

An overview of the research that led to the development of this website

This website was developed as part of a series of PhD research studies funded by the University of the West of England, Bristol. The first piece of research was an interview study and the second was a questionnaire study.

Initially, 13 parents/carers shared their experience of their child's burn injury, their access to support, and opinions regarding peer support – that is support from other parents who have shared similar experiences. Parents described many different experiences, both positive and negative, but the overwhelming message from most was that the burn injury had an overwhelming impact and the treatment was challenging for both parents and children. The findings suggested that many parents would value having access to information about coping, as well as the perspectives and experiential knowledge that other parents have. However, there were few opportunities to meet other parents and there could be emotional and practical barriers that made accessing professionally-led support difficult for parents. The idea that support could be provided online also emerged.

Next, I explored these findings further using a questionnaire, which was completed by 57 parents/carers. I found that most parents did want to access information and peer support online. They thought that this could be particularly important when feelings of guilt or the pain they felt when recalling the events meant that parents didn't want to talk about their experiences, or when pressures on their time and the distance that they might have to travel made it practically too difficult to access support for themselves. If you want to read about the findings of these studies in more detail, more information is provided on the following pages.

Study 1: Interviews

What was the aim of this study?

When a child experiences a burn injury it can also have a major impact on their family. Parents may experience distress including anger, anxiety and guilt, and often extra caring responsibilities such as looking after the injured child, their siblings, travelling to and from hospital, and trying to get life back to normal. National Burn Care Guidelines recommend that professional support for parents and families is provided by children's burn units, but also that there should be support from parents who have shared a similar experience – peer support. However, peer support is very limited within the UK. Therefore, the study had three broad aims, to:

- 1) Explore parents' experiences of having a child suffer a burn injury
- 2) Explore whether parents access support following their child's injury and whether they find it beneficial
- 3) Establish parents' opinions of peer support and whether they would value this following their child's burn injury

What did I do?

I interviewed 13 parents/caregivers who had a child who had experienced a burn injury. Interviews took place via Skype, telephone, face-to-face, or by email. The interviews explored parents' experience of the injury, treatment, support, and opinions of peer support.

What did I find?

Several key themes were apparent in the interviews; these are listed and described below. Parents described many different experiences, both positive and negative, but the overwhelming message from most was that the burn injury had an overwhelming

impact and the treatment was challenging for both parents and children. A variety of surgery and treatments had been faced including treatment in intensive care units, skin grafts, scar revision surgery, scar management with creams and pressure garments, and physiotherapy. Overall, parents found the support they received from professionals to be helpful but it was also felt that online support might be useful.

Theme 1: Loss

Fear of losing the child. Some parents talked about how, in the immediate aftermath, they feared that they would lose their child due to the injury itself, or because their child would go into shock. Some parents also feared that social services may deem the accident to be evidence that they were a bad parent and take their child away. The fear of losing a child could also return if there were medical complications.

Loss of the perfect child. Some parents talked about their child's burn scarring and being saddened at the loss of their 'perfect' child. Regardless of how parents felt about their child's scars, parents had concerns about the negative impact this might have on their child's future.

Action to repair. For most parents, there was a wish that the scars could be undone. Some parents described a "constant quest" for new treatments to repair the damage, anxious that there might be a new treatment available that they didn't know about. Some parents also tried to compensate their child for the injury and its impact in other ways. Parents spoke about "spoiling" and being "soft" on their injured children to compensate them for what they had been/were going through.

Theme 2: Change

Scars remind me. For some parents, their child's scarring would always be a reminder of the traumatic event, something that they didn't do right, their guilt, and the worst day of their life. However, some parents also saw their child's scars as marks of bravery.

Impact on self-perception – a failed protector. Some parents felt that their child's accident occurred because they had in some way failed their child. They felt that they had, for a split second, not adequately fulfilled their role of protecting their child. The

desire to prevent a future accident led many parents to become wary of danger, which could lead to some parents becoming over-protective.

Engagement with others. For many parents, the injury led to them using services that they had never thought about or even knew existed, such as social services, physiotherapy and occupational therapy, psychology services and burns camps. In some cases, this reduced their contact with friends and family, and impacted on their relationship with their spouse. Some parents were also concerned that whilst their injured child was unwell, siblings may have been neglected.

Theme 3: Isolation

Physical isolation. Parents described the hospital as being like a “cocoon” or a “bubble”, being “cut off from the outside world”, often alone with their injured child and in single rooms due to hospital infection control procedures.

Psychological isolation. Although parents are surrounded by a team of different health professionals, and often other family members and friends, they can still feel very much alone and as though they are the only one who has ever been through this or felt this way.

Theme 4: Psychosocial Support

Barriers to accessing support. Although most parents said they knew that professionally-led support was available to them, they discussed challenges that could act as barriers to them accessing this support. These included the demands on their time of caring for their injured child, the financial impact, their distance from the hospital, feelings of guilt or blame, and their focus on getting their child well as they were the ones injured, not themselves. Talking about the event and its impact could also be too emotionally painful for parents.

Support from someone who knows what it feels like. Most parents had been offered support by a professional, such as a clinical psychologist or a nurse, and the majority of those who accepted it thought it was helpful. In most cases, support was offered to parents whilst their child was in hospital. Some parents had accessed other forms of

support, such as peer support, burns camps, social services, and chance meetings with other parents at the hospital. For some parents, having face-to-face interaction was important when sharing personal experiences and those who had accessed peer support, often informally, found it helpful.

Seeking support online. It can be difficult for parents to receive support because they need to overcome the challenges and barriers described above. Some parents had already looked on the internet for other parents that they could share experiences with or learn from, however, appropriate resources and online support was noticeably lacking. Parents discussed different ways support could be provided. Whilst face-to-face interaction was important to some, other parents felt more confident writing to somebody. Some advantages of support via the internet discussed by parents were that the internet provides anonymity, allows images to be accessed, is accessible if/when needed and in their own time, and support can be received from many other parents.

What happened next?

This study provided a lot of information and opened up a number of interesting areas which were to be explored in more detail in the next study. The results highlighted that a burn injury is a very challenging and emotional experience that does not simply get better when the child leaves hospital. Although support is available, it can be difficult for parents to access this. Parents' needs, and how they might better access support, needed to be looked at in more detail.

There was a lot of positive interest in this research from parents, charities, and health professionals involved in the treatment and care of young burn patients and their families. Therefore, following on from this study we developed a questionnaire to be completed by a larger group of parents of burn-injured children. This questionnaire aimed to make sure the key themes and issues were also important to other parents. Overall, we hoped that this research would contribute to the development of a peer support resource for parents.

Study 2: Questionnaire

What was the aim of the study?

This study aimed to confirm the findings of the interview study with a larger number of parents.

What did I find?

Fifty-seven parents/guardians completed the questionnaire. Whilst it was clear they had different experiences, both positive and negative, some experiences were common to most parents; these are listed below.

Following the accident, the majority of parents said that they were sad that, all of a sudden, their child was different and they hoped that their skin would return to the way it used to be. Most parents said that they did everything they could to try to reduce the scarring, and more than half of parents said they were concerned that there might be new treatments available that they had not heard about.

Although most parents reported to see their child's scars as part of them, many said they worried about how they would be affected by them in the future. For most parents, the scars were a reminder, not only of the pain their child had been through and might go through in the future, but also of how brave and strong their child was.

Many parents said that they felt guilty about what happened and, since the accident, they were more safety conscious than they used to be and could be over-protective. Some parents also worried about how the accident impacted on the injured child's sibling(s). In addition to this, it could be upsetting for parents when other people asked about their child's injury.

Just over half of parents reported to feel isolated when their child was in hospital; some parents continued to feel this way when they went home. Half of parents agreed with

the statement, “I felt like I was the only person that felt like this” and reported that they and their partner had never spoken about how they felt regarding the accident.

The majority of parents who completed the questionnaire had accessed support, but some had not. Most frequently, support was received from nursing staff, family, and psychosocial professionals (psychologist/counsellor/psychotherapist). The majority of parents agreed that the support they received was helpful but there was less agreement that they received enough support, or that it met their needs. Generally, parents were in agreement that support was accessible when they needed it.

Most respondents would rather access professional support face-to-face. However, parents also looked for supportive resources on the internet. The majority of parents believed that peer support would be valuable to them and the strongest preference was for this to be provided online. Participants felt that it was important to be able to contact other parents whose child’s injury was similar to their own child’s. Most parents also said that they would have liked to have met someone a little bit ahead of themselves who could explain to them what their future would be like.

More than half of the participants agreed that significant barriers to accessing support were: not knowing where to get it; feeling too embarrassed, ashamed or guilty; the experience being too painful to talk about; and not having the time to access it. Therefore, many parents focussed on getting their child well and did not think about their own needs.

Many parents had looked to the internet for supportive resources, and almost half had used the internet to try to find other people who were experiencing similar challenges. Parents tended to think that the internet was a reliable resource that could help them to understand what health professionals had told them about their child’s injury and treatment. Parents also agreed that it would be helpful to hear about other parents’ experiences on the internet, that looking at a burn-specific website would reassure them that they were not alone, and that the internet could be useful to help parents’ decide if they themselves should seek support. There was also agreement that the internet was a

useful source of support if parents did not want to tell people around them (family or professionals) about how they felt.

Parents who participated in this research raised some additional important points:

1. It is important that parents have access to support in their own time, when they feel ready and want to access it.
2. There is a lack of up to date information currently online for parents.
3. Everyone has different emotional responses, so what is useful to some parents might not be useful to others. In the development of an online resource, it would be important to be sensitive to the fact that not all parents feel the same and they do not all want the same kinds of support.
4. Not all parents trust advice or information on websites.

What happened next?

The results highlighted that a burn injury is a very challenging and emotional experience and, although support is available, it can be difficult for parents to access this. The next step was to develop this website specifically for parents of children who have had a burn injury. It was hoped that this could provide trustworthy information on a range of topics including parents' stories; their role in rehabilitation and pain management; managing trauma, stress and sleep; strategies for living with the consequences of a burn-injury; relaxation techniques; as well as signposting to other information and sources of support.

Now that the website exists, what happens next?

You can contribute to the ongoing research into the value of this website by completing the questionnaire found in the 'Feedback' section.