

## **Using photo-elicitation to explore families' experiences of burn camp**

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Armstrong-James, L. (2015). Body image and psychosocial adjustment following the amputation of a limb. *Journal of Aesthetic Nursing*, 4(6), 288-289.

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Williamson, H., Hamlet, C., White, P., Marques, E., Cadogan, J., Perera, R., Rumsey, N., Hayward, L. and Harcourt, D. (2016). Study protocol of the YP Face IT feasibility study: Comparing an online psychosocial intervention versus treatment as usual for adolescents distressed by appearance-altering conditions/injuries. *BMJ Open*, 6(10), e012423.  
<https://doi.org/10.1136/bmjopen-2016-012423>

Green, E, Cadogan, J, Harcourt, D. (2018). A qualitative study of health professionals' views on using iPads to facilitate distraction during paediatric burn dressing changes. *Scars, Burns & Healing* 4, 1–9. <https://doi.org/10.1177/2059513118764878>

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Williamson H., Antonelli, P, Bringsén, A, Davies, G, Dèttore, D., Harcourt, H., Hedin, G.,Jurgutis, A., Stepukonis, F., Tural, U., Yalçın, D., Persson, M. (2018). Supporting patients with body dissatisfaction: a survey of the experiences and training needs of European multi-disciplinary healthcare professionals *Nursing Plus Open*.  
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<https://doi.org/10.1136/bmjopen-2016-012423>

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Young, A., Brookes, S., Rumsey, N. and Blazeby, J., 2017. Agreement on what to measure in randomised controlled trials in burn care: study protocol for the development of a core outcome set. *BMJ Open*, 7(6), p.e017267. <https://doi.org/10.1136/bmjopen-2017-017267>.

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Lessons learned from research nurses in UK cleft services. *Journal of Clinical Nursing*.  
<https://doi.org/10.1111/jocn.14188>.

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Harcourt, D., Hamlet, C., Billaud Feragen, K., Garcia-Lopez, L-J., Masnari, O., Mendes, J., Nobile, F., Okkerse, J., Pittermann, A., Spillekom-van Koulil, S., Stock, N.M. & Williamson, H. (2018). The Provision of Specialist Psychosocial Support for People with Visible Differences: A European Survey, *Body Image*, 25, 35-39.

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Guest, E., Griffiths, C. & Harcourt, D. (2018). A qualitative exploration of psychosocial specialists' experiences of providing support in U.K. burn care services, *Scars, Burns & Healing*, 4, 1-10. <https://doi.org/10.1177/2059513118764881>

## **Abstract**

A qualitative study using photo-elicitation was conducted to investigate the experiences of family members attending a residential burn camp. Six families were provided with cameras and asked to take photographs of their time at camp. They were subsequently interviewed about their experiences of camp, using their photographs as prompts. Thematic analysis of interview transcripts identified three main themes: benefits for the family as a whole (new activities and experiences and lasting impacts); benefits for the child (having fun without feeling different) and benefits for the parent/carer (support from those who understand). This is the first study to specifically investigate the experience of the whole family at a burn camp, and suggests that attendance may offer a number of benefits for parents/carers and children. Photo-elicitation was an effective method for encouraging participants to recall and discuss their time at camp, and should be considered in future burns research.

## **Introduction**

Burn camps are specialist residential activity programmes which offer children who have sustained a burn injury a safe environment in which to meet others who have been through similar experiences and to access activities designed to help them deal with the challenges of their injury (Gaskell, 2007). A reduction in motor skills following an injury, for example, may mean that children with burns participate in fewer physical activities than their peers (Pan, dos Santos, Nascimento, et al, 2017), however appropriate activity programmes can contribute to a child's adjustment and improve quality of life (Grice, Barnes & Vogel, 2015). Helping young people to achieve success in physical activities at burn camps may help them feel better about what their bodies can accomplish, subsequently prompting self-acceptance (British Burn Association, 2018). Burn camps may also offer many other psychosocial benefits (Bakker, Van Der Heijden, Van Son, et al, 2011) by allowing children

to access positive experiences such as making friends and developing new skills (Adams, Girolami, Joseph, et al, 2002). It is thought that nurses are ideally placed to advocate the use of activity camps as a therapeutic intervention, and aid families in choosing an appropriate camp to meet the needs of their child (McCarthy, 2015), and it is therefore important to understand the potential benefits of such programmes.

Whilst most previous research has studied the effects of camp on the children with burn injuries themselves, it is acknowledged that adult family members are also dealing with the trauma and can exhibit clinically significant levels of psychosocial distress following the injury (Haag & Landolt, 2017). Siblings are also affected, often experiencing a number of difficulties relating to the burn, such as the teasing of their brother or sister by others, and feeling excluded or ignored whilst parents/carers focus on their sibling (Phillips, Fussell & Rumsey, 2007). However, the family has been shown to be instrumental in a child's recovery and a need for the development of nursing intervention programmes based on the experiences of the whole family has been suggested (Moi & Gjengedal, 2014). Burns camps can be a way of supporting the family as whole, but to date they have not been evaluated. The current study explored family members' experiences of a specialized family burn camp, aiming to advance knowledge about the care offered to families of young people with burn injuries.

## **Background**

There is a distinct lack of published research into the effects of family camps within the burn population, although this has been investigated in other populations. Cancer camps have similar goals to burn camps, including improving coping skills, emotional adjustment, social skills and self-esteem (Martiniuk, Silva, Amylon & Barr, 2014). While some cancer camps only involve the young person with cancer, it has been suggested that camp should be offered as a therapeutic intervention to both young people with cancer and their healthy siblings (Hancock, 2011). Peer support camps for siblings of children with cancer have

demonstrated a number of psychosocial benefits using pre-post measures including improvements to anxiety, depression, social competence, self-perceptions, and perceived impact of the illness (Sidhu, Passmore & Baker, 2006; Kiernan, Gormley & MacLachlan, 2004). While these studies demonstrated the extent of benefits that may be available to siblings attending camps, the solely quantitative nature of the research prevented further exploration of these effects, so it is unclear specifically what siblings found helpful.

However, similar results have been found using alternative methods such as Likert scales and open-ended questions to investigate a camp for both children with cancer and their siblings.

Wu, Prout, Roberts et al (2011) suggested that camp provided recreation, respite and peer support. More specifically, campers discussed the opportunity to have a break from their everyday lives, the supportive environment of camp, and a sense of belonging, while parents referred to the level of peer support available, and the increase to confidence and independence that their children experienced.

A more innovative technique was employed by Packman, Mazaheri, Sporri et al (2008) who implemented projective drawing to measure the benefits of camp for siblings of children with cancer, and also explored parents' perceptions of the camp. Siblings and parents were asked to draw both a whole person and a picture of everyone in their family doing something, which were scored to ascertain whether the pictures contained any emotional indicators (EIs) of emotional disturbance. Results indicated that EI scores decreased significantly for both parents and siblings after the camp and the authors recommend the use of creative techniques within further therapeutic camp research.

Although several cancer camp studies have explored parents' perceptions of the camps attended by their children, there is limited research investigating whether parents may also benefit from attendance. In a systematic review of 20 studies examining the effects of cancer camps (Martiniuk et al 2014), only one study (Barr, Silva, Wong et al, 2010) involved



a camp attended by parents. While Barr et al found that families who chose to attend camp scored significantly better on measures of coping, family function, social support, and health-related quality of life post-attendance, it is unclear whether families who are better adjusted attend camp, or whether camp attendance led to the higher scores on the measures. Further research would benefit from a deeper exploration of families' experiences at camps.

Existing quantitative research into the psychosocial impact of children's attendance at burns camps has shown inconsistent findings (see Maslow & Lobato, 2010 for a review of this literature prior to this date). Rimmer, Pressman, Takach et al (2012) found that camp had helped young people in a multitude of ways, including improved problem-solving, goal-setting and communication skills. Whilst one study found general improvements in self-esteem (Rimmer, Fornaciari, Foster et al, 2007), other results have been equivocal (Arnoldo, Crump, Burris, et al; Biggs, Heinrich, Jekel, et al, 1997). Bakker et al (2011) found no change in self-esteem scores amongst camp attenders compared with young people with burns who did not attend camp, although a small improvement in satisfaction with appearance was noted amongst the campers.

In contrast to the inconsistent quantitative findings, qualitative research has consistently shown that camp attendance can enhance coping skills and confidence (Gaskell, 2007), facilitate new friendships (Maertens & Ponjaert-Kristoffersen, 2008) and increase confidence with scars (Cox, Call, Williams, et al, 2004). However, research to date has only focused on camps for the injured child. In addition, previous studies have used focus groups (Cox et al, 2004; Williams, Reeves, Cox, et al, 2004) or evaluation forms with open-ended questions (Maertens & Ponjaert-Kristoffersen, 2008), but these traditional methods may not be the most appropriate when conducting research with young children (Epstein, Stevens, McKeever, et al, 2006) as participants may struggle with language and abstract ideas (Clark, 1999) and may quickly become bored in a traditional interview (Capello, 2005). It is

therefore important for researchers to consider using alternative methods that are both engaging and easy for young people to follow.

It has been suggested that whilst researchers tend to rely on language-based methods (e.g. interviews, questionnaires), children feel more confident using visual methods (Prosser & Burke, 2011) such as photo-elicitation, which uses photographs to elicit more meaningful data during interviews (Frith & Harcourt, 2007). This approach aims to extract the significance that the participant attaches to the images (Prosser & Burke, 2011) and can give participants a 'voice' that is not 'heard' when using other approaches (Harding, Harding, Jamieson, et al, 2009). Compared with traditional interviews, this can also help to address issues of power (Ford, Bray, Water, et al, 2017), provide richer information (Miller, 2015), remove formality and incorporate a sense of fun (Samuels, 2004) and help children to express themselves (Carter & Ford, 2013). Photographs are especially beneficial when exploring participants' experiences as they encourage them to report their own recollections (Smith, Gidlow & Steel, 2012), and can demonstrate the meaning of an experience to those not participating (Loeffler, 2004) by providing insight into the photographer's 'private world' (Frith & Harcourt, 2007).

Photo-elicitation has been successfully used to evaluate a variety of outdoor activity programmes. When studying a camp for children with cancer, Epstein et al (2006) presented children with 13 photographs representing different aspects of the camp, such as the rock wall and the view of the lake, and asked children a set of pre-determined questions about each photograph. They found that facilitating the children to take the lead in the interview allowed them to discuss their feelings about the camp in a relaxed and comfortable setting. However, the authors speculated on whether using researchers' photographs led to a missed opportunity to discover what the children would have photographed.

Other studies have provided children with cameras and asked them to take their own photographs at camps for young people with heart disease (Bultas, Steurer, Balakas et al, 2014), outdoor education experiences (Loeffler, 2004) and residential outdoor programmes (Smith et al, 2012). Young people in these studies reported a wide range of benefits including friendship and inclusion in a peer group, fun, and the safe environment of the camp. The instructions in these studies varied. Bultas et al for example provided participants with cameras and asked them to take pictures to show why the camp was “special”, which could have influenced the type of pictures taken, as children may have felt discouraged from taking pictures of things they disliked. Furthermore, this may have limited children’s responses, as Bultas et al reported that their interviews concluded within five minutes and lacked depth. Smith et al (2012, p372) provided participants with more open instructions, such as asking them to take pictures to “show what school camp was like”. Loeffler (2004) stated that student photography during outdoor experiences is essential due to its ability to keep outdoor experiences alive long after they have ended, while Smith et al concluded that the use of cameras and photographs was an effective way to engage young people in research.

These studies demonstrate that photo-elicitation is an effective method for evaluating outdoor activity experiences, including those relating to therapeutic camps, and was therefore selected as an appropriate technique for the current study. Given the lack of previous research into family camps, the specific research question underpinning this study was: What are families’ experiences of attending a family burn camp?

## **Method**

### **Setting**

The family camp in the current study was run by an independent charity which aims to provide support to young people with burn injuries and their families across the South

West of England. Camp attendees are known to the charity through receiving treatment from the South West Children's Burns Service. The camp that was the focus of the current study was held over three days at an activity hotel in South West England, and has been running annually for five years. Families and volunteers eat together and the camp structure is flexible in allowing families to decide how they spend their time. However, a group activity (bowling) is organized on the first evening to encourage the families to get to know each other and a group session for parents/carers, run by an experienced clinical psychologist and a camp volunteer, is held on the second day, while volunteers look after the children. This parent/carer session is not a structured therapeutic session, but aims to provide an opportunity for participants to informally discuss their experiences with others in a similar situation.

### **Participants**

Eight families were invited to the family camp, and seven attended. Six of these families (21 family members in total) elected to take part in the study. The ages of the children attending camp ranged from 2-14 years old and the time since injury ranged from three months to 11 years. The family groups are outlined in Table 1. The child with the burn (index child) is listed first, followed by the other family members. All names are pseudonyms.

### **Procedure**

Ethical approval was obtained from the first author's University Research Ethics Committee (Reference No: HLS/13/09/116). One month prior to camp, the organizers sent information packs and consent forms on the researcher's behalf to each family that had been invited to attend. As suggested by the camp organizers, the researcher met the families on arrival. This provided an opportunity to introduce herself and the study, ensure families understood the nature of the study and had time for questions, and determine who wanted to take part. All participating family members signed the consent forms, apart from the two-year

old. Each family was given a disposable camera to photograph their experiences during the weekend. In an attempt to avoid influencing what they chose to photograph, it was suggested that the families pretend they were taking photographs to post on Facebook in order to show their friends what happened during their time at camp (an approach used by Smith et al, 2012). Participants were reminded about issues relating to consent, for example that they may not take pictures of the general public or the family who had not consented to be in the study.

Each family took an average of 21 photographs, mainly of the activities available at the hotel, their own family group and the other families who had consented to be in the study. Two sets of photographs were developed from each camera, one for the researcher and one for the family to keep as a gesture of appreciation for taking part. Each family's photographs were sent to them in advance of their interview, to allow them to decide whether there were any pictures they particularly wanted to include or exclude during the interviews. Previous research has asked children to separate pictures representing particular concepts (Swank, Smith-Adcock & Puig, 2017), or to choose 5-15 photographs that showed something important about their experiences (Pyle, 2013). Participants in the current study were interviewed in their family groups to promote interaction between family members (Creswell, 2007). Each family was asked to select around 10 salient photographs to discuss, to ensure the interviews were not too long as children can lose focus quickly (Capello, 2005), and to help the families think about which images best represented their experiences (Loeffler, 2004). The photographs in this study were used to prompt engagement in the research and interview rather than as data in their own right.

Families chose the time and place for their interview, and all elected to be interviewed within the family home. The interviews were guided by a schedule designed to uncover as much detail as possible about each image and the interviewees' experiences of camp in general (appendix 1). The content of photographs can be rather mundane (Smith et al, 2012)

and they may appear meaningless to a researcher who does not understand the context or significance of the image (Radley & Taylor, 2003). Information about each image, such as who took it and why, is therefore necessary to uncover a deeper understanding of each photograph's meaning and context (Dockett & Perry, 2005).

The questions from previous studies using photo-elicitation to explore activity programmes were examined, and similar questions were asked in the current study, to encourage participants to explain what was in each picture, why they had taken it, why it was important to them, and how it made them feel. Further questions asked which photo showed the most important part of camp, and whether there were any images that they would have liked to have taken, but did not take at the time. Other studies have found that this strategy produces some of the most meaningful data (Lassetter, Mandleco & Roper, 2007). Finally, the interview moved on to more general questions about camp, asking participants if they would change anything about it, and their experiences of using the camera to take pictures of their time there.

Interviews lasted between 30 and 60 minutes, were audio recorded and transcribed verbatim. The data were analyzed using thematic analysis (TA), selected due to its flexibility and ability to provide a rich, detailed account of data (Braun & Clarke, 2006). The lead analyst (LA-J) attended a TA workshop at the University of the West of England run by Braun and Clarke, as preparation for using the six-phase process described by the authors (2006): 1) familiarization with data; 2) generating initial codes; 3) searching for themes; 4) reviewing themes; 5) defining and naming themes; and 6) producing the report.

After a thorough familiarization with the data, which began with transcribing it (phase 1), the researcher identified features of the data that were considered interesting in the context of the research question (phase 2). Once the list of codes and data extracts had been finalized, the researcher began searching for themes within the data (phase 3). The relationships

between codes and potential themes were considered and six initial themes were generated: camp in general; activities; family; other people; group session; burn injury scars. These six themes were then reviewed (phase 4) and reworked into three main themes (phase 5): the benefits for the family as a whole (new activities and experiences and lasting impacts); the benefits for the child (having fun without feeling different) and the benefits for the adult (support from those who understand).

Once theme was verified by another member of the research team (DH), the themes were written up to produce the final report (phase 6). A summary of the findings was sent to participants to ensure that the researcher's interpretations were an accurate reflection of their experiences (Long & Johnson, 2000). The researcher also kept a reflexive journal of personal thoughts and feelings both before and after each interview, to consider how these may have affected the data collection and analysis.

## **Results**

This section provides a discussion of the themes identified from the interviews and includes quotes from participants (all names are pseudonyms). A thematic map to visually represent the themes is provided in figure 1. An example of the photographs taken by the participants is provided in figure 2.

### **Benefits for the family as a whole - new activities and experiences and lasting impacts**

Participants discussed how camp had provided them to spend time with the family as a whole.

*Helen (mother):* We've given a lot of attention to Lucy in the last year, and they obviously don't have as much, and Ben has obviously noticed.

Several participants described how the camp helped families to make a positive out of a negative, suggesting that camp can provide participants with happier memories in place of their traumatic memories about the injury.

*Leah (mother):* Do you think as well that it puts a nice touch on something that was actually a horrible experience...to actually have something really nice come out of it?

*Chloe (child):* Yeah... I think it's going to put a better view of what can happen to children and adults and it can also bring a good thing, not only sad memories.

*Leah (mother):* Honestly, it's changed the way we've been for the last few weeks. Things have been a lot different, we've been a lot happier, a lot nicer, we talk about it all the time.

One of the mothers also felt that her daughter had previously been struggling at school due to the timing of the burn injury, which occurred at the beginning of secondary school. Although she had since returned to school, Helen felt that it was much more difficult for her to make friends, and enjoyed seeing Lucy make a new friend so easily at camp. Helen hoped that this friendship could be maintained after the camp.

*Helen (mother):* I like that one, because that shows that Lucy's been able to make a positive out of a negative, and that she's gained a friend, which would be great for them to sort of chat and hopefully meet up

Two families referred specifically to benefits that had been evident since leaving camp. Parents Pete and Rachel, who felt their relationship with one of their sons (the brother of the child with the burn injury) had been very tempestuous in recent months, described how enjoying the camp activities had inspired them to continue spending more time together:

*Rachel (mother):* But then also it's something Ethan (brother, 14) enjoyed, it's more like a grown up activity.



*Pete (father):* Because if that's what he wants to do, and that's an opportunity to kind of just keep it going...while Jonathan's swimming I could take Ethan off to a gym or something, sit in the steam room.

Many of their photographs depicted the time spent together as a family. Interestingly, while many children named the activities as their favorite part of the weekend, several identified photographs of their family together as their favorite picture.

*Interviewer:* Why do you like that one the best?

*Jonathan (child):* Because we're all together

Similar to children's camps, this family camp also provided opportunities to try new and often challenging activities and to develop new skills.

*Chloe (child):* And then afterwards you got to examine everyone and then you had a few different turns at it, and then you got to see how everyone made improvements.

*Leah (mother):* Yeah, you got some practice and then they told you where you was going wrong didn't they? And then we got to do it again as a competition.

### **Benefits for the child - having fun without feeling different**

The children with burn injuries talked about having fun with other children who had been through similar experiences, without worrying about feeling or looking different.

*Jonathan (child):* I thought we were all the same

Several children said they did not speak to their usual friends at home or school about their burns, but could open up to the other children at camp because they could relate to each other.

*Lucy (child):* It was nice, to meet them...people who had burns and stuff, so I could like chat to them and stuff...my friends at school don't really chat about my

burns and I don't really chat to them about it and I could like chat to those people....

Some of the children had previously worried about showing their scars and felt very self-conscious in public situations such as going swimming, but felt more confident engaging in these activities at camp and in the company of others with burns scarring.

*Helen (mother):* She used to do a lot more but because of her burn she refuses to go swimming most of the time now

*Lucy (child):* When I went with my friends, people were like staring at me and I didn't like that....people had burns there, and I felt more, I'm not sure what the word is...

*Helen:* A bit more comfortable

*Lucy:* Yes

Interestingly, some children were worried about going to camp because they did not have any scars, or did not think they were severe enough to warrant their attendance at camp.

*Rachel (mother):* Jonathan (child, 10) had worries "oh he doesn't have any scars, how would he look compared to the others" and should he even be there at camp, because he didn't have scars and he thought other children might have scars. However, scarring (or the lack of it) was not such an issue once they had arrived at camp.

*Emily (child):* When I went there I didn't see people as in their burns, I saw them as the person they were.

The children particularly enjoyed the non-organized activities, such as the funhouse where they could simply have fun together without adult supervision.

*Chloe (child):* That was quite fun as well because it was like a space where we weren't around like adults and it was sort of a place for like kids only, whereas a lot of the other things you had to be with the adults.

While the children with burn injuries did refer to the chance to meet other young people with scars, siblings mainly focused on the chance to have fun and try out new activities.

*Tilly (sister, 8):* I did lots of activities and they were really fun

### **Benefits for the adult - support from those who understand**

The adults discussed the value of being able to speak to others who could understand their feelings associated with having a child with a burn injury. They referred to the parents'/carers' meeting which allowed them to discuss their experiences in a safe environment. For most, even those whose child had sustained their burns several years previously, this was the first time they had spoken to other parents/carers who had been through a similar experience:

*George (father):* It's been very much on Helen, so it's nice for her to share at last with another mother, and you know someone else really, with a similar experience.

Because it was a year of you very much on your own, wasn't it?

Speaking to the other families also helped participants realize they were not alone, creating a bond that encouraged them to share their experiences and feelings more freely.

*Kathy (mother):* Oh yeah, absolutely, we were all strangers with the same thing in common, so we weren't strangers at the end. After the parents' meeting we weren't strangers.

Realizing that their reaction to the injury was 'normal' and experienced by other people seemed to help them to be more accepting of their feelings.

*Helen (mother):* Every child is different and every child goes through a different experience so your experience is obviously different to their...but it's how you deal with your experience...it's quite nice to hear from other people how they're dealing with it.

The camp seemed to be beneficial to all the families, irrespective of whether their child's injury had occurred recently or some time ago. Some parents/carers talked about feelings (including a sense of blame for their child's injury) which they had suppressed for a long time and described how talking to other families had helped them to let go of these feelings.

*Jack (father):* I mean people like changed their way of thinking, like blaming themselves when to put it simply it's just not their fault. It's just wrong place, wrong time.

Although parents may have been told that they were not to blame for the burn, it emerged that hearing this from other families was extremely powerful.

*Pete (father):* It provides the opportunity for people to share that experience, to get some support and understanding from people who've been there...and maybe help to remove some of those guilt complexes that some of those folks are carrying with them.

Those for whom their child's injury was still quite recent gained a sense of hope from those whose children had sustained burn injuries some time ago.

*Hannah (mother):* To see people at different stages...for some people it was still quite new, quite fresh and emotions were quite raw. And others it's been a longer time period and I think that's quite nice for the children to see, other people who have not necessarily just gone through it.

Participants felt it would be helpful to speak to other families on a regular basis, to share experiences with supportive individuals, and had discussed staying in touch with the others and meeting up again in order to continue newly-built friendship:

*Helen (mother):* I think if you'd had longer with them then you could have opened up even more and chatted even more. So if that group had been able to continue as maybe once a month.

## **Discussion**

This study has made a number of important contributions to the literature surrounding a particular population of families, the care that can be offered to the family following the injury, and the methods used within the study. Rather than focusing solely on the child with the burn injury, it allowed each member of the family the opportunity to make their voice heard, providing a more comprehensive picture of the family's experience as a whole. Furthermore, in contrast to previous research focusing on interventions for the child with the burn injury alone, this study examined an intervention offering care to the wider family members. Finally, to the authors' knowledge it is the first study utilizing photo-elicitation interviews as a method of evaluating a family burn camp. The findings leading to these original contributions will now be discussed in more detail.

Overall, experiences were positive and attendance had been beneficial to the children, parents/carers and family units as a whole, through opportunities to try new activities, have fun without feeling different, and gain support from other families who could understand what they had been through.

The benefits to the family as a whole related to the opportunities to try new activities and experiences. While previous research has indicated that some siblings feel that they are treated differently after another child in their family has sustained a burn injury (Lehna,

2010), this camp provided an inclusive environment for the family as a whole. Several participants also discussed the possibility of continuing the activities they had tried at camp together in the future.

The benefits to the children with burn injuries related to camp providing opportunities to have fun and enjoy activities without feeling different. One of the aims of burn camps is to provide individuals with positive experiences such as taking part in activities, meeting new friends and learning new skills (Biggs et al, 1997) and these findings indicate that the family camp met these aims. Findings were consistent with previous qualitative studies of child-only camps which found meeting others helps young people to feel 'normal' and accepted (Bakker et al, 2011; Gaskell et al, 2010). Previous studies have revealed that burn camp can lead to an increase in confidence and self-esteem (Williams et al, 2004), as a result of young people achieving things which they did not realize they were capable of (Maertens & Ponjaert-Kristoffersen, 2008), such as learning new skills and making new friends (Gaskell, 2007). Several of the young people specifically referred to activities which their parents did not attend, such as the fun house. Parents/carers of children with burns can become very protective (Rizzone, Stoddard, Murphy, et al, 1994) so this may have been an opportunity for the children to experience independence.

Findings from the siblings were more limited. Their comments focused on the chance to try new activities and meet new friends, rather than issues surrounding the burn itself. The importance of including the entire family in a patient's treatment and rehabilitation has been emphasized previously (Bakker et al, 2013; Wiechman & Patterson, 2004) and, in contrast to interventions that focus on the child alone, the camp facilitated this process of allowing all family members to be involved. Although one sibling found camp to be socially beneficial, siblings on the whole did not report any psychosocial benefits, so it is possible that family camp simply provided them with an enjoyable break rather than addressing issues relating to

their brother or sister's injury. However, although the siblings were forthcoming about the fun they experienced at camp, they became more reticent when asked questions relating to their brother or sister's burn injury. Research into the experiences of siblings of children with burn injuries is limited, but research into the experiences of siblings of children affected by cancer has demonstrated that siblings use avoidance as a coping strategy, even going as far as pretending their brother or sister was not sick (Heiney, Goon-Johnson, Ettinger & Ettinger, 1990). Therefore, it is possible that the siblings in this study were engaging in avoidant behavior towards their brother or sister's burn injury.

Alternatively, while parents/carers were invited to a session to talk specifically about their feelings towards their child's injury, children did not partake in any activities designed specifically to target psychosocial issues surrounding the injury. Although young people with burns in the current and previous research report numerous benefits from simply spending time with other young people with burns, it is possible that the experience of being around other young people did not produce the same level of benefit among siblings. Siblings who are experiencing psychosocial concerns may require a more structured intervention to target specific concerns.

The benefits to the parents/carers in the current study focused on the chance to talk to others who had had similar experiences, a finding which supports previous research (Gaskell et al, 2010). Although there is a fairly small body of evidence into the effect of a burn injury on the child's parents, it has been reported that parents often experience feelings of intense guilt (Partridge et al, 1995), especially if they feel they could have prevented the injury (Rizzone et al, 1994). Parents reported discussing both of these issues within the group, claiming that the peer support from other parents helped them realize that the injury was an accident, and in some cases, helped them to let go of their feelings of guilt. Providing more of

these opportunities for parents may be a service development worth considering within burn care services.

Few studies have investigated support groups for parents/carers of children with burn injuries, but the benefits of such groups for parents/carers of children with disabilities have been reported (Kerr & McIntosh, 2000; Law, King, Stewart, et al, 2001). Parents/carers who share a similar experience may be 'uniquely qualified' to support one another (Kerr & McIntosh, 2000), boosting the skills needed to cope with a child with special healthcare needs (Law et al, 2001). The beneficial effect of the parent/carer group described by the participants' suggests that a peer support group for parents/carers of children with burn injuries might be helpful.

Photo-elicitation was chosen in an attempt to engage participants and was considered successful; families enjoyed using the cameras to create memories of their time at camp. The use of photographs during the interviews was also intended to retain the young people's interest in the interviews (Samuels, 2004). It was observed during the interviews that while young people did not tend to mention spending time with a family as a benefit, they selected photographs showing the family together as their favorite picture. This observation lends support to claims that photographs are a useful tool when interviewing children, particularly as a vehicle for self-expression, as they had not mentioned spending time with their family until this point. Overall, photo-elicitation was an appropriate and useful method for the current study, and should be considered for future research with young people and their families.

The current study has clinical implications for nurses, specifically in regards to their role in providing appropriate support and advice to families and other staff. Nurses make up the largest part of multi-disciplinary burn teams (Al-Mousawi, Mecott-Rivera, Jeschke, et al, 2008) and may hold the role of burn-team leader, overseeing the ongoing education of the



team and care of each individual patient (Butler, 2013). The often enduring nature of nursing staff within a burns team facilitates trusting relationships with families and other staff (Al-Mousawi et al, 2008), meaning that nurses are well-placed to offer support and advice. Therefore, it is crucial that nurses are able to identify appropriate interventions based on individual needs, and make recommendations to families and other burn care staff as necessary. It is important for nurses to promote the involvement of friends and family in a patient's ongoing rehabilitation (Moi, Vindenes & Gjengedal, 2008) and the promising results from the current study suggest that family burn camps may be considered as a means to achieve this.

### **Limitations and future research**

The family burn camp is for 8-18 year olds and their families, but the current study only included young people up to 14 years of age. Future research could aim to include those aged 14-18 years, particularly since appearance-related concerns may become particularly acute during adolescence (Rumsey & Harcourt, 2004).

Unlike the study by Bultas et al (2014) all of the participants in the current study were first-time campers. Therefore it is not known whether the positive benefits they experienced were due to attending camp for the first time. As many of the parents in the current study reported that the camp was the first time they had ever spoken to other families about the injury, it is possible that they would find the experience to be less powerful during subsequent camps. Conversely, it may be that repeated attendance to camp produces a cumulative effect through familiarity and strengthening of relationships. Further research could investigate the differences between first-time and repeat campers, as this could have implications for future selection processes.

In addition, this study explored the experiences of camp over a single weekend, so the researcher had no previous knowledge of how these families were coping with the injury

prior to this. This study could now be used to inform a larger, quantitative pre-post study, to investigate the impact of family camps on issues relating to appearance, confidence in social situations, and perceived social support over the short and longer term.

### **Conclusion**

In conclusion, this study has advanced knowledge about the care that can be offered to families following a burn injury. The camp in the current study provided various benefits to the families that attended. The interviews suggested that the camp met guidelines proposed by the U.K.'s National Burn Care Standards (National Network for Burn Care, 2013), helping the families to realize that they are not alone. Family burn camp should be considered by nurses when recommending support to young people with burn injuries and their families, in order to promote the involvement of family within recovery. Photo-elicitation successfully engaged participants in the research and prompted conversation within the interviews. Therefore, it is suggested that this method could be appropriate in further research with young burn survivors and their families, particularly when asking them to recollect their thoughts and feelings about previous experience or interventions.

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The Authors declares that there is no conflict of interest

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## Appendix 1

### Interview guide for photo-elicitation interviews

Thank you for meeting with me today. Today we'll be looking at the photos which you selected and talking about how they show your time at camp, so I'm really interested to hear from each of you. We'll talk about each photo in turn, and then there will be a few more questions at the end to find out what else you thought about camp. Everything you say is confidential, which means that I'm not going to tell anyone what you say, so do feel free to be as open and honest as you like. I'm not here on behalf of [the charity] so if you thought camp was good then that's great, but if there was anything you didn't think was good feel free to talk about that as well. Does that all sound ok?

#### For each picture discussed

What is in this picture?

Why did you decide to take this picture?

Why is this picture important?

What does this picture say about your time at camp?

How does this picture make you feel?

#### Follow up picture questions

Are there any pictures that you wished you had taken but didn't? What are they?

Which picture shows the most important part of camp and why?

Which is your favourite picture and why?

#### Follow up general questions

Have you been to camp before? If so, how did this camp compare?

Is there anything you would change about camp?

How did you find using the camera to take pictures of your time at camp?

Do you think that these photographs would help to tell other families what it's like to attend camp?

Is there anything else you would like to say about camp?

**Table 1.****Structure of the families who attended camp and participated in this study**

<b>Name</b>	<b>Family member</b>	<b>Age (if under 18)</b>	<b>Time since burn</b>
<b>Jonathan</b>	Index child	10	1 year
<b>Pete</b>	Father		
<b>Rachel</b>	Mother		
<b>Ethan</b>	Brother	14	
<b>Chloe</b>	Index child	10	3 months
<b>Leah</b>	Mother		
<b>Amy</b>	Aunt		
<b>Ollie</b>	Index child	8	6 years
<b>Sarah</b>	Mother		
<b>Jack</b>	Father		
<b>Kieran</b>	Brother	11	
<b>Emily</b>	Index child	11	Unknown
<b>Kathy</b>	Mother		
<b>Megan</b>	Index child	12	11 years
<b>Hannah</b>	Mother		
<b>Nathan</b>	Brother	9	
<b>Lucy</b>	Index child	13	1 year
<b>Helen</b>	Mother		
<b>George</b>	Father		
<b>Tilly</b>	Sister	8	
<b>Ben</b>	Brother	2	

Figure 1. Thematic map

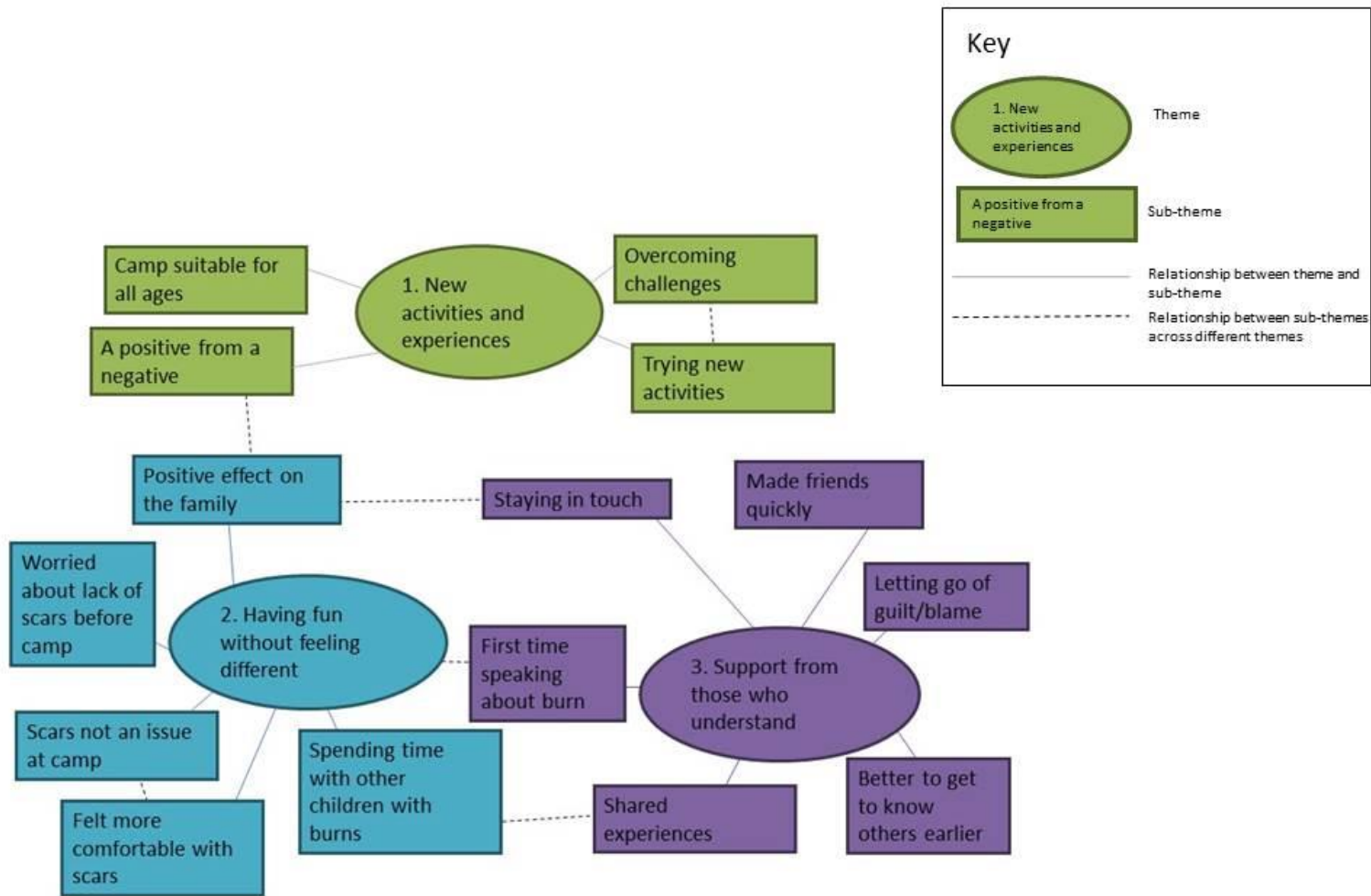




Figure 2. A family at burn camp

