

The aftermath of burn injury from the child's perspective: A qualitative study

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Abstract

A burn injury event and subsequent hospitalization are potentially distressing for children. To elucidate the child's experience of pediatric burn injury, children's reflections on the burn event and its aftermath were examined. Semi-structured interviews were conducted with eight children (12–17 years old). Using thematic analysis, interview transcripts were coded and codes were combined into overarching categories. Three categories were identified: vivid memories; the importance of parental support; psychosocial impact and coping. Implications for care are discussed in terms of assessing children's appraisals, paying attention to the parent's role, and preparing families for potential psychological barriers after discharge.

Keywords

adolescence, family, pain, posttraumatic stress disorder, qualitative methods

Introduction

A pediatric burn injury is an emotional experience that suddenly disrupts a child's life. The injury event and its aftermath often involve pain and invasive medical procedures, and the child is at risk of lifelong scarring. Burns affect the child on a physical as well as a psychosocial level. In the integrative model of pediatric medical traumatic stress (Kazak et al., 2006; Price et al., 2016), it is assumed that different phases in the course of an injury or illness may be potentially traumatic for a child. Several studies have indicated that children may experience acute and posttraumatic stress symptoms after a burn injury (Egberts et al., 2018b; Landolt et al., 2009; Saxe et al., 2005). One of the symptoms characteristic of

posttraumatic stress is re-experiencing of the traumatic event (i.e. flashbacks, intrusive memories, and nightmares). The content of these re-experiencing symptoms has not been examined in children with burns. Consequently, it is unclear whether the event in itself, the treatment, or both are subject of re-experience.

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Adjusting to burns can be challenging (Jones et al., 2017). The few qualitative studies that have been conducted showed that children report changes on the emotional, behavioral, and social level. These included avoidant and hyper-vigilant behavior (McGarry et al., 2014), appearance concerns (McGarry et al., 2014), and negative reactions from peers (Lau and Van Niekerk, 2011; Williams et al., 2004). At the same time, children also described a positive reframing of their experiences and the potential to experience personal growth (Lau and Van Niekerk, 2011; McGarry et al., 2014; Williams et al., 2004). These studies have increased the knowledge about children's own perspective of adjusting to burn injury and have highlighted experiences of vulnerability alongside those of resilience. Yet, knowledge gaps remain, in particular regarding the content of children's emotional (intrusive) memories after hospitalization and the child's perception of their parents' role in the aftermath of the injury. These topics are well suited to be explored within qualitative research and will be addressed in the current study. The aim of this study was to qualitatively examine the way in which children recall the burn injury event, how they reflect on the hospitalization period, and the way they cope with their injury.

Methods

Participants and procedure

The study is part of a larger qualitative research project in which child, parent (Egberts et al., 2018a), and nurse (De Jong et al., 2017) perspectives on parental presence during child wound care were examined, as well as child and parent reflections on the accident and hospitalization period. Children in between the age of 12 and 18 years old were eligible to participate in the current study if they had been hospitalized for a burn injury in one of the three Dutch burn centers for a minimum of 24 hours and had undergone at least one wound care procedure. At least 3 months after the child's discharge, a local researcher approached children and their parents by telephone or during check-up contact

to explain the study purpose. All families were provided additional written information and could take their time to consider the child's participation. Families were thereafter contacted by the first author to ask whether the child was willing to participate. Written informed consent was provided by all participating children and their parents. Purposive sampling was used to achieve variation in characteristics such as child age, gender, and burn type. Child and burn characteristics were obtained from the medical file and parents completed a questionnaire for socio-demographic information.

The final sample consisted of eight children (four boys, four girls). Mean age of the children was 14.85 years old (standard deviation (SD)=1.84, median=15.11, range=12–17). The mean estimated percentage total body surface area (TBSA) affected by partial- or full-thickness burns was 9.88 percent (SD=12.04, median=6.75, range=5–34). Children had a mean hospital stay of 21.25 days (SD=15.97, median=16.00, range=8–50). Four children had undergone at least one surgery during initial hospitalization. Six of the burn injuries concerned flame/fire burns, while two were scalds.

The study was conducted according to the principles of the Declaration of Helsinki (revision, Fortaleza, Brazil, 2013). The Institutional Review Board of the Faculty of Social and Behavioral Sciences of Utrecht University approved the study.

Data collection

Semi-structured, face-to-face interviews were carried out at the child's home, on average 7 months after discharge from the hospital (range 4–17 months). A trained female researcher/psychologist (M.E., MSc) conducted six interviews and two interviews were conducted by a trained master student in clinical psychology. Interviews were digitally audio recorded and lasted 35 minutes on average (range 17–55 minutes).

To establish rapport, the interviewer started off talking with the child about general topics not directly related to the burn injury (e.g. hobbies, family, or school). The purpose of the

research was explained again and children were told that they could stop the interview at any time, for example in case of topics they did not like to discuss. This was often explained while one of the parents was still present. For seven children, parents were not present during the remainder of the interview, while one child preferred to have his mother in the same room. One interview included a short break because of the child's distress. After the break, the child expressed her wish to continue the interview. After each interview, children were asked how they had experienced the interview. Regardless of the interviewer's perception of support needs, all parents and children were reminded about the possibility for psychosocial aftercare in case of remaining concerns.

Topics in the interview guide included the way children looked back on the accident that had caused their injury and the hospitalization period. Special attention was paid to thoughts and feelings related to the accident, hospitalization, and the injury's aftermath, and to the role their parents had played during wound care and hospitalization. Questions were open-ended and follow-up questions were asked to obtain a more in-depth understanding of the child's experience. In line with the constant comparative method, the interview guide was adapted continuously, based on the information obtained within previous interviews. Children were recruited until no new relevant knowledge was obtained concerning the topics of children's emotional memories and parental presence during wound care (data saturation). During all interviews, the interviewer recorded field notes on non-verbal cues and environmental factors that were relevant in interpreting the interview information.

Data analysis

All interviews were transcribed verbatim and imported in the software program MAXQDA 12 (2016). To ensure confidentiality, names were replaced by pseudonyms. Thematic analysis was used to analyze the interview data and included the use of the constant comparative method (Boeije, 2010). The goal of the analysis

was to establish overarching patterns of meaning (themes) across all participants. For each interview, meaningful fragments were extracted from the text and assigned a code that reflected the content of the fragment. Specific incidents from new interviews were compared to already existing codes to identify similarities and differences, and to refine the concepts. The first (M.E.) and last author (N.V.L.) independently coded all transcripts. Codes were discussed at regular time points during the coding process. When differences emerged, these were discussed until consensus was reached. After this open coding process, relationships between codes were discussed and codes were combined into overarching categories. The other members of the research team provided comments on the overarching categories. Memos were written to record the process of interpreting the data and combining the codes.

Results

Three overarching categories summarizing children's reflections of the burn injury event and its aftermath were identified: (1) vivid memories; (2) the importance of parental support; (3) psychosocial impact and coping.

Vivid memories

Children had vivid memories related to the burn injury and the hospitalization period. The content of the more emotional, negative memories could be broadly separated into three types: experiencing the accident, the look of the wounds and scars, and pain. Besides these memories, children also reported positive memories of their hospital experience.

Experiencing the accident. Most children remembered the burn event and accompanying emotions in detail. Children remembered feeling scared, frightened, shocked, worried about potential outcomes, or thinking they might not survive. The realization of the severity of the injury was also described as emotional. They seemed to appraise their injury as more severe

when they realized that admission to a hospital far from home was required.

Shortly after the accident and hospitalization, children often thought about the burn accident, which could evoke emotions such as sadness, fear, and anger. The frequency of accident-related thoughts generally decreased with time. Some children had experienced, or still experienced, moving or static accident-related visual intrusions; for example, the moment flames came toward the child, running around while on fire, trying to extinguish flames, or seeing hot water fall over. Intrusions could be triggered by the place where the event had happened, the object that had caused the injury, the smell of a barbecue, by being alone in a quiet place (e.g. during nighttime), or by watching fire-related material on television:

At first I had really bad flashbacks, but now it has gotten less. But if I see someone now, say, on television and they're on fire, then I really do still get flashbacks. (Charlotte, 15-year-old girl)

Some children described experiencing the same physical sensations (e.g. pain, heat, or loss of strength) and emotions (e.g. fear) while experiencing these intrusions.

The look of the wounds and scars. Seeing the burn wounds for the first time was confronting for several children. Some were shocked by the look of the wounds and some thought their wounds looked disgusting. Seeing the wounds could evoke catastrophizing thoughts in children, such as thoughts about being permanently changed by the injury in terms of functioning (e.g. being scared to never walk again and being bound to a wheelchair forever) or appearance:

I remember I was really shocked and I thought: Now, that's never going to recover. That I thought: Oh, that is so ugly. My legs will never be beautiful again. I did think that at the time. (Charlotte, 15-year-old girl)

At the time of the interview, one girl reported difficulties with looking at her scars, because it reminded her of everything that had happened.

Children described seeing the process of wound closure as a positive feeling, since it meant they were recovering.

Pain. While some children could well remember and describe the pain they had experienced during the accident, emergency care, and hospitalization, other children could not. Wound care procedures were described as painful, especially when wounds needed to be debrided ("taking the little pieces of skin off") or when certain types of dressings were removed. Severe pain was described as an overwhelming feeling that could not be ignored. Children expressed frustration, sadness, anger, and feelings of powerlessness, for example when medicines were not able to take their pain away:

Even though you were given medication, two hours beforehand. But that the pain then is still so all-encompassing. That even with the medication it still hurts, and that was the worst. Because you think: oh medication will help kill the pain. [...] then you don't know what hits you. That you suddenly experience so much pain, that's just hard to understand. (Tess, 16-year-old girl)

One boy felt health professionals could not relate to the amount of pain he was in and expressed a feeling of invalidation when doctors tried to reassure him that his legs would be recovered in a couple of months. Fear of pain prior to wound care was also reported by some children. They described that immediately after wound care, they already felt anticipatory anxiety in terms of the next day's procedure. Two children occasionally re-experienced the pain they had felt during the accident or hospitalization. Several ways of coping with (anticipated) pain were described: the thought that pain and wound care were necessary for healing, acceptance, deep breathing, and relaxation techniques. Children also reported it helped if they could take dressings off or clean the wounds themselves, this made them feel more in control and positively influenced their perceptions of pain:

And doing it myself was really nice, because then you know you have more control over it. You do

trust them, but it's still scary if someone else is doing something to your skin. (Jennifer, 12-year-old girl)

Positive hospital memories. Despite the difficult time the children had gone through, they also had positive reflections on the hospitalization period:

And it sounds strange, but that I sort of had a nice time there precisely because I was so vulnerable and found it so frightening, that the people there helped me so much. (Jennifer, 12-year-old girl)

Children remembered health professionals' interest, sympathy, knowledge, and competence. Children also had positive memories of the ambience in the hospital, the humor, the support and attention they had received from family and friends, and the fun activities they had engaged in:

The people who shared warmth and humor with me and how they empathized. And the good things I took away with me, the nice memories. (Noah, 14-year-old boy)

The importance of parental support

Parents were seen as a great source of support during the hospitalization period and after discharge. Concerning wound care procedures, most children preferred their parent's presence because of the safe and familiar feeling it provided, although children also reported parental presence was not always necessary or parents did not have to be present all the time:

Maybe I could have done it alone, but I was really glad my mother was with me. Just a familiar face with me. My mother also saw me in pain then, she also knows what I looked like then. (Vince, 17-year-old boy)

The parent was considered a familiar person in a new and unfamiliar environment, which could comfort, practically and emotionally support, and reassure the child during the procedure. Being present also enabled parents to see the wounds and how the child was doing. This was thought to ease conversations about

the wounds and the child's experience during wound care. Disadvantages of parental presence were also mentioned by children. Some (older) children imagined it had been stressful for their parents to see them suffer and some parents had shown obvious signs of distress during wound care, such as crying. These distress reactions sometimes made children take into account their parents' feelings and to reassure their parent that they were doing fine. Children also mentioned to "need a break" from their parent every now and then, and that nurses and child life specialists were sometimes better able than parents to distract the child from pain during wound care.

Children were thankful that parents stayed with them throughout their stay, which made them feel "at home" and comfortable. Many children experienced improved family relationships, including those with siblings. They attributed this to the amount of time they spent with their family members in the hospital or to the fact that they had been through a tough time together. After discharge, children also talked with their parents about the injury and its aftermath.

Psychosocial impact and coping

The majority of children reported to have adjusted well to the burn injury. Some children explicitly mentioned not feeling different from their "pre-burn self" and said their life had returned "back to normal." However, two types of concerns were evident in the stories of several children: the concern it might happen again and reactions of others.

Concern it might happen again. Children were more cautious and careful after the injury and family members had become more careful as well. Reactions ranged from being somewhat more careful around the cause of the injury to systematically avoiding it. Because of their experience with the accident, children believed that one small thing (such as a sudden movement or moment of inattention) could have major consequences:

Also if someone does something like lighting a leaf that's dry. You just never know. Maybe there's some petrol there and then 'boom'. Then it's instantly one giant flame again. You just never really know. (Vince, 17-year-old boy)

They feared that they or others might be injured again. Some children were hyper-vigilant around fire or hot water. They said to be constantly "on guard" and expected that an accident could happen any time. Often, children thought that their parents were also more careful or protective because of the injury, especially in relation to hot water and fire. One 12-year-old girl was not allowed to cook or be in the kitchen anymore while her mother was cooking.

Reactions of others. The accident, hospitalization, and remaining scars evoked questions, remarks, and attention of other people. Children reported to have received a lot of positive comments, praises, and expressions of understanding. Sometimes, children valued other people's interest and curiosity, but occasionally this was unwanted. Some children disliked the look of their scars and the idea of exposing scars could lead to fear of others' negative reactions, which could result in the decision to (initially) cover the scar.

Coping. Children described several ways of coping with the burn injury and its consequences. First, *processing the trauma* was considered helpful: They talked about what happened with friends and family, and looked at pictures that were taken during hospitalization to process what had happened. Second, children described to "face their fears," sometimes in a step-by-step manner (*gradual exposure*). Fears included being around fire or the place where the injury had happened, and exposing scars. Third, the burn injury was *put into perspective*. Some children reported they "had been lucky," and that "it could have been worse." Comparing themselves to others that were worse off (e.g. children with more severe injuries that they had seen in the hospital) made children feel better about their own situation:

I've also seen a girl, she was just covered from top to toe in bandages. Even her face, everything. It can always be worse. Then I think to myself, I shouldn't complain so much because that girl there, that's even worse. (Vince, 17-year-old boy)

Fourth, children *focused on positive outcomes*. They focused on the fact that they had received good care, and that their injuries had healed:

It's a good thing that technology is so good these days. Otherwise, I don't think I would have looked like this now. It's all healed really nicely. (Noah, 14-year-old boy)

They also identified positive aspects in what happened. One girl reported it had been a "lesson learnt" for her, and that she wanted to use her experience to teach other people about the risks of burn injury. Fifth, a few children described (repeatedly) thinking about why the accident happened to them and not to someone else (*ruminating*). Finally, *avoiding* places and objects that reminded the children of the accident was reported by a couple of children:

Since the accident I've never drunk tea again. (Tess, 16-year-old girl)

Also, avoiding to talk or think about the event was described occasionally.

Discussion

This qualitative study increased our understanding of children's experiences in adapting to burn injury and offers implications for care (see Table 1 for a summary).

The perceived (life) threat during the accident, thoughts and feelings related to pain and seeing the wounds, specific cues (e.g. the parent's distress) and pre-injury beliefs (e.g. 'needing hospitalization means there is a chance I will die') played a key role in children's appraisal of the burn event. This can contribute to a sense of threat that potentially leads to posttraumatic

Table 1. Implications for care based on the current findings and previous literature.

	Implications for care
Trauma	
Appraisals of accident and hospitalization	<ul style="list-style-type: none"> – Assess child's appraisals of accident and injury severity – Screen for increased risk of long-term traumatic stress – Provide psychoeducation about common emotional reactions
Long-lasting intrusions	<ul style="list-style-type: none"> – Assess the content of intrusions – Provide eye movement desensitization and reprocessing (EMDR) therapy in case long-lasting intrusions are part of posttraumatic stress disorder (PTSD) or cause significant impairment
Appraisal vulnerability to future harm	<ul style="list-style-type: none"> – Target appraisals in cognitive therapy to decrease posttraumatic stress
Hospitalization phase	
Parental presence during wound care	<ul style="list-style-type: none"> – Offer parents the opportunity to be present if the child prefers this – Discuss the parent's role during wound care – Evaluate the emotional impact of wound care on all family members
Minimizing distress and pain and providing a sense of control	<ul style="list-style-type: none"> – Assess meaning of pain, pain-related cognitions and reactions to seeing the wounds – Use nonpharmacological strategies (e.g. procedural preparation, distraction, deep breathing, positive reappraisal, and mental imagery) in addition to pharmacological treatment – Use cognitive restructuring to target catastrophizing thoughts
Coping	
Attention to resilience	<ul style="list-style-type: none"> – Identify and reinforce the child's helpful coping strategies – Emphasize importance of social support – Pay attention to positive aspects in the child's injury experience
Parents' support in child coping	<ul style="list-style-type: none"> – Educate parent's about coping assistance – Provide opportunity for parents to express worries about the child's recovery
Peer support	<ul style="list-style-type: none"> – Offer opportunities for peer support (e.g. support groups or burn camps)

stress symptoms. This is in line with the integrative model of pediatric medical traumatic stress (Kazak et al., 2006; Price et al., 2016) and prior child trauma studies (e.g. Cox et al., 2008; Ehlers et al., 2003). Assessing the child's appraisals and risk of longer term psychological symptoms as well as adequate information provision and psychoeducation about common emotional reactions after the injury can be a first step in reducing the risk of posttraumatic stress (Kazak et al., 2006; Price et al., 2016).

The current study was the first to examine the content of children's possible intrusions after burn injury. Intrusions were found to be predominantly images and thoughts related to the accident, such as seeing flames. Sometimes, physical sensations such as pain were part of these

intrusions. Isolated intrusions related to (pain experienced during) wound care procedures were not reported. However, a minority of children reported a co-occurrence of accident-related intrusions as well as clear and vivid pain memories. It suggests that children with traumatic stress symptoms experience and remember higher levels of pain. This supports prior research indicating that posttraumatic stress predicts pain and not the other way around (Brown et al., 2014). Moments of peak emotional distress in the memory of a traumatic event, the so-called hotspots, can contain a sense of current threat and are therefore important targets in treatment for posttraumatic stress disorder (PTSD) (Grey et al., 2001; Holmes et al., 2005). Likely, for most children, emotional distress and life-threat

appraisal are highest at the time of the accident, which makes it more likely for these moments to be re-experienced. For future research, it is relevant to further unravel the interplay between traumatic stress reactions present shortly after the burn event, pain, and long-term intrusive memories. Overall, the results highlight the need to consider the content of the child's intrusions. If children continue to experience distressing intrusions as part of PTSD, psychological treatment may be indicated, such as eye movement desensitization and reprocessing (EMDR) therapy. This therapy is specifically focused on disturbing images from the trauma memory and has been shown to reduce distressing intrusions in posttraumatic stress symptoms in children after single-incident trauma (De Roos et al., 2017; Diehle et al., 2015).

The uncontrollability of pain and the expectations of negative future outcomes that were triggered by seeing the wounds were clearly remembered by some children. In addition, catastrophizing thoughts occurred in relation to pain and to anticipated outcomes of the injury (e.g. feeling helpless and imagining the worst), which has also been reported in a previous qualitative study (McGarry et al., 2014). Associations between pain catastrophizing and pain intensity (e.g. Crombez et al., 2003; Vervoort et al., 2011) and between catastrophizing and posttraumatic stress symptoms are well established (Carty et al., 2011; Van Loey et al., 2018). Attention may be paid to the meaning the child attaches to pain and seeing the wounds by exploring and treating possible catastrophizing interpretations.

Children emphasized the importance of parental support in the aftermath of the injury. After discharge, parents were considered important in talking with the child about the injury and experiences with wound care, or by promoting certain adaptive coping strategies. On the other hand, parents were sometimes seen as having become more protective and promoting avoidant coping strategies. Early research on this topic suggests a relationship between parent's coping assistance and the child's coping, but only if children reported on

their parent's coping assistance strategies (Marsac et al., 2014). Overall, a responsive parenting style in all phases after the injury, characterized by parents identifying the child's needs and acting on those needs, is important (Alisic et al., 2012). For clinical practice, the results emphasize the value of offering parents the opportunity to be present during wound care. The child's wish for their parent's presence should be considered and the emotional impact of wound care on all family members should be evaluated (Egberts et al., 2018a). Furthermore, specific attention may be paid to the way in which parents can support their child's recovery, for example, by providing psychoeducation, discussing parents' worries about the child's recovery, and providing coping advice.

Although most children had adjusted well, two concerns did become evident in the children's descriptions. First, children were frightened that an accident might happen again and some displayed extreme avoidant or safety behavior. This appraisal of vulnerability to future harm is associated with more posttraumatic stress symptoms (Bryant et al., 2007). A decrease in these appraisals and safety-seeking behaviors has been shown relevant in lowering child posttraumatic stress in cognitive-behavioral therapy (Meiser-Stedman et al., 2017). Second, some children were concerned with the look of their scars and with reactions of others. Peer support is important in adjusting to burns, and support groups and burn camps may facilitate dealing with appearance-related concerns and negative reactions of others (Bakker et al., 2011; Lau and Van Niekerk, 2011; Williams et al., 2004).

Children were also able to recognize positive experiences and demonstrated the presence of resilience. They remembered people's interest and support (i.e. from family, friends, and health professionals) and improved family relations, which is consistent with other studies (Alisic et al., 2011; Lau and Van Niekerk, 2011; McGarry et al., 2014). The majority of coping strategies children reported could be classified as approach-oriented coping strategies (e.g. cognitive restructuring, seeking social support,

problem-solving), while a minority was more avoidance-oriented (Aldridge and Roesch, 2007; Roth and Cohen, 1986). Specifically, avoidant coping has been associated with more posttraumatic stress (Marsac et al., 2017; Stallard et al., 2001), while approach-oriented coping has not clearly been shown to reduce the risk of posttraumatic stress (Marsac et al., 2017). In clinical practice, attention could be paid to the type of coping strategy used by the child.

There are several limitations to the current study. First, this study included children aged 12 and older. Therefore, results are not transferable to younger children, such as infants, toddlers, and preschoolers; young children's strong dependence on their parents and limited cognitive capacities may result in different experiences of burn injury. Second, the children in the study differed in their abilities to reflect on and articulate their experiences. As a consequence, the stories of children better able to communicate their experiences might be reflected to a greater extent than those of children less able to communicate their experiences. Third, the findings only reflect experiences within a Western culture and care system. Therefore, findings may not transfer to other cultures and other care systems. Fourth, although qualitative studies generally do not necessarily require large sample sizes, a sample size of eight children could still be regarded relatively small.

In conclusion, this study highlights potential sources of distress in children related to the burn event and wound care procedures, as well as challenges after hospitalization. By better meeting the support needs of children with burns and strengthening adaptive responses that are already present, positive psychosocial outcomes may be fostered.

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