


# An evaluation of the impact of a burn camp on children and young people's concerns about social situations, satisfaction with appearance and behaviour

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## Abstract



**Introduction:** This evaluation aimed to assess the impact of a burn camp on children and young people's concerns about social situations, satisfaction with appearance and behaviour.

**Methods:** Young people completed the Perceived Stigmatisation Questionnaire (PSQ), Social Comfort Questionnaire (SCQ) and Satisfaction with Appearance Scale (SWAP) one month before camp (n=23), on the last day of camp (n=21) and at a three-month follow-up (n=13). Parents completed the Strengths and Difficulties Questionnaire (SDQ) one month before camp (n = 22) and at follow-up (n=12). Parents and young people also completed open-ended questions before camp and at the follow-up.

**Results:** Results in this evaluation were mixed. While parents' reported scores on the SDQ were poorer after camp, young people's reported outcomes on all three measures improved at the end of camp. PSQ and SWAP scores were maintained and improved, respectively, at the follow-up. Qualitative responses were generally consistent with these scores. Significant improvements were found between the scores before camp and at the three-month follow-up for both the SWAP and PSQ. These results indicate that the burn camp may help to improve young people's satisfaction with their appearance and concerns about social situations. However, there was no comparison group and there was a significant loss of participants at follow-up.

**Conclusion:** Burn camps may therefore offer a range of psychosocial benefits to young people with burn injuries. This was the first evaluation to demonstrate a positive impact of a burn camp on satisfaction with appearance and concerns about social situations using outcome measures validated with the burns population.

## Keywords

Burn camp, psychosocial, young people, support, intervention, parent

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## Lay Summary

Burns camps are residential programmes for young people with burn injuries which allow them to meet others who have been through similar experiences, and try out a range of activities in a supportive environment. Previous research has evaluated several aspects of burn camp on young people, including self-esteem, social relationships and emotional/behavioural wellbeing, but has produced conflicting results. This may be because the questionnaires completed by the participants with burn injuries used in these studies were designed for the general population. The current evaluation therefore utilised three questionnaires designed specifically for the burns population with the young people, as well as a generic outcome measure with the parents. Twenty three young people completed questionnaires relating to their feelings about their appearance and social experiences, and twenty two parents completed questionnaires relating to their feelings about their children's behaviour. Results in this evaluation were mixed. The evaluation indicated that, while parents rated their children's behaviour as worse following the camp, the young people felt more positively about their appearance and social experiences after camp. As previous research has found that young people can struggle with their appearance and social situations following a burn injury, this evaluation suggests that a burn camp can be of benefit for these issues. However, it should be noted that significantly fewer participants completed the questionnaires at follow-up compared to the initial questionnaire. In addition, this evaluation did not include a comparison group of young people with burn injuries who did not attend burn camp.

## Introduction

Burn injuries are associated with a range of psychosocial difficulties in children and young people aged  $\leq 18$  years, such as depression, anxiety, and worries about appearance and social situations.<sup>1</sup> Burn camps are specialist residential activity programmes for young people with burn injuries, to allow them to meet others who have been through a similar experience. Although the majority of burn camps do not offer specific psychological interventions, they can offer many psychosocial benefits such as making new friends and learning new skills.<sup>2</sup> The aim of these camps is to provide young people with a fun and supportive environment, in which they carry out activities such as caving, zip wire or swimming, designed to help them deal effectively with the challenges of a burn injury.<sup>3</sup> It is thought that helping CYP (children and young people) to succeed at physical activities may help them feel better about what their bodies can do, which promotes a more positive body image and improves self-esteem.<sup>4</sup>

Previous research has demonstrated remarkable consistency across qualitative studies with young people, parents and staff alike, indicating that they believe the experience of attending camp to be hugely beneficial. For example, Williams et al.<sup>5</sup> conducted focus groups with 52 young people across three burn camps in the USA and found that they provided campers with a sense of acceptance, a greater sense of purpose within life, and increased confidence and self-esteem. Maertens and Ponjaert-Kristoffersen's

qualitative study<sup>6</sup> found that young people, parents and staff reported a number of benefits for the young people attending a camp in Belgium, including new social skills and relationships, increased confidence and a sense of achievement at taking part in activities.

Research employing mixed methods has found similar results from the qualitative elements of their studies. For example, Gaskell<sup>3</sup> collected both qualitative and quantitative data over a five-year period and found that a UK-based camp helped young people to cope positively with their burns as well as improved their confidence and social skills. A later study by Gaskell et al.<sup>7</sup> collected qualitative and quantitative data from five European burn camps using self-report questionnaires and Likert scales. Young people and parents referred to the benefits of shared experiences, friendship and increased ability to put the injury in perspective, as well as improved self-confidence, appearance esteem and social skills. As evidenced by these studies, it is clear that results from the qualitative burn camp literature have produced consistent results. However, the findings from the quantitative elements of these mixed methods studies have not replicated those of the qualitative elements and other studies using solely quantitative techniques have also produced inconsistent results.

For example, a review by Maslow and Lobato<sup>8</sup> reported that the majority of quantitative research into burn camps used the Rosenberg Self-Esteem Scale (RSES),<sup>9</sup> a generalised measure of self-esteem. While some research<sup>10,11</sup> has not identified any improvement in self-esteem, Rimmer et al.<sup>12</sup>

discovered that campers' self-esteem improved from the beginning to the end of camp, although this effect was relatively minor. The cause of these conflicting findings remains unclear. Gaskell<sup>3</sup> refers to the complex nature of self-esteem and the multifaceted constructs of which it is formed, so it is possible that a single measure of self-esteem may be insufficient to properly evaluate the effects of camp. Indeed, Rimmer et al.<sup>12</sup> suggested that future research may benefit from implementing alternative measures of self-perception.

Research conducted since Maslow and Lobato's<sup>8</sup> review has taken additional psychosocial constructs into account. For example, Bakker et al.<sup>2</sup> examined the relationship between camp, self-esteem and satisfaction with appearance at three time points: three weeks pre-camp, then one week and 16 weeks after camp. They also used the RSES but included a burns-specific measure of satisfaction with appearance (a Dutch version of Lawrence et al.'s Satisfaction with Appearance Scale [SWAP]).<sup>13</sup> The study included a comparison group of young people who had had a burn injury but who chose not to attend camp. Results did not identify a change in self-esteem for either the camp attendees or comparison group, in either the short or longer term. However, a small improvement in satisfaction with appearance was noted among the campers when comparing the pre- and post-camp measures, although this effect was not maintained at the 16-week follow-up. However, the Dutch version of the SWAP had not been validated before their study and the authors suggested that their results regarding the effect of camp on appearance need replicating.

Tropez-Arceneaux et al.<sup>14</sup> utilised a number of outcome measures at a burn camp in Nicaragua and determined that camp significantly improved levels of anxiety, depression and self-esteem. However, the camp differed from burn camps in previous, and the current, research as it included both educational and applied 'classroom-type' activities involving reflection on depression, anxiety and self-esteem. The authors also identified cultural differences between their camp and the camps studied in previous research in the US. While the results from this study are very positive, they therefore may not be generalisable to other burn camp research.

The lack of significant findings in many of the earlier quantitative studies may be due to the strong focus on self-esteem, despite qualitative evidence that campers experience benefits that extend beyond this.<sup>8</sup> The positive results from Bakker et al.'s study<sup>2</sup> suggest that investigating additional constructs such as satisfaction with

appearance may provide a more comprehensive evaluation of camps. Although Gaskell<sup>3</sup> examined constructs other than self-esteem (such as social competence, social worries and satisfaction with appearance), she speculated that a lack of consistent findings in her study may be due to the measures used, as generalised measures may fail to consider the issues commonly experienced by young people with burn injuries.

Overall, there remains a need for further research implementing measures of a range of psychosocial constructs appropriate for the young burns population. Kent<sup>15</sup> recommends that research should assess the effect of stigmatisation within disfiguring conditions, while Jenkinson et al.<sup>16</sup> suggest that measures designed to assess constructs such as appearance satisfaction or social confidence should be considered when conducting research into interventions for young people affected by appearance-altering conditions. These suggestions tie in with the previous qualitative findings, which have indicated that camp can improve feelings towards appearance<sup>17</sup> and confidence within social situations.<sup>3</sup> Furthermore, parents' qualitative responses in the aforementioned studies have referred to a wide range of positive outcomes for their children, including a number of emotional, social and behavioural benefits such as increased confidence, improved conduct with other people and a new sense of independence. In summary, there is a need to evaluate a range of psychosocial constructs using appropriate quantitative measures. However, it is also considered important to include a qualitative element alongside quantitative methods in order to contextualise results and explain any unexpected findings.<sup>18</sup>

Based on the aforementioned research, the current evaluation aimed to determine whether attendance at a burn camp led to a quantifiable improvement in appearance satisfaction and social concerns as reported by young people with a burn injury, and parents' reports of their children's general behaviour. Furthermore, the evaluation set out to use measures deemed more appropriate and specific than the generalised measures used in previous research. The specific research questions were as follows:

1. Does the burn camp impact on young people's concerns regarding social situations?
2. Does the burn camp impact on young people's satisfaction with their appearance?
3. Does the burn camp impact on young people's behaviour?
4. Does the burn camp offer any additional benefits to the young people that attend?

**Table 1.** The demographic characteristics of the participants.

Demographic characteristic	n
Gender of young people	8 boys, 15 girls
Mean age of young people, years (range)	13.7 (10–17)
Ethnicity of young people	15 white, 1 Asian, 3 black, 4 mixed/multiple ethnic groups
Time since injury, years (range)	8.14 (1–15)
Previous camp attendance	22 yes, 1 no
Mean number of previous camp attendances, n (range)	4.10 (1–18)
Gender of parents/carers	2 men, 20 women
Ethnicity of parents/carers	15 white, 2 Asian, 2 black, 2 mixed/multiple ethnic groups
Relationship status of parents/carers	2 single, 15 married/domestic partnership, 1 widowed, 4 divorced
Parent/carers' relationship to child	21 parent/carer, 1 grandparent

## Method

### Design

This was a mixed-methods evaluation including both quantitative outcome measures and open-ended questions to encourage qualitative responses. Johnson and Onwuegbuzie<sup>19</sup> suggest there are a number of advantages to using mixed-methods, which can focus on the strengths of qualitative and quantitative techniques, while attempting to minimise the weaknesses. For example, narrative can be used to add depth to statistical findings from a quantitative study, which can in turn add precision to qualitative findings. Corroborating evidence from the two methods can also help to draw a stronger conclusion about a particular research question.<sup>20</sup>

This evaluation took place at the National Burn Camp, which has been run by the Burn Camps UK charity<sup>21</sup> since 1996. Children and young people aged 8–17 years from burn clubs around the country are invited to Grafham Water Centre in Cambridgeshire, UK. The camp runs over seven days and is usually attended by around 50 children and 20 volunteers; parents do not attend. Although children arrive at the camp with their individual burn clubs, they are then split into groups according to age, and participate in a morning, afternoon and evening activity each day. Morning and afternoon activities take place at the centre and include kayaking, wall climbing, archery, high ropes and mountain biking. The evening activities usually occur off-site and include trips to a cinema, swimming pool and bowling alley.

### Participants

Young people with burn injuries aged 10–17 years who had been invited to attend the UK National Burn Camp and their parents/carers were eligible to take part. All had been treated for a burn and were referred to the camp through their individual burn clubs, located across the country. Decisions about the readiness of each child to attend camp are made on a case-by-case basis by the child's own burn club. Fifty-one children attended the camp, 23 (45% of total attendees) of whom elected to participate in the evaluation. Twenty-two (43% of total attendees) parents/carers of the young people who participated in the evaluation also took part. Twenty-two of the children had attended a burn camp before (average of four previous camp attendances). Participants' demographic characteristics are outlined in Table 1.

Twenty-three young people and 22 parents completed the first questionnaire pack before camp; 21 (91%) of the children attending camp completed the pack on the last day of camp. The three-month follow-up packs containing child and parent measures were returned by 13 young people and 12 parents (57% and 55% of participating young people and parents, respectively).

### Quantitative measures

Participants completed the following measures one month before camp, on the last day of camp and three months after camp.

*Perceived Stigmatisation Questionnaire (PSQ).* The PSQ is the first questionnaire designed to measure stigmatising behaviours experienced by those with a visible difference, and was originally validated with a sample of adult burns patients.<sup>22</sup> The PSQ has 21 items and contains three factors (absence of friendly behaviour, confused and staring behaviour, and hostile behaviour), which convey social acceptance, social discomfort and social rejection to the perceiver. Total and subscale scores can be calculated. The PSQ has been validated for use within the paediatric burns population, demonstrating reliability scores in the range of 0.81–0.89,<sup>23</sup> and is suitable for the full age range of participants in the current evaluation (10–17 years).

*The Social Comfort Questionnaire (SCQ).* The SCQ has eight items and aims to measure an individual's perceived violation of privacy and feelings of social isolation.<sup>23</sup> Total scores are in the range of 1–5 on both measures and higher scores indicate higher levels of perceived stigmatisation and social comfort, respectively. The SCQ has been validated for use within the paediatric burns population, demonstrating reliability scores of 0.78,<sup>23</sup> and is suitable for the full age range of participants in the current evaluation (10–17 years).

*The Satisfaction with Appearance Scale (SWAP).* The SWAP measures subjective satisfaction with appearance and the social-behavioural impact of burn scars.<sup>24</sup> The SWAP has 14 items and has been validated for use in the burns population<sup>24</sup> and used within previous paediatric burns research.<sup>2,25</sup> Total scores are in the range of 0–78, with higher scores indicating greater dissatisfaction with appearance. It has demonstrated a high level of internal consistency (Cronbach's alpha,  $r = 0.87$ ) and test-retest reliability of ( $r = 0.59$ ).

*Strengths and Difficulties Questionnaire (SDQ).* The SDQ is a behavioural screening tool designed for completion by parents of children aged 4–16 years<sup>26</sup> which has been used with paediatric burn patients aged 8–18 years.<sup>3</sup> It contains 25 items divided into five subscales: emotional symptoms; conduct problems; hyperactivity/attention; peer relationship problems; and pro-social behaviour. Each subscale scores 0–10, with higher scores on the first five subscales indicating a higher incidence of problem behaviours, and higher scores on the pro-social subscale indicating an increase in behaviours such as sharing or volunteering to help others. Scores from the first four subscales can also be added to calculate a total difficulties

score. Goodman<sup>27</sup> found that the SDQ demonstrated acceptable levels of internal consistency (Cronbach's alpha 0.73) and test-retest reliability (0.62).

*Open-ended questions.* The questionnaire packs administered one month before camp and at the three-month follow-up also included open-ended questions, to compare young people's and parents' expectations before the camp with their views afterwards, an approach previously adopted by Maertens and Ponjaert-Kristoffersen.<sup>6</sup> Pre-camp questionnaires asked young people and their parents about their expectations of camp and what, if anything, they were worried about. The three-month follow-up questionnaire asked what the young people had enjoyed about camp, whether they had gained anything from it, what was good about it and what, if anything, they would change.

### Data collection

Ethics approval was granted by the first author's institutional Research Ethics Committee (reference no. HLS/13/06/85). Participants were sent an evaluation pack including an invitation letter, participant information sheet, consent form and a copy of the questionnaire booklet. Participants who wanted to take part in the evaluation were asked to provide written informed consent (parental consent for those aged < 16 years) and asked to return the completed questionnaires (baseline data) using a pre-paid envelope. The researcher collected data on the last day of camp in person (at a predetermined time that minimised disruption with camp activities) and data were collected via post for the three-month follow-up.

### Results

Data analysis was conducted by the first author (LAJ) and reviewed by another member of the research team (DH). Quantitative data were analysed with SPSS v20 using a Wilcoxon signed ranks test. Content analysis was employed to analyse responses to the open-ended questions – this involves the formation of categories and then quantifying the number of times a particular response, or section of text, falls into that category.<sup>28</sup> As the current evaluation examined the impact of a burn camp on specific psychosocial constructs, it utilised a pre-set coding approach. Vaismoradi et al.<sup>29</sup> outline a procedure for conducting content analysis in healthcare research consisting of three stages: preparation; organising; and reporting. Preparation

involves transcription of responses and a complete immersion in the data. Organising involves grouping the responses into categories; in this case, the topics outlined in the research questions. The final stage involves the reporting of the results from the first two stages. These stages were all completed by the first author. Reliability was ensured by asking a second member of the research team to review the codes.<sup>30</sup> The number of responses exceeds the number of participants in those instances where participants gave multiple responses.

The results in this evaluation were mixed. It should also be noted that no comparison group was included in the evaluation and that there was a significant loss of participants at follow-up. Therefore, while the results may be indicative of the impact of burn camp, they should be interpreted with caution. A summary of the quantitative results is shown in Tables 2 and 3, and both quantitative and qualitative responses are discussed below.

### *Does the burn camp impact on young people's concerns regarding social situations?*

PSQ scores are in the range of 1–5, with higher scores indicating higher levels of perceived stigmatisation. Higher scores on the PSQ as a whole indicated that participants perceived fewer stigmatising behaviours on the last day of camp when compared to pre-camp data; this effect was maintained at the follow-up (Figure 1). The difference between the PSQ scores before camp and at follow-up was statistically significant and demonstrated a large effect size ( $P = 0.02$ ,  $r = -0.64$ ), indicating it was both statistically and substantively significant. In terms of the subscales, participants reported positive changes (an increase in others' friendly behaviour and less confused/staring and hostile behaviour) on the last day of camp compared to pre-camp scores, but an increase in hostile behaviours and less friendly behaviour at the three-month follow-up compared to scores on the last day of camp. None of these effects were statistically significant; however, a medium to large effect size was found between the pre-camp and follow-up scores on the confused/staring subscale, with fewer hostile behaviours reported at the follow-up ( $P = 0.084$ ,  $r = -0.48$ ).

SCQ scores can be in the range of 1–5, with higher scores representing higher levels of social comfort. Participants' reports of perceived social comfort improved from before camp to end of camp, but had then decreased again by the three-month follow-up (Figure 2). While none of the

differences were found to be statistically significant, a medium to large effect size was found between the scores on the last day of camp and at the three-month follow-up, with lower levels of social comfort reported at the follow-up ( $P = 0.09$ ,  $r = -0.49$ ).

Before the camp, three young people discussed feeling anxious before their first time at camp, but all agreed that this worry was soon alleviated: 'At my first camp I was worried about being lost in the crowd but as soon as I got there I never wanted to leave' (girl, aged 13 years). The most common aspect of the qualitative responses relating to social issues before the camp tended to be related to making new friends, which was referred to by 15 young people and four parents, while five young people and ten parents talked about the chance to meet other young people who had been through a similar experience: 'I love spending time with people who understand my feelings and have similar experiences as me' (girl, aged 13 years). This relates to item 2 on the SCQ: 'No one can understand me'. Two parents hoped that camp would provide their child with the chance to meet a range of people from different backgrounds, while one thought it might improve communication skills: 'Communication with people she does not know, due to soon applying to uni' (mother of girl, aged 17 years).

At the follow-up, only three young people talked about friendship generally, whereas ten felt that they had benefitted from meeting others with similar experiences; these responses were also given by four and eight parents, respectively. In contrast to these positive outcomes, three young people felt that they had experienced negativity from one member of their group: 'The negative people, being with them and how that affects the rest of the group' (girl, aged 17 years).

### *Does the burn camp impact on young people's satisfaction with appearance?*

Scores on the SWAP are in the range of 0–84, with higher scores indicating greater dissatisfaction with appearance. Participants reported feeling more satisfied with their appearance on the last day of camp when compared to the pre-camp measure; this improved again at the follow-up (Figure 3). Only the difference between scores one month before camp and at three-month follow-up was found to be statistically significant; furthermore, this result also demonstrated a large effect size ( $P = 0.03$ ,  $r = -0.65$ ), producing

**Table 2.** Summary of scores from the Perceived Stigmatisation Questionnaire (PSQ), Social Comfort Questionnaire (SCQ), Satisfaction with Appearance Scale (SWAP) and Strengths and Difficulties Questionnaire (SDQ).

	Pre-camp	Last day	Follow-up
<i>Outcome measures completed by young people</i>			
PSQ total*	1.99 (0.60) n=22	1.86 (0.55) n=21	1.86 (0.52) n=13
PSQ Absence of friendly behaviour subscale	2.12 (0.62) n=22	1.96 (0.59) n=21	1.98 (0.59) n=13
PSQ Confused/staring behaviour subscale	2.05 (0.84) n=22	1.90 (0.65) n=21	1.85 (0.76) n=13
PSQ Hostile behaviour subscale	1.70 (0.79) n=22	1.66 (0.73) n=21	1.68 (0.70) n=13
Social Comfort Questionnaire (SCQ)*	3.94 (0.65) n=23	3.97 (0.74) n=21	3.93 (0.64) n=12
Satisfaction with Appearance Scale (SWAP) <sup>†</sup>	20.05 (9.12) n=22	17.80 (9.92) n=20	13.18 (9.98) n=11
<i>Outcome measures completed by parents</i>			
SDQ total <sup>‡</sup>	7.91 (6.87) n=22		9.08 (4.60) n=12
SDQ Emotional subscale	1.95 (2.19) n=22		1.50 (1.68) n=12
SDQ Conduct subscale	1.55 (1.44) n=22		1.67 (1.30) n=12
SDQ Hyperactivity subscale	3.14 (2.90) n=22		3.58 (2.54) n=12
SDQ Peer problems subscale	1.27 (1.91) n=22		2.33 (2.61) n=12
SDQ Prosocial subscale	8.77 (1.63) n=22		7.83 (2.21) n=12

Values are presented as mean (SD).

\*PSQ and SCQ scores are in the range of 1–5 on both measures (higher scores indicate higher levels of perceived stigmatisation and social comfort, respectively).

<sup>†</sup>SWAP scores are in the range of 0–78 (lower scores indicate greater satisfaction with appearance).

<sup>‡</sup>SDQ subscales score 0–10 (higher scores on the first four subscales indicating a higher incidence of problem behaviours; higher scores on the pro-social subscale indicating an increase in behaviours such as sharing or volunteering to help others). A total problem score is calculated by adding the scores of the first four subscales together.

a result that is both statistically and substantively significant.

The qualitative data revealed that only one young person referred to appearance before camp, appreciating that they did not anticipate that they would feel embarrassed about their scars while they were there: ‘I love that everyone is in the same situation so there is no need to feel embarrassed about scars’ (girl, aged 16 years).

This can be considered in the context of the first two items on the SWAP: ‘Because of changes in my appearance caused by my burn, I am uncomfortable in the presence of my friends/strangers’. One parent thought that her daughter would be able to talk to other young people about her scars: ‘Speak to other children about their scars as she did on last camp’ (mother of girl, aged 14 years). Before the camp, two parents hoped that

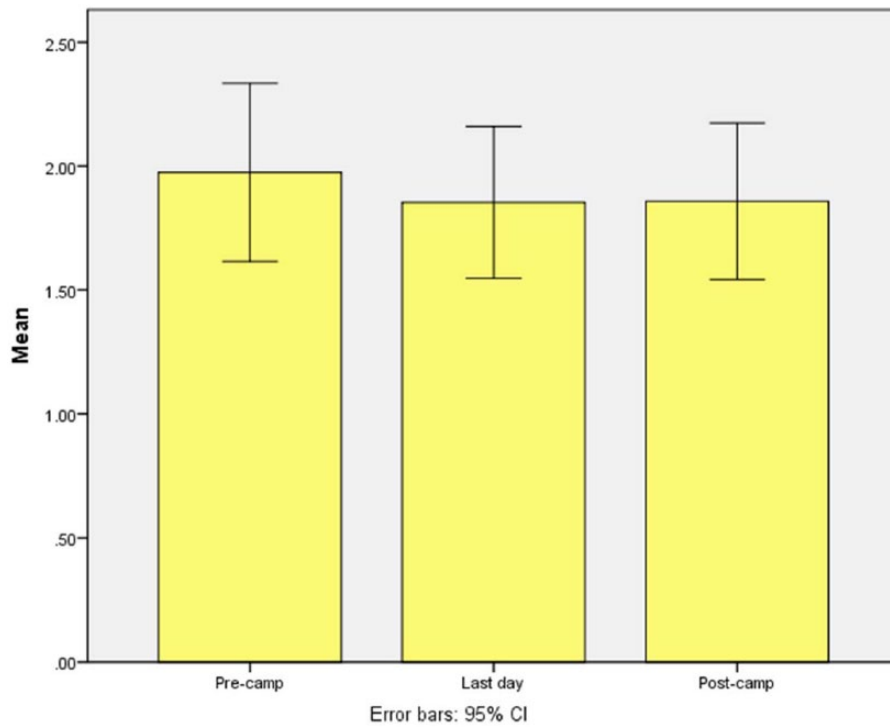
**Table 3.** Summary of significance values and effects sizes between the three time points.

	Pre-camp – last day	P (sig) value	Effect size	Last day – follow-up	P (sig) value	Effect Size	Pre-camp – follow-up	P (sig) value	Effect size
<i>Outcome measures completed by young people</i>									
Perceived Stigmatisation Questionnaire (PSQ)	1.99 (0.60) - 1.86 (0.55)	0.32	Small r = -0.22	1.86 (0.55) - 1.86 (0.52)	0.78	Very small r = -0.02	1.99 (0.60) - 1.86 (0.52)	0.02*	Large r = -0.64
PSQ Absence of friendly behaviour subscale	2.12 (0.62) - 1.96 (0.59)	0.39	Small r = -0.19	1.96 (0.59) - 1.98 (0.59)	0.50	small r = -0.19	2.12 (0.62) - 1.98 (0.59)	0.97	Very small r = -0.01
PSQ Confused/staring behaviour subscale	2.05 (0.84) - 1.90 (0.65)	0.27	Small r = -0.25	1.90 (0.65) - 1.85 (0.76)	0.82	Very small r = -0.06	2.05 (0.84) - 1.85 (0.76)	0.08	Medium to large r = -0.48
PSQ Hostile behaviour subscale	1.70 (0.79) - 1.66 (0.73)	0.83	Very small r = -0.05	1.66 (0.73) - 1.68 (0.70)	1.00	Very small r = 0.00	1.70 (0.79) - 1.68 (0.70)	0.11	Medium r = -0.36
Social Comfort Questionnaire (SCQ)	3.94 (0.65) - 3.97 (0.74)	0.81	Very small r = -0.01	3.97 (0.74) - 3.93 (0.64)	0.09	Medium to large r = -0.49	3.94 (0.65) - 3.93 (0.64)	0.61	Small r = -0.15
Satisfaction with Appearance Scale (SWAP)	20.05 (9.12) - 17.80 (9.92)	0.43	Small r = -0.18	17.80 (9.92) - 13.18 (9.98)	0.88	Very small r = -0.05	20.05 (9.12) - 13.18 (9.98)	0.03*	Large r = -0.65
<i>Outcome measures completed by parents</i>									
Strengths and Difficulties Questionnaire (SDQ)							7.91 (6.87) - 9.08 (4.60)	0.11	Medium to large r = -0.46
SDQ Emotional subscale							1.95 (2.19) - 1.50 (1.68)	0.33	Small to medium r = -0.28
SDQ Conduct subscale							1.55 (1.44) - 1.67 (1.30)	0.55	Small r = -0.17
SDQ Hyperactivity subscale							3.14 (2.90) - 3.58 (2.54)	0.20	Medium r = -0.37
SDQ Peer problems subscale							1.27 (1.91) - 2.33 (2.61)	0.12	Medium to large r = -0.45
SDQ Prosocial subscale							8.77 (1.63) - 7.83 (2.21)	0.09	Large r = -0.5

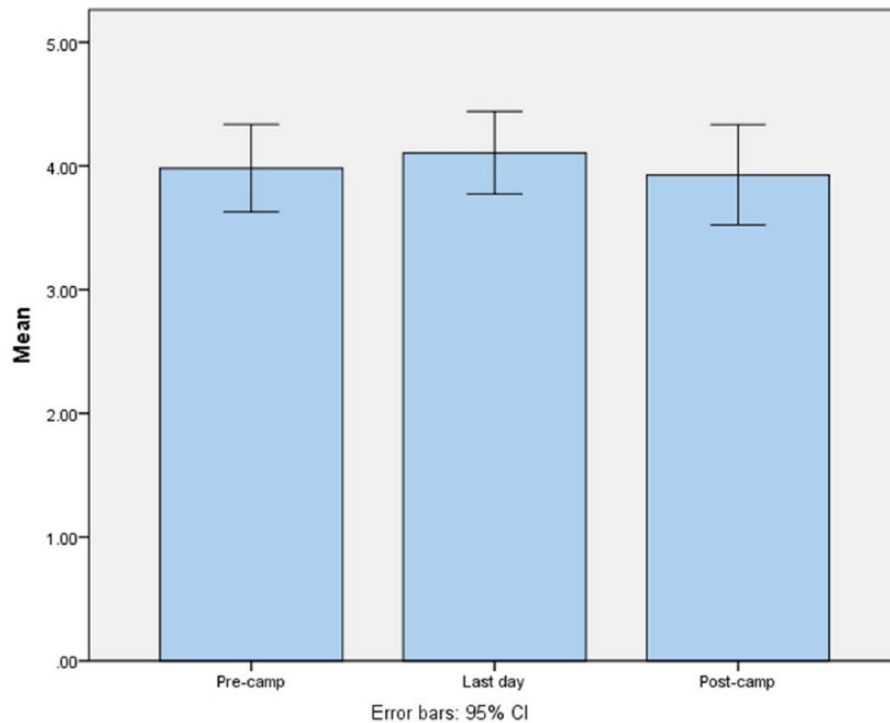
Values are presented as mean (SD).

\*Significant difference at  $P < 0.05$  level.





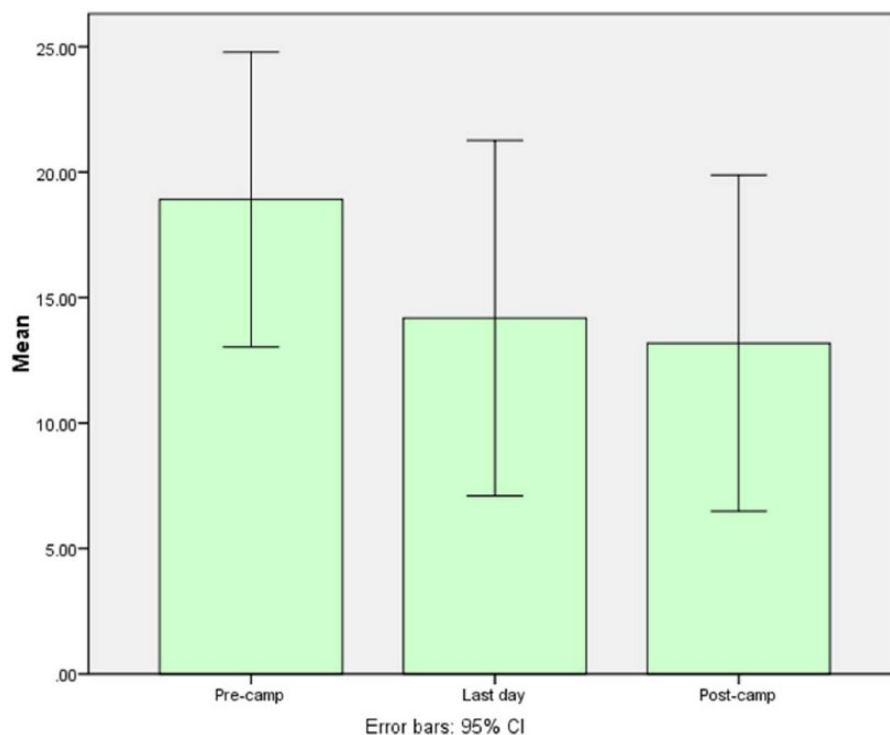
**Figure 1.** Young people's scores on the Perceived Stigmatisation Questionnaire.



**Figure 2.** Young people's scores on the Social Comfort Questionnaire.

their child's appearance-related confidence would improve, while another hoped it would provide their child with some perspective on their injury: 'Understand she is not the only one

with a burn scar' (mother of girl, aged 12 years). While appearance-related confidence and perspective were not referred to by any young people before camp, they were considered to be a



**Figure 3.** Young people's scores on the Satisfaction with Appearance Scale.

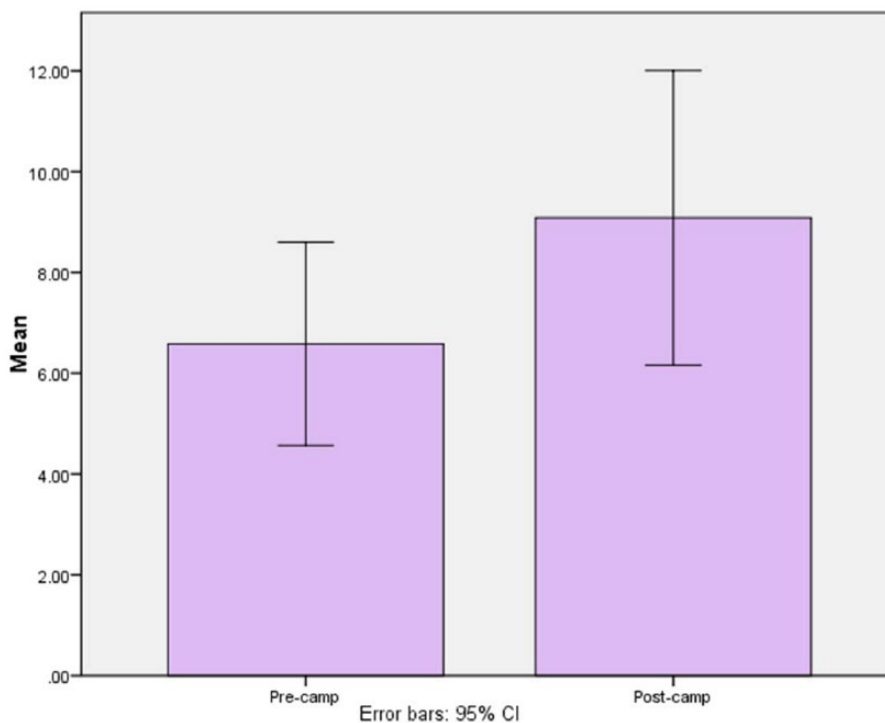
benefit by three and two young people, respectively, at the follow-up: 'I'm not the only one with scars. Also, people have it much worse than I do' (girl, aged 17 years).

### *Does the burn camp impact on young people's behaviour?*

Total difficulties scores on the SDQ can be in the range of 0–40, with higher scores indicating a higher level of problem behaviours. Overall, parents' scores on the SDQ indicated a higher incidence of problem behaviours in terms of the emotional, conduct, hyperactivity and peer problem subscales, and reduced pro-social behaviour at the three-month follow-up compared with the pre-camp scores (Figure 4). Although these effects were not found to be statistically significant, a medium to large effect size was found for the overall SDQ ( $P = 0.11$ ,  $r = -0.46$ ) and peer problems ( $P = 0.12$ ,  $r = -0.45$ ) subscale scores, while a large effect size was found on the prosocial subscale ( $P = 0.09$ ,  $r = -0.5$ ). All of the mean scores fell within the 'close to average' range outlined on the SDQ scoring instructions,<sup>31</sup> indicating that these were not clinically significant problems.

The qualitative responses indicated that one young person and three parents were concerned about behavioural issues before camp: 'That

people will make me angry and I do something immature' (girl, aged 11 years). We suggest that this reflects feelings and behaviours that are similar to item 5 on the SDQ: 'Often has temper tantrums or hot tempers'. One young person and two parents hoped that camp would help young people to become more accepting of their injury. Confidence in social situations was referred to by 12 parents before camp and nine at the follow-up, and while no young people mentioned this before camp, six thought that their confidence had improved at the follow-up: 'My confidence has improved so much. I used to be so shy and would have no confidence at all. Since camp my confidence has went right up' (boy, aged 16 years). Improved confidence relates to item sixteen on the SDQ: 'Nervous or clingy in new situations, easily loses confidence'. Before camp, two parents felt that camp may help their child become more mature, while another hoped it would help her daughter gain compassion: 'I hope [she] will gain compassion towards others' (mother of girl, aged 13 years). This relates to the first item on the SDQ: 'Considerate of other people's feelings'. One parent thought camp may teach her son to be more independent before camp and two parents thought increased independence had been a benefit at the follow-up.



**Figure 4.** Parents' scores on the Strengths and Difficulties Questionnaire.

### *Does the burn camp offer any additional benefits to the young people that attend?*

Responses to the open-ended questions indicated that some young people and parents thought that camp had provided additional benefits. Young people tended to focus on having fun and the activities they engaged in, referred to by 18 young people and four parents before camp and 16 young people and three parents at the follow-up. At the follow-up, two parents thought that camp may lead to opportunities to arrange support for both parents and older children: 'I think we could have a get-together for the parents or share emails so the parents as well could organise some get-together' (mother of boy, aged 11 years), while one recognised that young people had the chance to talk to adults with burn care knowledge. One parent also felt that camp had provided a positive from a negative: 'Continues to provide a positive focus for them after a terrible experience that could have such a negative effect on them' (mother of boy, aged 13 years).

### **Discussion**

This evaluation explored the impact of a burn camp on young people's reports of concerns about social situations and satisfaction with

appearance and parents' reports of their child's behaviour. The analysis of qualitative data from both the children and parents revealed findings very similar to those reported in previous research,<sup>2,3</sup> referring to the chance to spend time with other children with burn injuries, gain confidence, increase self-esteem, master new skills and learn to accept their scars. While the current evaluation used a generic measure of parent-rated behaviour (the SDQ), it employed three measures of children's social concerns and satisfaction with appearance that have been developed and tested specifically with those with burn injuries. The SCQ aims to determine young people's level of comfort within social situations, whereas Gaskell's study<sup>3</sup> used the Social Worries Questionnaire (SWQ),<sup>32</sup> which includes similar items to the SCQ, such as those relating to meeting new people or crowded situations. Both Gaskell's research and the current evaluation failed to find any significant impact of camp on the SWQ or SCQ scores, respectively, suggesting that camp attendance may not impact on young people's feelings of social comfort, irrespective of the measure used.

Children's reports of stigmatising behaviours from others, such as staring, name-calling or bullying, decreased in frequency from one month before camp to the last day of camp and slightly increased again at the three-month follow-up.

These findings suggest that children felt less stigmatised while at camp, and although perceived stigmatisation scores worsened slightly after leaving camp, scores at the follow-up were still better than before camp. The confidence gained at camp which was described in the qualitative data may have helped children to become less troubled by such behaviours, or to re-evaluate previous misconceptions of others' behaviours as less stigmatising; this effect appears to have been maintained, to an extent, after camp. Although other quantitative burn camp studies have not examined perceptions of stigmatising behaviours, participants in Cox et al.'s qualitative study<sup>17</sup> referred specifically to camp as a place where they knew they would not be stared at or judged on the basis of their appearance.

Young people reported greater satisfaction with their appearance on the last day of camp than one month before camp and again at the three-month follow-up. While it is important to remember that numerous other factors may have had an influence on all results in the three months since leaving camp, these results suggest that the burn camp may have played a part in helping young people to feel more positive and accepting about their appearance, a finding supported by several of the participants' qualitative responses. When asked how camp had helped them, the majority of responses related to 'confidence', 'learning they are not alone', 'acceptance' and 'putting the injury into perspective'. Therefore, it is possible that camp challenged young people's negative thoughts about their appearance, which continued to improve once they returned to everyday life.

These results can be compared to those of Bakker et al.,<sup>2</sup> who used a non-validated Dutch version of the SWAP and found that satisfaction with appearance improved in the short term (comparing the scores three weeks before camp and one week after camp) but not in the longer term (comparing the scores three weeks before camp and 16 weeks after camp). Bakker et al. did not compare the scores one week and 16 weeks after camp. The differences between Bakker et al.'s findings<sup>2</sup> and those of the current evaluation may relate to the use of the translated version. McKenna and Doward<sup>33</sup> point out that translation is just the first stage in creating a version of a measure in a different language and that full adaptation can only be achieved after a full assessment of psychometric properties. Therefore, until the Dutch version of the SWAP is validated, caution is needed when comparing the results of Bakker et al.'s study<sup>2</sup> and the current evaluation.

Analysis of the SDQ demonstrated that parents reported a higher frequency of problem behaviours three months after the camp than they had done one month before camp. A possible interpretation of these findings is that the generic nature of the SDQ means it may not be capturing behaviours which are specifically affected by a burn injury. However, one could also speculate that 'worsening' SDQ behavioural scores may be the result of improvements in participant self-confidence—a qualitative finding most commonly reported by parents. Changes in confidence may have led to an increase in behaviours rated as problematic by parents. For example, while a parent might indicate on the SDQ that their child fights more with other children, a possible interpretation is that greater confidence may have increased their willingness to participate in group discussions and argue a point in which they believe to be true; behaviours which are not listed as specific items on the SDQ. Blakeney et al.<sup>34</sup> suggest that an increase in scores labelled as 'delinquent' or 'externalising' demonstrates an increase in young people's assertiveness and expression of feelings, including those which may be construed as negative (e.g. anger). Therefore, the increase of 'problem' behaviours may not necessarily be construed as a negative finding; however, it should be interpreted with caution and warrants further research. Furthermore, parents might find it beneficial to be presented with a summary of this evaluation before future burn camps, to inform them of the possible impact camp may have on their children and allow them to make a fully informed decision about whether they consent to their child attending.

It is also notable that all the parents reported pre-camp scores that fell into the 'close to average' range outlined by the SDQ scoring instructions,<sup>26</sup> indicating that they considered their children to exhibit a low incidence of problem behaviours at this point. It is not known whether children displaying a higher incidence of problem behaviours would have benefited any more from camp than those who attended in the current evaluation. Similar to Gaskell,<sup>3</sup> who speculated whether camp may benefit some children more than others, the sample size in this evaluation was too small to compare the scores of young people scoring high or low on each measure.

While behavioural difficulties were not found to be significant in the current evaluation, it is important to be aware that these may be present among young people with burn injuries. Burn injuries are more common in households with a lower socioeconomic status (SES),<sup>35</sup> which can

be defined by a number of factors such as ethnicity, large families and single parents, low income and unemployment, illiteracy or low levels of education.<sup>36</sup> A number of these factors have been identified as risk factors for behavioural problems in the general population, such as children with single parents, parents who do not have a formal education or skilled job, or parents with substance problems.<sup>37</sup>

Therefore, it is important to pre-empt these behaviours and consider appropriate ways to intervene if they do arise. The UK's National Burn Care Standards<sup>38</sup> state that burns services must have suitably trained health professionals available to support patients with a burn injury and their families. Previous research by Armstrong-James<sup>39</sup> demonstrated that psychologists within burns services in the UK aimed to conduct psychosocial screening of all inpatients, to identify any difficulties at an early stage. Psychologists in the study also reported that they received outpatient referrals at various stages of the care pathway, which originated from a range of sources including multidisciplinary team (MDT) meetings and other staff, outpatient clinics and burn clubs. Families attending the National Burn Camp may therefore already be receiving support from the psychology service in the burn care team and families should engage with these services if difficulties do occur.

The small sample size is a limitation of the current evaluation, which resulted from non-participation by some attendees and then attrition. No reasons for attrition were reported. This is indicative of the difficulties in recruiting for, and maintaining interest in, burns research.<sup>40</sup> It has been suggested that the lack of personal contact related to postal questionnaires may contribute to attrition rates;<sup>40</sup> however, this was considered the most suitable method for the pre-camp and follow-up questionnaires in the current evaluation since participants were based across the UK.

A comparison group may have added rigour to the evaluation; however, the lack of a comparison group in previous studies is indicative of the difficulties in using an appropriate comparison group. A process of randomisation was considered for the current evaluation, in which children who had expressed an interest in camp would be randomly allocated into a group which would attend camp and a waiting list control. However, it was decided that such a process would be unethical as it would be denying children the chance to attend the camp, which only runs once a year.

The current evaluation only involved one camp so it is not possible to generalise findings to

others. However, the similarity of the qualitative responses in this evaluation to past research investigating a variety of other camps suggests that generic benefits may be experienced by children attending a burn camp, irrespective of practical factors, such as its location, staff and the activities on offer. It is also important to note that only one child in the current evaluation had not been to a burn camp before, while the other participants had, on average, been four times previously. Therefore, it is not known if the benefits of attending camp for the first time are the same as for those who are returning. While the longitudinal nature of Gaskell's study<sup>3</sup> distinguishes it from other burn camp research, future studies could map responses from individual participants to examine whether cumulative attendance at camp produces any different effects.

It is also important to remember that the sample consisted solely of participants who had chosen to attend the burn camp, and furthermore that those most favourably disposed towards camp may have been more likely to volunteer to take part. Since burn camps have been found to improve social difficulties, it is possible that some of the young people who could potentially gain the greatest benefits from going to the burn camp may actually be avoiding it. This suggests that some young people could benefit from additional support before attending camp, and this issue should be explored in future research.

While the current evaluation included a follow-up questionnaire to explore young people's and parents' views surrounding the benefits of camp, additional research could examine the impact on home and family life after a return from burn camp in more detail. A separate evaluation of a family burn camp involved photo-elicitation interviews, in which several of the participants discussed the lasting impact of the camp since their return.<sup>41</sup>

It may be beneficial, for example, for someone to discuss the burn camp with each young person and their parent(s), to explain the nature of the camp and address any concerns about attending. The findings from this evaluation could be used to inform the information given to young people and parents when invited to camp, for example by providing quotes relating to other people's experiences of camp. Demonstrating how other people may have had the same worries before camp, e.g. 'At my first camp I was worried about being lost in the crowd but as soon as I got there I never wanted to leave', may help to alleviate potential campers' concerns. Quotes from previous campers such as 'I love spending time

with people who understand my feelings and have similar experiences as me' or 'I love that everyone is in the same situation so there is no need to feel embarrassed about scars' could help to demonstrate the benefits of the burn camp.

In conclusion, the qualitative findings from the current evaluation concur with previous research indicating that the inclusive experience of spending time with other young people who have been through a similar experience is a consistent benefit of camp attendance. The quantitative findings indicated that, in the short term, camp may indeed improve feelings of social comfort and body satisfaction, while reducing perceptions of stigmatising behaviours. While social comfort scores had decreased again at the three-month follow-up, perceived stigmatisation scores were maintained and satisfaction with appearance had improved further. Although parents reported a higher incidence of problem behaviours after camp than before, this may have reflected children's increased confidence. While it is important not to assume that any observed effects at the follow-up were due to the burn camp alone, these findings do lend support to the importance of using outcome measures which specifically address constructs relevant to those affected by a burn injury rather than generic outcomes intended for use with any young people. Overall, the results from this evaluation indicate that burn camps may provide a number of psychosocial benefits to the young people that attend. The strength of this evaluation was that it revealed largely consistent qualitative and quantitative results, so it may be considered a step in closing the gap between the two methods of data collection in burn camp research.

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