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Original Article

Parent-perceived isolation and barriers to psychosocial support: a qualitative study to investigate how peer support might help parents of burn-injured children

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Abstract

Introduction: Burn injuries can be traumatic and distressing for the affected child and family, with a prolonged period of recovery. This research explores parents' experiences of support following their child's injury and their thoughts on peer support specifically.

Methods: Thirteen semi-structured interviews were conducted with parents/caregivers, a mean of three years after their child's injury, either face-to-face or remotely. Responses were analysed using thematic analysis.

Results: Analysis produced four themes and 11 sub-themes. These described parents' experiences of loss, change, isolation and access to psychosocial support. This paper focuses on themes of isolation and parents' access to psychosocial support.

Discussion: Findings indicate that parents access psychosocial support following their child's injury and often find it helpful; however, there is a prevailing sense of isolation. Parents often seek information online and find that this is lacking. Many parents reported that peer support would be valuable to them, particularly the sharing of experiential knowledge.

Conclusion: An online resource may be beneficial for parents, but further research is needed to confirm the exploratory data gained to date, ensuring that any resource developed would meet the identified needs of parents.

Keywords

Burns, paediatric, psychosocial, parents, peer support, challenges

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Lay Summary

Burn injuries can be traumatic and distressing for the affected child and family. This article describes research exploring parents' experiences of support following their child's injury and their thoughts on peer support specifically. Peer support is support from another parent who has also had experience of having a child with a burn injury. Thirteen parents were interviewed either face-to-face, over the telephone, via Skype or by email. The findings suggest that parents do access psychosocial support following their child's injury and often find it helpful. However, parents continue to feel isolated following the accident. This experience of isolation can be emotional or physical in nature. The hospital environment can cut parents off from the outside world in the early stages post-burn. Later, the experience of isolation can be maintained by poor communication. In an attempt to overcome this feeling of isolation, parents often seek information online but find that this is lacking. Many parents reported that peer support would be valuable to them, particularly learning from the knowledge of other parents who have been in similar circumstances before. An online resource may be beneficial for parents and aid sharing of this information. However, further research is needed to confirm these findings in order to ensure that any resource developed would meet the needs expressed by parents.

Introduction

Children are particularly vulnerable to burns; they are the fifth most common cause of non-fatal childhood injuries. Common causes of burn injury are hot fluids and surfaces, flames, chemicals and electrical sources.[1] The majority of children cope well following a burn injury.[2] However, for some, the trauma of the injury and the painful medical procedures required to treat them can result in fear and helplessness.[3] These experiences can affect the developing child cognitively, emotionally, psychologically and socially.[2,4]

Burn injuries to children can also have a significant psychosocial impact on parents, especially mothers, affecting their health and psychological wellbeing.[5] Parents can experience reactive distress including stress, anger, anxiety, depression, post-traumatic stress symptoms (PTSS), guilt, marital and financial problems, and increased responsibility and load due to dividing their time to meet the needs of any uninjured siblings, work, hospital and home.[4,6]

For burns requiring surgical intervention, recovery and rehabilitation can be time-consuming, often with a prolonged period in hospital. This can result in persistent distress for the injured child and those close to them due to painful medical treatments, reminders of the event and scarring.[7] Within the hospital environment, the stress involved in caring for a child undergoing unpleasant or painful procedures can go unrecognised.[8] Failure to appreciate and address such distress may contribute to the significant proportion of parents (19–52%) who experience PTSS within the first year after their

child's injury.[9] This can negatively influence family dynamics and relationships that can, in turn, influence the long-term psychosocial adjustment of the injured child.[10]

Research suggests that parental coping predicts how well children adjust to their injury.[7] Compliance with medical care can also be associated with the support of loved ones, which can impact upon the child's psychosocial and physical recovery.[9] Positive social relationships correlate with better adjustment; however, social support that is overly concerned can have a negative effect with patients becoming over-reliant on caregivers and also de-motivated. Therefore, when the non-injured have difficulties coping and processing the trauma, this can impede the adjustment of the injured.[11] Consequently, parents have a unique and integral role in the provision of their child's medical care, as well as the child's psychosocial recovery, following the trauma of a burn injury.

Simons et al.[12] examined whether parents' coping predicted the functional outcomes of children after burn injury. They reported that high parental anxiety and poorer coping strategies were related to poorer functional outcomes. This calls for the whole family to be considered the 'patient' during the post-burn period.[8] However, in providing effective parental support to enable parents to support their child, it is vital for parents' psychological and social needs to be identified.[13]

The literature regarding parental and family support is descriptive, demonstrating awareness of the issues and concerns affecting family members,[14] stress and coping,[9] and the influence of

the family on the long-term psychological adjustment of burn-injured children.[2] Research has also tended to focus on the response of mothers as they are traditionally the primary caregiver and, therefore, most likely to accompany the child to hospital.[15] Most burn services within the United Kingdom provide specialist psychosocial support for those affected by burns and their families.[13] It is also recommended that a support group should be available enabling patients, families and/or carers to access peer support.[16] However, the provision of such support within the UK, particularly for parents/carers, is limited.[17]

The importance and impact of peer support is also an under-researched area[17] and there is no single model that can fully explain the impact on parents. Qualitative studies of parents of children with other health problems or additional needs, including dyslexia, chronic lung disease and diabetes, suggest that parents perceive benefits such as shared social identity, learning from others' experiences, personal growth and mutual support from peer support programmes.[18–20] The under-representation of parents of children with burn injuries in the peer support literature hinders the development of evidence-based support interventions for this group. Support services that are not based on evidence can lack insight into what support is needed, how it is best provided, when and to whom.[21] This qualitative study had three broad aims: (1) explore parents' experiences of having a child suffer a burn injury; (2) examine parents' experiences of accessing support for themselves following the injury; and (3) establish parents' opinions of peer support and whether they would value this following their child's injury.

Method

Design

Given the limited research in this area, a qualitative approach was adopted.[22] To facilitate participant engagement, this study employed a variety of qualitative interviewing methods to collect data.[23]

Ethical approval

This study obtained ethical approval from the Research Ethics Committee of the Faculty of Health and Applied Sciences at The University of the West of England, Bristol (REC Ref. HAS/16/06/151).

Patient and public involvement

Parents participating in other ongoing burns-related studies at the Centre for Appearance Research (CAR) reviewed the appropriateness of the study information and research questions, and provided feedback on the interpretation of the interview data. One of these parents also participated in the current study.

Recruitment

Information was disseminated to potential participants during September 2016 via a variety of media platforms, burns charity websites and emails to parents who had previously consented to being contacted about burns care research opportunities at the CAR. The advertisements directed parents to a website that hosted the study information, consent form and space to add their contact details should they wish to participate. The first author used these contact details to arrange an interview with consenting parents.

For inclusion in the study, parents had to be English-speaking, aged at least 18 years, with a child who suffered but survived a burn injury before the age of 18 years requiring hospital treatment. Exclusion criteria were non-accidental injury and when the child had died because of their injury.

Participants

Fourteen parents and one grandparent contacted the first author to take part in a semi-structured interview. Two parents subsequently opted out by ceasing communication once the interview was arranged. This left a final sample of 12 parents (11 mothers) and one grandfather who had a significant role in the upbringing and care of his grandchild, particularly since the injury. Participants were recruited from a diverse range of locations around the UK. All participants provided written informed consent before interview and verbal consent before interview recording.

Procedure

A semi-structured interview schedule was created to capture the unique experiences of the participants, while simultaneously ensuring that the core areas of interest were covered: the experience of having a child suffer a burn injury, access to support and perceptions of the value of peer support. The interview schedule was guided by questions

Table 1. Child's injury details.

Parent's pseudonym	Child gender	Child age at injury (years)	Time since injury (years)	Cause	Total body surface area (%)
Beth	Female	3.00	15.33	Scald	33
Carol	Male	1.43	.79	Scald	12
Cathy	Female	1.27	.60	Scald	20
Colin	Male	4.87	1.73	Scald	10
Fran	Male	12.19	1.24	Flame burn	5
Jess	Female	13.00	1.21	Flash flame	15
Jim	Female	.81	1.70	Scald	-
Mary	Female	1.41	5.26	Flame burn	50
Sally	Male	1.36	3.19	Scald	7
Sarah	Male	2.31	.22	Scald	-
Sue	Male	1.43	.82	Scald	-
Theresa	Female	.60	3.45	Scald	30
Trish	Female	3.35	1.74	Scald	18

included in previous studies considering psychosocial support needs for families following burn injury[5] and perceived sources of social support in adult burn survivors.[24] To meet the study aims, additional questions were generated regarding parents' thoughts or experiences of peer support, whether such support could be valuable to parents of burn-injured children, and when following the injury it might be appropriate to offer such support. The semi-structured interview schedule is available from the first author on request.

Participants were offered a choice of interview method: one chose face-to-face, two chose Skype, five chose telephone and five chose email interviews. Those requesting to participate via email were sent the interview questions and responded in their own time. Follow-up emails were exchanged to clarify meaning and seek more information where necessary. Email interviews were saved as text files for analysis. All spoken interviews, which lasted a mean of 60 minutes (range = 50–75 min), were audio recorded and transcribed verbatim. It was possible for more than one parent of the same child to participate in the research, although only one parent from each affected family took part.

Analysis

Once all interviews were completed, thematic analysis[25] was used inductively to analyse the qualitative data. There was in-depth analysis of the eight spoken interviews, supplemented by examination of the data from the five email responses. There was less depth to the data from email responses, but this approach to analysis ensured that the data, at least for the group studied, was relatively complete;[26] the goal being to produce knowledge about the experiences of the injury event, treatment and support of parents of burn-injured children. All data analysis was conducted by the first author with supervisory input from the other authors. Member checking then validated the interpretation and adequacy of the data.

Results

Demographics

Parents had a mean age of 40.2 years (age range = 29.0–50.4 years) and the grandfather was aged 63.0 years. Ten participants identified as 'White British', two as 'British' and one as 'British Indian'. At the time of interview, eight participants were employed, two were homemakers, one was a carer and another a student. The grandfather was retired. Ten participants were married, one was single, one was separated and one did not disclose this information. Details of their child's injury are presented in Table 1.

Table 2. Themes and sub-themes.

Themes	Sub-themes
Loss	a. Fear of losing the child b. Loss of the perfect child c. Action to repair
Change	a. Scars remind me b. Impact on self-perception c. Engagement with others
Isolation	a. Physical isolation b. Psychological isolation
Psychosocial support	a. Barriers to accessing support b. Support from someone who knows what it feels like c. Seeking support online

Themes

During the interviews, a broad range of experiences was reported. When interviews focused on participants' experience of support, it became clear that there were similarities in the experiences described, parents' needs and the types of support felt to be beneficial. Table 2 shows the four themes identified within the qualitative data: losses experienced by parents; changes imposed upon them; perceptions of isolation; and access to psychosocial support. This paper will focus on themes 3 and 4: isolation and psychosocial support. Focusing on these two themes allows for a comprehensive discussion of how the hospital environment and psychosocial support provided can impact upon parents' experience of isolation and also how development of an online resource can overcome some of the challenges to accessing support that parents face. Quotes have been selected that best illustrate each point, while attempting to represent as many interviewees as possible. Pseudonyms have been used to protect the identity of participants.

Isolation

Isolation, both in the emotional and physical sense, emerged as a significant challenge that parents faced when their child was newly injured. This could be emphasised early on by the (at least temporary) restrictions on parents' ability to work and interact with friends and family members. Initially, the hospital could be perceived as a 'bubble' or a 'cocoon', leaving parents 'cut off from the outside world'. The sense of isolation changed over time, with parents perceiving more psychological than physical

isolation later. This sense of isolation could be maintained by a lack of communication between spouses. Even when the family was reunited, limited communication could result in feelings of isolation. It could seem as though no one else had shared their experience.

Physical isolation. Parents found themselves suddenly in the 'contained environment' of a hospital with their injured child, often in single rooms due to infection protocols, sometimes in high dependency or intensive care units where visitors were not permitted, in a situation they had never contemplated. Parents' focus on being there to support their child, particularly when they were the only parent present, meant they neglected some of their own basic needs.

> 'I was basically stuck in a room for a week with [my son]; I had to leave him, at his most vulnerable to get food. Which was hard as he didn't want me to leave, so some days I would eat little if anything.' [Sue]

Psychological isolation. Although parents were surrounded by a multidisciplinary team, and sometimes other family members and friends, they still felt very much alone, 'like you are completely by yourself'.

> 'I felt like I was the only person that felt like this… You feel like you're the only person it has ever happened to.' [Carol]

Participants alluded to the fact that staff working in paediatric burn services encouraged parents to try to look after themselves and conserve their strength for when the child was discharged and

they would be required to take over their care at home. However, the value of this advice and support could be difficult to accept as some parents felt that staff did not have the same experiential knowledge as they had.

> 'At the hospital they said frequently to me "Save your strength. When you get home you're going to need it. This gets far worse when you're home." And, of course, when you're in Intensive Care you can't imagine anything being worse… the hospital can tell you that but they probably don't really know what it means. They've heard it but they don't actually probably recognise what that means in your day to day life…' [Mary]

Parents reported that it would have helped if someone, potentially another parent who had already experienced what they were going through, could have informed them of common/typical emotional and behavioural reactions of parents to their child's injury and how to cope with difficulties should they arise. Although parents were able to acknowledge that this normalising information was disseminated by staff members in the burns service, there was a sense that this information might be better heard from a peer who was not talking from a medical perspective, someone 'a little bit ahead' who could talk with lived experience about what the future might hold, and begin to offer support and optimism. Beth suggested that in the first few days, 'if [a peer] actually said to me, you know, it is going to be ok, that'd have meant a lot more to me than the nurses saying it would be'. Participants thought that the distressed parent would better hear this advice if it came from 'someone that's already gone through it'.

> 'I think the people that were telling me that … how it was going to end up were all medical people and not parents, so they were all telling me very factual things about the scar and none of them said "It will be like this".' [Theresa]

Psychosocial support

Support was defined loosely for parents during the interview and could include informal support from friends and family, peers, hospital staff and higher-level formal face-to-face intervention, or any other resource that they found supportive. Most parents reported to have been offered support following their child's injury; however, not all of them accepted it. Those who did access some form of support generally found it helpful.

Most parents reported being offered one-to-one support with a psychosocial professional, such as a psychologist. For some, it was important that the person they spoke to about their feelings had experience working with families in similar situations, for others it was simply important that they were not a family member. Access to a psychosocial specialist could help parents manage feelings of blame and assist them in 'accepting it and moving on rather than trying to turn the clock back and change anything'. This was achieved in at least one case by offering alternative perspectives that did not place the parent in a role where they were at fault.

> 'I think it was just helpful to talk to somebody that wasn't a family member that had maybe seen it before… talking to a psychologist just allowed me to take ME out of it in a way and talk more about the injury and how we were going to deal with it.' [Tracey]

As well as formal support offered by psychosocial professionals, some parents also found key members of staff to be supportive, offering advice, comfort and distraction for the child, which parents described as beneficial.

> 'She's [nurse specialist] been an absolute stand out support and she's rung her at home as well… I think that's a source of comfort that there's a general interest in the child. When they speak about the person or they speak about my daughter in a caring way and I think that's significant to [my daughter] and myself.' [Jim]

> '[Nursery Nurses] were just the best – …they visit all the rooms and round the beds and just play with all the kids and … that's what you wanted.' [Carol]

Barriers to accessing support. Although most participants were aware of the provision of professionally led support for themselves, one was not.

> 'If there were some kind of easily accessible information around then that might have been useful but certainly a suggestion by the doctor, even if they weren't saying "Would you like this?" but even just saying "This group exists, I'll just give you this leaflet or this telephone number" or something, you know "Think about it" kind of thing. That would have been helpful.' [Fran]

Those who were aware of the presence of support discussed the challenges imposed on their routine

that could act as barriers to them accessing or receiving it, such as 'trying to balance working full-time, looking after the family and [the injured child's] on-going medical needs'. Although attempts to attend to their own needs were discussed by some parents, these actions were of low priority with parents putting their 'own needs last'. There was a sense that most parents accepted this was an unavoidable consequence of the injury and, as a result, most found ways to manage the challenges. This was because many of the tasks would likely contribute to the recovery of the child and, therefore, were actions that would help to repair the damage done (a sub-theme not discussed within this paper). Generally, caring for a child with a burn injury was immensely challenging on top of other parental demands and it affected the whole family. The presence of real-world and psychological barriers to support meant that parents focused on their child's needs at the expense of their own.

Real-world or practical barriers were the lack of resources, time or geographical factors causing difficulties for parents accessing support. These included long distances to specialist burns services, the time commitment involved in attending the child's multiple appointments and the financial impact of travel and parking. Financial difficulties could also be exacerbated if parents had to decrease their working hours or cease work altogether to care for their child.

Parents found that much of their time was consumed taking their child to their medical appointments, providing the necessary care at home, attending work and looking after any uninjured siblings. These demands left parents with little time to access support for themselves. In the majority of cases, it was reported that 'a psychologist' offered psychological support to parents during the inpatient phase. Once the child was discharged from hospital, and the parent experienced the aforementioned increased demands, uptake/continuation of formal support could be limited. One parent summarises some of the practical real-world barriers she experienced:

> 'You're in a specialist unit, for me living 90 miles away, it's a two hour drive away... the intensity of the level of care she needed was pretty much a full-time job ... [the support] was there easily accessible within the hospital environment but... I can't travel up to [the hospital] to see a psychologist and, if I'm in [the hospital] I've got my daughter with me. It's just practically a little bit difficult to access.' [Mary]

Other barriers preventing parents accessing support were psychological in nature and resulted in them being 'blinkered' to their own needs. Guilt was and, for many, continued to be felt following their child's injury. This became evident as an area in which parents could benefit from support. However, the reinforcement of their guilt could be a psychological barrier preventing parents from seeking support if they perceived that they were 'always explaining it and it always was because of something [they'd] done'. The child's scars (another sub-theme not explored in this paper) could also fuel guilt, and although the participating parents recognised this guilt, addressing it was difficult when they did not want to talk about it.

> 'You still feel a lot of guilt and you don't want to answer people's questions.' [Carol]

Recalling and talking about the event, and answering questions about their feelings, could cause parents to experience pain or upset. There was also the concern that if their child were to see them upset, this would have a detrimental impact on them. This desire to avoid pain and upset could act as another barrier to parents seeking or accessing support.

> 'We've never gone through that day; we've never re-lived it in any way whatsoever. ...if you came crashing down he'd feel bad,... you know it was just, yes, head up, stay strong, you've got to, there's no choice.' [Carol]

Parents can put on a brave face and be perceived by others to be coping by avoiding thinking or talking about what happened. One mother described a moment she was asked about the incident: her façade crumbled, exposing the emotional impact the event had had on her.

> 'It's emotional having to go through it... it was initially so difficult to even get out what had happened without feeling very, very upset ... as soon as you've got to tell somebody else what's happened, you know, you can be coping, or appearing to be coping fine, it's the articulation of it to somebody else that can then set you off, you know, it's the ... don't ask me if I'm fine, kind of thing.' [Fran]

Linking with the real-world barriers, parents described being 'blinkered' to focus on a narrow set of priorities, such as accompanying and supporting their injured child through treatment,

focusing completely on getting their child well again and maintaining a sense of normality as far as possible. Rather than thinking about themselves, they might only consider 'what do I do to keep going here?' in order to cope and 'hold it together'. This approach may mask a perception of weakness for needing support but might also be the only option when parents are unaware of what support is available.

> 'I just sort of dismissed it. When you've been the parent you don't realise how much you need to talk to people about it… I didn't want my family to think that I was weak.' [Carol]

Despite the provision of psychosocial support within burns services, due to the barriers described, parents may feel unsupported, or even be unsupported, at a time of heightened distress. This can result in unmet needs that could potentially be addressed by peers – other parents who have shared a similar experience and know what it feels like.

Support from someone who knows what it feels like. Access to support from peers is potentially more acceptable to those who hold concerns regarding judgement from others or being perceived as 'weak' for seeking support.

> 'We found it helpful to have brief informal chats with other parents on the hospital ward who you knew were feeling the same guilt and shame about the accidents that had occurred, and they were not judging you.' [Sally]

The interviewer asked participants specifically for their thoughts or experiences of peer support. Most parents described how peers could be a valuable source of emotional and practical support, which would have been appreciated. Some parents had accessed peer support informally and found it helpful; it allowed them to feel 'more normal rather than feeling singular', and to appreciate that accidents do happen and, for some, even that they were fortunate that their child's injury or the circumstances were not worse. Due to the experiential knowledge possessed by peers, parents were able to sympathise and empathise with each other in a way that professionals were not.

> 'I found it very reassuring to see that accidents do happen and talking to others hearing what they went through made me feel like I wasn't alone. I felt a problem shared is a problem halved and felt

it was good to talk to get things off my chest. Talking to other parents in similar situations made me feel stronger about the whole incident. I felt that other parents were very sympathetic as they had been through a similar situation and could empathise which made me feel that I wasn't alone.' [Cathy]

When considering how such an intervention could be delivered, participants spoke about how access to online sources of peer-based support could be convenient.

Seeking support online. It could be difficult for parents to engage in the traditional model of face-to-face psychosocial support, as overcoming the barriers described above requires substantial resources and effort. Some of the parents interviewed had already turned to the Internet as a medium for sharing and gleaning peer experiences and many had searched for information online. This was a self-directed effort, rather than under the advice of others; however, the provision of appropriate resources and online support was noticeably lacking.

> 'I remember coming home from the hospital and reading about other people's recoveries and things like that but there wasn't too much… It was adults that had been burnt and put their stories on.' [Carol]

Most parents discussed the benefits of having 'something on the Internet' that they could access if/when they needed it and in their own time. Rather than the Internet being a substitute for face-to-face support and experience sharing, it could be a preference. It was alluded that some might feel 'more confident to type' about their experiences than they would be to talk in real time. The Internet could provide support at a distance, allowing parents to be more in control of, and selective about, what information they access or share, and when, than they would be in a face-to-face situation. As well as overcoming some of the real-world barriers to accessing psychosocial support, the provision of an online resource could help to alleviate the sense of isolation felt by parents and overcome some of the psychological barriers to support.

Discussion

This paper has presented a selection of findings from a qualitative study, the aims of which were to explore parents' experiences of having a child

affected by a burn injury. The focus of this paper has been the isolation experienced by parents, the psychosocial support available and the challenges faced by parents that can act as barriers to this support being accessed. A potential method of delivering peer support in order to overcome some of these barriers has also been presented.

It was apparent that many parents felt isolated as a result of their child's injury. This might seem unlikely in a busy hospital environment, but parents are often a significant distance from home, uninjured family members and their support network, in an alien environment, often with little understanding about the procedures taking place. Smith et al.[8] speculated whether this issue could go unnoticed by professionals whose focus is on treating the injuries of the child and other patients on the ward. One way to help parents to feel more integrated, and therefore less isolated, while accompanying their child in hospital, might be to include them in the ward round discussion of their child's care,[27] although this suggestion is not without its challenges for staff who would be required to provide additional input to assist parents' understanding and engagement in this process.

Although the provision of peer support is limited, particularly for parents in the UK,[17] it is apparent that professionally led psychological support was available to most parents who participated in this study, particularly during the inpatient phase. Lawrence et al.[14] also reported prevalent, although varied, post-burn injury psychosocial support within the UK. Most parents stated that they had been offered, and generally accessed, such support, finding it helpful to speak to someone who had seen what they were going through before. However, real-world and psychological barriers to accessing support were experienced, mostly following the child's discharge from hospital. When children were treated as outpatients, the time taken to attend appointments, lengthy scar management regimes and distance from the hospital where the support was located meant that parents often focused solely on their child's recovery. Parents' geographical distance from the service has also been identified by staff as a barrier to providing psychosocial support within UK burn services.[28]

Other barriers to support were psychological in nature; for example, parents felt guilty and did not want to talk about what they perceived they 'didn't do right at the time'. Bakker et al.[29] found that permanent scarring moderated the relationship between mothers' feelings of guilt and PTSS over a ten-year period, suggesting that a group intervention could help to reduce self-blame and guilt, reducing the influence of these emotions on subsequent PTSS, particularly for mothers.[6]

As found in previous studies,[5,30] the importance of validating and normalising feelings was also highlighted. Parents reported that it would have helped if they had been informed of common emotional and behavioural reactions of parents to a child's injury and how to cope with such difficulties. Additionally, encouraging communication within couples could reduce psychological isolation. Grief studies have shown that couples may attempt to protect each other by avoiding conversations about their loss and holding in their feelings, resulting in more grief for themselves and their partner.[31] Due to the experiential knowledge possessed by peers, parents may be more accepting of such advice from other parents, rather than staff, as parents know what it feels like and are able to sympathise and empathise in a way that professionals are not.

Within this study, some participants expressed their willingness to offer support to others. This was also evident in Badger and Royse's[32] study, suggesting that the value of this service was recognised by adult burn-survivors and mutual aid involves reaching out to others. Peers possess unique specialised coping information, perspectives and experiential knowledge that can make mutual aid effective.[33] The idea that experiential knowledge could be a valuable resource in healthcare appeared in the 1970s driven by the self-help movement.[34] Following this, the sharing of patient experiences emerged as a valued source of knowledge and support within healthcare.[35]

Parents in this study discussed the anticipated value of peer support. The buffering hypothesis explains how social support is the most powerful factor for overcoming stressful events.[36] Previously, Cahners and Bernstein[37] described the apparent comfort gained from talking to those who have been there. More recently, Kornhaber et al.[38] found that peer support had a significant impact on burn-survivors' psychosocial rehabilitation, providing encouragement, inspiration, hope and reassurance. In line with the helper therapy principle, helping others can result in a positive upward spiral for the helper, and the helped can become helpers themselves, expanding the resources of the group, thereby building the social capital.[39]

Structured peer support networks for adults with burn-injuries have been created in North America and Australia and report positive

outcomes,[40] but the lack of burns-specific peer support in the UK appears to be due to difficulties with recruitment and maintenance of interest and enthusiasm.[17] Most parents participating in this study agreed that peer support would have been useful to them. However, the majority of participants felt that a formal support group was not needed – a finding also supported by Phillips et al.[5] Thus, some consideration of how the provision of peer support could be developed for parents is required, while remaining mindful that peer-to-peer interactions may not be universally beneficial.[41]

Parents in this study discussed how access to online support from peers might overcome some of the barriers to professionally led support. Bakker et al.[6] commented that web-based information might be useful to reach many parents from multiple hospitals, providing information about potential reactions in children to help parents identify their child's symptoms. However, as discussed above, information regarding parent reactions and symptoms may also be beneficial for parents, normalising their experience and highlighting when they might benefit from support.

Traditionally, websites have presented scientific information about health issues, but patients are increasingly communicating their experiences online. These experiential accounts are now often included on health websites[42] and, for some, can be an important supplement to the medical information provided by healthcare professionals. Potential positive effects of identifying with peers online, reported in research of other health conditions, include creating a sense of communality and belonging,[43,44] comparing and validating knowledge and information,[35] facilitating the exchange of practical tips and advice,[43,44] and enabling normalisation and expectation management.[45]

Although this study recruited an appropriate number of participants for qualitative research,[46] and participating parents were treated by various services around the UK, there are limitations. The responses from parents indicate important considerations in the development of parent-focused support within burn care, but it could be argued that the range of interview techniques employed is a study limitation, particularly as different techniques produced varying depths and quantities of data. However, flexibility in qualitative data collection can improve participant access to research, particularly when focusing on sensitive topics[23] such as this, where shame and guilt can affect openness.

Other limitations are that the age of participants' children at the time of injury was in the range of 0–13 years and, consequently, the results may not be applicable to parents of teenagers. With only one participant identifying as British Indian, and the exclusion of non-English-speaking participants, the sample also lacks cultural diversity and is not representative of burns referrals in the UK.[47] However, the participating parents may represent those actively seeking support; particularly as studies have shown that many people are keen to participate in research altruistically, where sharing their experiences may improve the lives of others.[48] A strength of this research is recruitment of parents who have lived with the burn and its consequences over varied periods of time. This adds to our understanding of the range of parent experiences, allowing us to consider different needs in the development of a parent-focused intervention, as there is evidence that initial stress symptoms tend to decline over time in most parents.[49]

It is worth noting that a significant minority of paediatric burn-injuries are non-accidental;[50] this was a specified exclusion criterion as these parents likely have different needs to those whose child experienced accidental injury. It was also apparent from the data that other life circumstances and stressors aside from the injury might influence the experience of having a child suffer a burn. Considering the strengths and limitations of this study, the exploratory data gained require confirmation through subsequent research. Thus, a quantitative study will follow with the aims of confirming these findings in a larger sample of parents and asking more specific questions to investigate the most valuable way forward in the development of support for this cohort. In future, it is important that the perspectives of both mothers and fathers are gathered in order to apply the findings to the development of interventions for parents, rather than solely for mothers, and to also ensure that a range of needs are met.

Conclusion

Parents of burn-injured children can feel isolated following their child's injury, even when the physical wounds have healed. Many real-world and psychological barriers may prevent parents accessing psychosocial support and further contribute to this feeling of isolation. Developing online support for parents of burn-injured children, hosting peers' personal experiences, offers promising and exciting opportunities to empower parents.

Such a resource could provide accessible and tailored advice for supportive care, which can be informed and promoted by professionals.

Declaration of conflicting interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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