feeling about themselves is expanded.

A Learner centred approach - Encourages all stakeholders to put the learner and their potential development first before other considerations that are provider centred. We tend to set up systems that make it easier and more effective for us to do our work as the provider at the expense of the learner which can diminish their engagement and learning experience.

Collaboration and Partnerships – The design, delivery and supervision of a program is then a complex venture and beyond the simple act of timetabling activities with fixed leaders per activity. Imagine trying to deliver a program without a sound knowledge of the young person’s injury, current treatment and the modifications required with the activity to help the young person achieve a positive outcome. The skills to make these decisions do not sit neatly with one person or agency. To meet the complex need means we need everyone’s attention, skill, contribution. Multiple disciplines and multiple teams working together.

Experiential learning - Moments of action, reflection and learning become the key pieces for participants and facilitators to focus their efforts and discussions. As the learning builds momentum participants can experience “altered thinking, modified attitudes and the repertoire of possible behaviours is expanded” [50, p. 23]. Ultimately these changes can be applied beyond the here and now of the program and research has demonstrated lasting changes for participants.

This summary has attempted to shine the light on the invisible elements of a program that can be lost in the hype or energy from participants. They generally talk about the different activities and their experience of them. How the experiences are delivered and led is what defines a quality program. The program and intent with these elements have a cumulative effect for the participant. When the above key elements are missing the effect can negatively impact the efficacy of a program and by extension the potential benefit for young people.

We encourage all conversation and reflection about the culture and approach taken in the design, delivery, and supervision of programs for young people with any injury, complex history or ability. We wish every success to the reader who wants to duplicate the program, recognise it is a complex endeavour and extend the hand of collaboration.

Time				
	Group 1 8 – 10 years	Group 2 11 – 13 years	Group 3 14 -15 years	Mentors 16 -18 years
Day 1				
08:30am	Meet at QCH for a 9am departure			
10:30 - 12.15	<p>Approximate arrival time</p> <p>Welcome – General house keeping</p> <p>Move into Cabins</p> <p>Introductory Games</p> <p>Split into groups – Group Development Activities</p> <p>Climate setting & Working Agreement</p>			
12.30	Bornhoffen Lunch			
	Collect boxed afternoon tea – Fresh fruit available			
1.15 – 5.00	Bushwalk	Canoe Experience	Raft Building Challenge	Trust & Leadership development
5.00	<p>Bornhoffen staff go off duty - duty of care handed over to QCH</p> <p>Free time</p>			
6.00	Bornhoffen Dinner			
7.00	Evening program run by Bornhoffen Staff			
	Group Games	Glow Worms	Glow Worms	Expedition prep

Day 2				
6.45	Sweep and Tidy Cabins			
7.00	Bornhoffen Breakfast			
8.15	Morning Warm Ups			
	Collect boxed morning tea – Fresh fruit available			
8.30 – 12.15	Low Ropes/ Orienteering	Static Ropes Course	Advanced Creeking	Hike to Grassy Ridge/ set camp
12.30	Bornhoffen Lunch			Expedition lunch
	Collect boxed afternoon tea – Fresh fruit available			
1.15 – 5.00	Lower Waterfall Abseil	Camp out preparation/ Flying Fox	Dynamic High Ropes	Hike onto Turtle Rock – Caving and Abseiling
5.00	Bornhoffen staff go off duty - duty of care handed over to QCH Free time			
6.00	Bornhoffen Dinner	Expedition dinner		
Evening	Natural Bridge - Glow Worms	Campfire and games	Campfire and games	Campfire and Group Theory
Campsite	Stay in Cabins at Bornhoffen	Camp in tents at Synergy Corner	Camp in tents at Blue Yabby Clearing	Camp in tents on Grassy Ridge
Day 3				

6.30	Pack Bags, Sweep and Vacate Cabins/ Pack away camp			
7.00 – 8.00	Bornhoffen Breakfast	Expedition Breakfast		
8.15	Morning Warm Ups			
	Collect boxed morning tea – Fresh fruit available			
8.30 – 12.15	Net Catch/ Intro to Creeking	Return to Bornhoffen and return camp equipment/ Intermediate Creeking	Return to Bornhoffen and return camp equipment/ Giant Waterfall Abseil	Return to Bornhoffen and return camp equipment/ Giant Swing
12.30	Bornhoffen Lunch			
1.15	Load Buses & Depart for QCH			

The program remains flexible and may be modified due to weather, safety considerations or group needs.

Supplemental File 2 Semi-structured interview questions (Parent/Guardian)

Information and Consent

1. Prior to conducting this interview, the **Participant Information Sheet (Parent-Guardian)** should have distributed and read, and the **Consent Form (Parent-Guardian)** should have been signed and returned to the interviewer.

Introduction

1. **Introduction:** “Hi [Name], my name is [Name] from the University of Canberra. Thanks for agreeing to participate in this interview about [Name] and their experiences of the Camp Oz program for a research study.”
2. **Key points from Information Sheet:** Remind participant, as appropriate, about key points from the Information Sheet:
 1. **Length:** The interview is expected to last approximately **20 to 30 minutes**.
 2. **Voluntary:** Participation is **voluntary** and any questions can not be answered.
 3. **Audio recording:** Check whether participants are willing for the interview to be **audio recorded** and if yes, then start audio recording.

About your child

1. I’m wondering if it would be OK to ask some basic questions about [child’s name] burn injury?” If yes:
 1. “How long ago was [name’s] burn injury?”
 2. “How did [name] get his/her/their burn injury?” [mechanism of injury]
 3. “Where did [name] get burnt?” [on body]
 4. “How visible would you say [name’s] burn injury is to others?”

1	2	3	4	5
Not visible at all	A little visible	Somewhat visible	Pretty visible	Very visible

e. “How well do you think [name] has recovered from and adapted to his/her/their burn injury?”

1	2	3	4	5
Very poorly	Pretty poorly	OK	Pretty well	Very well

Initial engagement

1. Initial engagement:

1. “Could you tell me about **how [name] got involved** in Camp Oz?”

2. Indicators of need:

1. “What was happening in [name’s] **life at the time?**”. Prompt, if needed:

1. “Personal”

2. “Relationships?”

1. “At home?”

2. “With other kids?”

3. “At school?”

3. “Mental health and emotional well-being?”

4. “Physical health?”

5. “School attendance and academic performance?” (Learning and development)

6. “Behavioural conduct?”

1. “Getting into trouble?”

Camp Oz experience

1. “Could you tell me about [name’s] **experience** of Camp Oz – in other words, how did it go for him/her/they?” Prompt, if needed:

a. “What went well?” [and explore why?]

“What were the highlights/best things?” [and explore why?]

1. Experience of physical activities and burn injury?

2. Coping with being away from home, friends, etc.?

a. “What didn’t go so well?” [and explore why?]

“What were the low points/worst things?” [and explore why?]

Program outcomes

1. **Program effects:**

1. “Overall, what **effects**, positive or negative (if any), did Camp Oz have on [name]?” Prompt, if needed:

1. **Personal development**

“What did [name] learn about him/herself?”

e.g., Strengths? Weaknesses?

2. **Social development**

“What did [name] learn about others?”

e.g., How [name] responds to others? How others respond to [name]?

3. **Physical health**

“How did Camp Oz affect [name’s] physical health?”

e.g., burn injury, fitness, well-being?

4. **Body image**

“How did Camp Oz affect how [name] feels about his/her/their physical appearance?”

5. **Mental health**

“How did the program affect [names’s] mental health?”

e.g., thoughts, emotions/feelings?

6. **Behavioural conduct**

“How did the program affect [name’s] behavioural conduct?”

e.g., at school, social life, at home?

7. **School/Academic performance**

“How did the program affect [name’s] school attendance and academic performance?”

e.g., attendance, school enjoyment, academic achievement, training participation, co-curricular engagement?

8. **Outlook on the future**

“How did Camp Oz affect [name’s] outlook about his/her/their future?”

2. **Worthwhileness:**

. Overall, how **worthwhile** would you say the Camp Oz program has been for [name] (out of 10)?

(1 = useless / waste of time to 10 = extremely beneficial)

a. Why?

b. Would [name] like to **return** to Camp Oz (as participant? mentor?)

c. Why/why not?

d. Would you **recommend** Camp Oz to others?

e. Why/why not?

3. **Program improvements:**

. What **improvements** would you recommend for Camp Oz?

Other comments

1. “Do you have any **other comments** about [name’s] experiences of Camp Oz?”

Conclusion

1. **Thank-you:** “Thank-you very much for time today, we much appreciate it.”

2. **Stop recording**

3. **Results summary:** Check whether the interviewee wishes to receive a summary of the results. If so, collect email address (on Consent Form).

Information and Consent

1. Prior to conducting this interview, both the **Participant Information Sheet (Parent-Guardian)** and **Participant Information Sheet (Youth)** should have been distributed and read, and the **Consent Form (Parent-Guardian)** and the **Consent Form (Youth)** should have been signed and returned to the interviewer.

Introduction

1. **Introduction:** “Hi [name], my name is [name] from the University of Canberra. Thanks for agreeing to participate in this interview about your experiences of Camp Oz for a research study.”
2. **Key points from Participant Information Sheet:**
3. Remind participant about key points from the Participant Information Sheet:
 1. **Length:** The interview is expected to last approximately **20 to 30 minutes**.
 - a. **Voluntary:** Participation is **voluntary** and any questions can not be answered.
 - b. **Audio recording:** Check whether participants are willing for the interview to be **audio recorded** and if yes, then start audio recording.

About me

1. “I’m wondering if it would be OK to ask some basic questions about your burn injury?” If yes:
 1. “How long ago was your burn injury?”
 2. “How did you get your burn injury?” [mechanism of injury]

3. “Where did you get burnt?” [on body]
4. “How visible would you say your burn injury is to others?”

1	2	3	4	5
Not visible at all	A little visible	Somewhat visible	Pretty visible	Very visible

- e. “How well do you think you have recovered from and adapted to your burn injury?”

1	2	3	4	5
Very poorly	Pretty poorly	OK	Pretty well	Very well

Initial engagement

1. **Initial engagement:**

1. “Could you tell me about **how you got involved** in Camp Oz?”

2. **Indicators of need:**

1. “What was happening in **your life** at the time?”. Prompt, if needed:

1. “Personal”
2. “Relationships?”
 1. “At home?”
 2. “At school?”
 3. “With other kids?”

3. “Mental health and emotional well-being?”
4. “Physical health?”
5. “Other?”
6. “School attendance and academic performance?” (Learning and development)
7. “Behavioural conduct?”
 1. “Getting into trouble?”

Camp Oz experience

1. “Could you tell me about **your experience** of Camp Oz – in other words, how did it go for you?”. Prompt, if needed e.g.,:

1. “What went well?” [and explore why?]

“What were the highlights/best things?” [and explore why?]

1.Experience of physical activities and burn injury

2.Coping with being away from home, friends, etc.?

2. “What didn’t go so well?” [and explore why?]

“What were the low points/worst things?” [and explore why?]

3. Program outcomes

1. Program effects:

1. “Overall, **what effects**, positive or negative (if any), did Camp Oz have on you?” Prompt, if needed:

1. Personal development

“What did you learn about yourself?”

e.g., Your strengths? Your weaknesses?

2. Social development

“What did you learn about others?”

e.g., How you respond to others? How others respond to you?

3. Physical health

“How did Camp Oz affect your physical health?” e.g., fitness, well-being, burn injury?

4. Body image

“How did Camp Oz affect how you feel about your physical appearance?”

5. Mental health

“How did Camp Oz affect your mental health?”

e.g., thoughts, emotions/feelings?

6. Behavioural conduct

“How did Camp Oz affect your behaviour(al conduct)?”

e.g., at school, social life, at home?

7. School/Academic performance

“How did Camp Oz affect your school attendance and academic performance?”

e.g., attendance, school enjoyment, academic achievement, training participation, co-curricular engagement?

8. Outlook on the future

“How has Camp Oz affected your outlook on your future?”

2. **Worthwhileness:**

a. Overall, how **worthwhile** would you say the Camp Oz program has been for you (out of 10)?)

(1 = useless / waste of time to 10 = extremely beneficial)

b. Why?

c. Would you like to **return** to Camp Oz (as participant? mentor?)

d. Why/why not?

e. Would you **recommend** Camp Oz to others?

f. Why/why not?

3. **Program improvements:**

. What **improvements** would you recommend for Camp Oz?

Other comments

1. “Do you have any **other comments** about your experiences of Camp Oz?”

Conclusion

1. **Thank-you:** “Thank-you very much for time today, [name], we much appreciate it.”

2. **Stop recording**

3. **Summary of results:** Check whether the interviewee wishes to receive a summary of the results. If so, collect email address (on Consent Form).