Family scars after pediatric burns

Marthe Egberts

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Contents

Chapter 1

General introduction

My youngest son Kick was 14 months old when we went to France on holiday. We were staying in a cottage and of course everything was different from the situation at home.[...] Kick was pottering about in the kitchen when I filled my mug with hot water and put the kettle back on the stove. When I turned around I saw that Kick had got hold of the label of the tea bag. The mug fell over and the hot water was pouring over his face, arms, chest and back. Strangely enough I stayed very calm then. I immediately put him in a lukewarm bath and I saw pieces of skin coming off. "Is he going to die?" my eldest son asked, and I didn't know the answer. […] For four days I sat next to Kick in the hospital, where he was lying, dressed like a mummy. They removed the bandages twice every day which hurt him enormously. To distract him I always sang songs for him. Whenever I think back to these moments and these songs it makes my skin crawl. […] He had second-degree burns on his face, so these have completely disappeared now. But he does have burn scars on his chest, his arms and his back. Every time I see them, I feel an immense guilt. I have had therapy for this, and I know it is not my fault. But I can't turn off this feeling. I have also noticed I have become more and more anxious. […] He wanted to go freerunning and when he was 10 I agreed. But he does not allow me to watch him do it, because he can see my fear. "And that makes me afraid," he said, "and I am not afraid at all." I know better than anyone else that terrible things may happen, even when you are very careful. I think it took me 2 years before I had the courage to drink a cup of tea at home. At some point my husband said we really had to get through this. Kick is not restricted in any way and he is a cheerful child. I realized my husband was right. Of course having scars is awful, and they bother Kick at times. Then my heart breaks. But it could have been so much worse. Kick is still alive and healthy.

[mother of Kick, interview published in magazine Flair, July 2018]

A pediatric burn injury not only affects the child, but it may have a profound impact on the entire family as illustrated by the autobiographical account of the mother of Kick. To better understand the family impact of pediatric burns and to improve support provided to families, research should specifically include the perspectives of children and parents who have been through this stressful experience. Conducting research in a pediatric burn population can be challenging, since sample sizes are generally small and the phase in which families are recruited to participate in research is highly demanding and emotional. The current dissertation focuses on the way families are psychologically affected by pediatric burn injury and implications for clinical (after)care. In the present chapter, a general background to the studies is provided and the aims and outline of the studies that make up this dissertation are presented.

Physical aspects of pediatric burns

Each year, in the Netherlands, approximately 3300 children (0-19 years old) enter an emergency department with burns. Of these children, around 260 sustain burn injuries severe enough to require admission to one of the three specialized Dutch burn centers (van Baar et al., 2015). Children in the age of 0-4 years are particularly at risk of burn injuries, because of their rapid motor development, explorative behavior, and limited awareness of danger in their environment. Burns in these young children often concern scald injuries caused by hot fluids. Typical accidents include children pulling a cup of tea or pan with hot food towards them. In older children (5-19 years old), flame burns are more prevalent, for example caused by campfires, barbecues, or experimenting with fire. Pediatric burn injuries can also be non-accidental, when caused by child abuse or neglect. A retrospective study in one of the Dutch burn centers reported an incidence of suspected child abuse or neglect as high as 9% (Bousema et al., 2016).

The severity of the injury is dependent on the depth, size, and body location of the burn. In terms of depth, a distinction is made between first-, second-, and third-degree burns, based on the layers of the skin that are damaged. In first-degree burns, only the epidermis (the outer layer of the skin) is damaged and underlying skin layers are not affected. In second-degree burns, the lower dermis is affected. These types of burns can be further divided in superficial second-degree burns, which can heal spontaneously causing no or minimal scarring, and deep second-degree burns, which have a more difficult healing process and may need surgeries for wound closure. Third-degree burn injuries damage the subcutaneous fat layer of the skin and will not heal spontaneously. Both deep second-degree burns and third-degree burns will lead to permanent scarring. The extent or size of the burn injury is expressed by the estimated

percentage Total Body Surface Area (TBSA) affected by second- or third-degree burns. For example, the surface of the hand palm (with closed fingers) equals approximately 1% of the total body.

Understanding the family impact of pediatric burns from a trauma perspective

A pediatric burn injury can be a traumatic experience for both the child and its family. To better understand the potentially traumatic impact of pediatric burns on the family, the research in the current dissertation was guided by the integrative trajectory model of Pediatric Medical Traumatic Stress (PMTS; Kazak et al., 2006; Price, Kassam-Adams, Alderfer, Christofferson, & Kazak, 2016) and the cognitive model of posttraumatic stress disorder (PTSD) (Ehlers & Clark, 2000).

Integrative model of pediatric medical traumatic stress

The model of PMTS describes the child's and family's psychological reactions to pediatric illness and injury (Kazak et al., 2006). PMTS is defined as 'a set of psychological and physiological responses of children and their families to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences' (National Child Traumatic Stress Network, 2003). Posttraumatic stress symptoms, comprising reexperiencing, avoidance and arousal, are included in this definition. Within the model, it is emphasized that the psychological consequences of illness or injury should be viewed from a family perspective and that the family members' preexisting psychological functioning should be taken into account, since it impacts their risk of PMTS. Another assumption of the model is that in the acute phase, increased levels of stress are normal and that ultimately, most families are well able to cope effectively. A smaller number of families experience persistent or high levels of distress that interfere with functioning. The model also highlights the need to consider the child's developmental stage. For example, the role of parents and the way psychological reactions are expressed can differ between younger versus older children (De Young, Kenardy, & Cobham, 2011).

Different phases are distinguished in the model of PMTS, all containing potentially traumatic elements. The first concerns the peritrauma phase, which covers the period during and immediately following the potentially traumatic medical event. Applying this to pediatric burn injury, this concerns the burn event itself, often followed by first aid procedures, initial admission to an emergency department, and eventually, admission to a burn center. Experiencing the sudden nature of the injury, pain, and sometimes

perceived threat to life can be accompanied by intense emotions. In burn accidents, victims typically do not lose consciousness, which might increase the frightening nature of the event. For parents, witnessing the injury or being informed about the child's accident can be equally distressing (McGarry et al., 2015). The second phase includes the active medical treatment. In the treatment of burns, (daily) wound care procedures are needed, in which dressings are removed, wounds are cleaned and disinfected, dead tissue is debrided, and new dressings are applied. Despite pharmacological and non-pharmacological strategies to control pain, these procedures can cause high levels of pain and distress in children (De Jong et al., 2014). Attending these procedures may be stressful for parents as well. When the injuries concern deep second- or third-degree burns, children need to undergo surgery during initial hospitalization to close the wounds, whereby skin from healthy body parts is transplanted on the wounded area. The third and last phase of the PMTS model involves ongoing care or discharge from care. For children with burns, one to two years may pass before the scar has completely matured (Middelkoop, Monstrey, Téot, & Vranckx, 2011). Some children have to live with permanent scarring for the rest of their lives. Children with severe burns or contractures may need further scar reconstructions throughout their lives to improve function or appearance. After discharge, children may also be involved in rehabilitation programs, to improve their physical outcomes, and may have to wear specialized pressure garments to minimize the development of scars.

Cognitive model of PTSD

The cognitive model of PTSD (Ehlers & Clark, 2000) explains why some people experience persistence of PTSD after a traumatic event. It is proposed that the trauma is processed in a way that produces a sense of current threat. Two key processes are suggested to play a role. First, people negatively appraise the trauma and/or its aftermath (i.e., others' reactions, negative consequences of the trauma, and initial posttraumatic stress reactions). These appraisals maintain PTSD by producing negative emotions and by leading individuals to use dysfunctional coping strategies. For example, a person who has been injured in a traffic accident may now perceive other situations as more dangerous than they actually are. The likelihood of subsequent accidents happening might be overexaggerated, reflecting the appraisal that 'nowhere is safe'. As a consequence, situations in which an accident is feared might be avoided. Second, the autobiographical memory is suggested to be disturbed. This is characterized by inadequate elaboration and contextualization, a strong associative memory, and strong perceptual priming. Because individuals engage in dysfunctional coping strategies,

appraisals and memory have a lower likelihood of adaptation, thereby maintaining or enhancing PTSD.

Both the model of PMTS and the cognitive model of PTSD have a unique contribution in informing the research of the current dissertation. The model of PMTS will be used to understand psychological reactions within the family, in relation to pediatric injury and medical treatment, and taking to account the developmental phase of the child. In turn, the cognitive model of PTSD will be informative in explaining the persistence of PTSD on an individual level, by addressing the role of appraisals and the nature of the memory.

Psychological consequences of pediatric burns

Based on their literature review of the psychological consequences of pediatric burns for the child and its family, Bakker and colleagues (2013) concluded that most survivors of pediatric burn injury appeared to adapt well in the long term. In general, although increased levels of anxiety, acute- or posttraumatic stress, behavioral problems, and depressive symptoms are present in the first months postburn, in only a small group of children these problems persist in the long run (De Young, Kenardy, Cobham, & Kimble, 2012; Landolt, Buehlmann, Maag, & Schiestl, 2009; Rosenberg et al., 2007; Saxe et al., 2005; Stoddard et al., 2006). Studies also indicated a profound impact of pediatric burn injury on parents, with high symptom levels of depression, anxiety, acute- and posttraumatic stress in the first months postburn (Hall et al., 2006; Kent, King, & Cochrane, 2000; Phillips & Rumsey, 2008), and a considerable amount of parents experiencing persistence of symptoms several years after the injury (Bakker, Van Loey, van Son, & van der Heijden, 2010; LeDoux, Meyer, Blakeney, & Herndon, 1998; Phillips & Rumsey, 2008). However, most studies included in the review focusing on the period beyond the first year postburn had a cross-sectional nature and were conducted across a wide range of years postinjury. Since the review of Bakker and colleagues (2013), new studies with prospective and longitudinal designs have been conducted to examine the psychological impact of pediatric burns on the family, using a trauma perspective. These studies have resulted in valuable knowledge about family dynamics after pediatric burn injury. Still, significant knowledge gaps remain. Firstly, recent studies have mainly focused on young (i.e., 0-5 years) children and their parents (Bakker et al., 2014; Bakker, van der Heijden, van Son, & Van Loey, 2013; De Young, Hendrikz, Kenardy, Cobham, & Kimble, 2014; Haag & Landolt, 2017). Considering the importance of the child's developmental stage in understanding the impact of medical trauma (Kazak et al., 2006), these findings should not be automatically generalized to older children.

Psychological reactions and family dynamics may differ for younger and older children, as a consequence of the child's cognitive and emotional development, the child's coping skills, and the role of parents (De Young et al., 2011). Therefore, most studies reported in this dissertation particularly focus on older children and their parents. Secondly, knowledge gaps exist regarding risk factors for persistent child and parent psychological problems. Specifically, the role of experiences with wound care procedures in relation to traumatic stress has been unaddressed so far. In addition, the range of emotions parents can experience after a pediatric burn event and associations with psychological problems have not received much attention.

Trauma-related reactions within the family of the older child

Child and parents' posttraumatic stress symptoms are assumed to be related (Kazak et al., 2006; Price et al., 2016; Scheeringa & Zeanah, 2001). Support for the co-occurrence of symptoms has been found in pediatric burn injury samples (De Young et al., 2014; Haag & Landolt, 2017; Hall et al., 2006; Saxe et al., 2005; Stoddard et al., 2006), as well as other pediatric accidental injury populations (Kassam-Adams, Bakker, Marsac, Fein, & Winston, 2015; Le Brocque, Hendrikz, & Kenardy, 2010). In a study of young children (1-4 years old) with burns and their parents, it was found that a higher injury severity was indirectly related to higher child acute posttraumatic stress, via higher parent acute stress (Haag & Landolt, 2017). This mediation effect was found for mothers but not for fathers. Extending the time frame beyond the acute period, De Young and colleagues (2014) reported that higher parental traumatic stress within the first month was related to higher levels of child traumatic stress six months after the burn event, mediated through the child's traumatic stress within the first month. In addition, child and parent symptoms showed concurrent associations at both time points. These studies provide support for the assumption that child and parent symptoms of posttraumatic stress are related after pediatric burn injury. However, both studies have focused on young children. A review of Brosbe and colleagues (2011) suggested stronger parent-child posttraumatic stress associations for younger, compared to older children, potentially resulting from younger children being more dependent on their parents.

Conducting research in a population of older children (i.e., school-aged children and adolescents) with burns and their parents is challenging. First, recruiting a substantial sample of older children is difficult, since most children admitted to a burn center are young children. Also, school-aged children and adolescents can be hesitant about sharing their (emotional) experiences, and the period shortly after hospitalization may be demanding and stressful. These challenges might explain the scarcity of

prospective studies on posttraumatic stress symptoms in older burn-injured children (e.g., school-aged children and adolescents) and their parents. The few studies that have been conducted have only focused on concurrent parent-child associations and have found significant relationships between traumatic stress of children and parents within the first few weeks after the accident (Saxe et al., 2005), as well as three months postburn (Hall et al., 2006).

The advantage of conducting research in samples of older children, is that they can provide assessments of their own psychosocial functioning. In the assessment of posttraumatic stress, this is desirable, since children and parents may hold a different view of the child's traumatic stress reactions (Kassam-Adams, García-España, Miller, & Winston, 2006; Meiser-Stedman, Smith, Glucksman, Yule, & Dalgleish, 2007). A potential explanation of this difference may be found in the parent's own level of traumatic stress. Parents with higher levels of traumatic stress after child accidental injury have been found to observe more symptoms in their child, regardless of the child self-report (Kassam-Adams et al., 2006). In pediatric burns literature, prospective research in older children including multiple time points and multiple informants to assess child posttraumatic stress has been lacking. However, potential differences in perspectives of children and their parents on child adjustment, and parents' potential overreporting of child symptoms as a consequence of their own posttraumatic stress reactions, can inform clinical practice.

Besides the child's age, parent gender is a factor to consider when examining posttraumatic stress within the family. In pediatric research samples, the majority of participating parents comprise mothers (Phares, Lopez, Fields, Kamboukos, & Duhig, 2005). However, research that includes mothers as well as fathers suggests relevant differences that should not be overlooked. Mothers of young children with burns show higher levels of posttraumatic stress across time than fathers (Bakker, van der Heijden, et al., 2013). In addition, mothers' posttraumatic stress symptoms generally have stronger associations with child symptoms than fathers' symptoms (Morris, Gabert-Quillen, & Delahanty, 2012). The only known study to examine this potential mothers-father difference after pediatric burn injury showed that mothers', and not fathers', symptoms of acute stress were related to the (preschool) child's symptoms (Haag & Landolt, 2017). Whether this finding also holds for older children and symptoms of posttraumatic stress at a later time postinjury, is unknown. Nevertheless, the difference found highlights the relevance of including both mothers and fathers in research.

In sum, to better understand the underlying family dynamics after pediatric burn injury, prospective studies are needed that include both mothers and fathers,

multiple time points, and multiple informants of child reactions. This enables the examination of posttraumatic stress on the family level as well as the couple level, potential discrepancies in child and parent observations of child adjustment, and the way parents' own traumatic stress symptoms may impact their observations of child psychological symptoms.

Risk factors for long-term psychological symptoms

Role of wound care. Several aspects of burn injury and its treatment may be potentially traumatic for children and parents (Kazak et al., 2006; Price et al., 2016). This may be reflected in the way trauma reactions manifest. In qualitative studies, both the injury event and medical procedures such as wound care have been described as stressful and emotional experiences (McGarry et al., 2014; 2015). In clinical practice, the potentially traumatic nature of wound care is sometimes used as an argument to not admit parents during these procedures. On the other hand, parental presence during wound care might have benefits, for example in terms of supporting the child and modelling helpful coping strategies (Doctor, 1994; George & Hancock, 1993). Up to now, one study has focused on mothers' experiences surrounding their young child's wound care (Morley, Holman, & Murray, 2017). Yet, to identify aspects of wound care that can be targeted by burn care professionals in order to provide the best possible care, there is a need for an in-depth exploration of experiences surrounding wound care. This also comprises including the perspectives of parents of older children, fathers, parents that are absent during wound care, and children themselves. Moreover, it is important to know whether experiences with wound care are also reflected in parent and child reexperiencing symptoms of posttraumatic stress, because it might indicate whether wound care procedures and the role of parents might need a change in specific children or parents.

Role of emotions. The cognitive model of PTSD emphasizes the role of trauma-related emotions and appraisals (Ehlers & Clark, 2000). In addition, research in other trauma populations shows that trauma-related emotions may also be associated with depressive symptoms (e.g., Rizvi, Kaysen, Gutner, Griffin, & Resick, 2008). Parents may experience a wide range of emotions after the child's burn event, but apart from feelings of burn-specific guilt that have been longitudinally related to posttraumatic stress (Bakker et al., 2010), and general guilt that has shown cross-sectional associations with depressive symptoms (Sveen & Willebrand, 2018), other emotions have not been specifically addressed. Clarifying the possible importance of a broad range of parental

emotions in relation to posttraumatic stress and depression after pediatric burns, will give more insight into parents at risk.

Integrating knowledge from quantitative and qualitative research

The research presented in this dissertation is characterized by the complementary use of quantitative and qualitative methodology. Both approaches have a unique contribution in answering the research questions addressed. By integrating findings from quantitative and qualitative studies, we can obtain a richer and encompassing view of the family impact of pediatric burns.

Quantitative research allows to examine the topic under study in a structured way, resulting in quantifiable results. In the quantitative studies part of the current dissertation, validated and standardized questionnaires, assessed at several time points, will be used. By using advanced statistical modelling (such as multilevel- and path models), the complexity of the family system and the dependency of data are taken into account. These studies will allow us to draw conclusions about the prevalence of psychological symptoms, the course and predictors of these symptoms, and within-family associations.

To fully understand the impact of pediatric burns, this dissertation also examines the lived experiences of both children and parents using qualitative methods. Qualitative studies allow for a more in-depth exploration of the topic under study and can generate new knowledge and elicit questions that can be examined in future quantitative studies. The studies of Alisic and colleagues (2011; 2012) have been informative in offering a broader perspective on the impact of trauma on the family, by interviewing children and parents about their experiences with psychological recovery after child single-incident trauma. For pediatric burns specifically, two studies have qualitatively described child and parent experiences with burn injury throughout the several phases after the accident (McGarry et al., 2014; 2015). The findings have provided more insight into distressing aspects of pediatric burns, child and parent emotional and behavioral changes after the injury, and coping processes. Still, there are topics ideally suited to be explored within qualitative research, which not received much attention up to now. These include parent and child experiences with wound care, as well as their (intrusive) memories about the accident and hospitalization phase.

Research aims

The overall aim of this dissertation is to increase our understanding of the family impact of pediatric burn injury, with the ultimate goal of informing clinical practice about ways

to support families during hospitalization and in aftercare. Figure 1 graphically displays the framework used and the constructs examined in the current dissertation, guided by the model of PMTS (Kazak et al., 2006; Price et al., 2016).

By using a combination of quantitative and qualitative studies, we aim to study the impact on the family in breadth and depth. Within the quantitative studies, we aim to reflect the complexity of the family system and to examine the interrelatedness and predictors of children's, mothers' and fathers' psychological symptoms, by using prospective designs and advanced statistical modelling. In addition, we pay attention to the child's perspective on their own adjustment, as well as the parent's appraisal of their child's adjustment. The qualitative studies are focused on increasing our in-depth knowledge about children's and parents' experience of pediatric burn injury. Specifically, we examine parental experiences concerning their presence or absence during child wound care procedures, and the content and nature of child and parent (intrusive) memories after discharge.

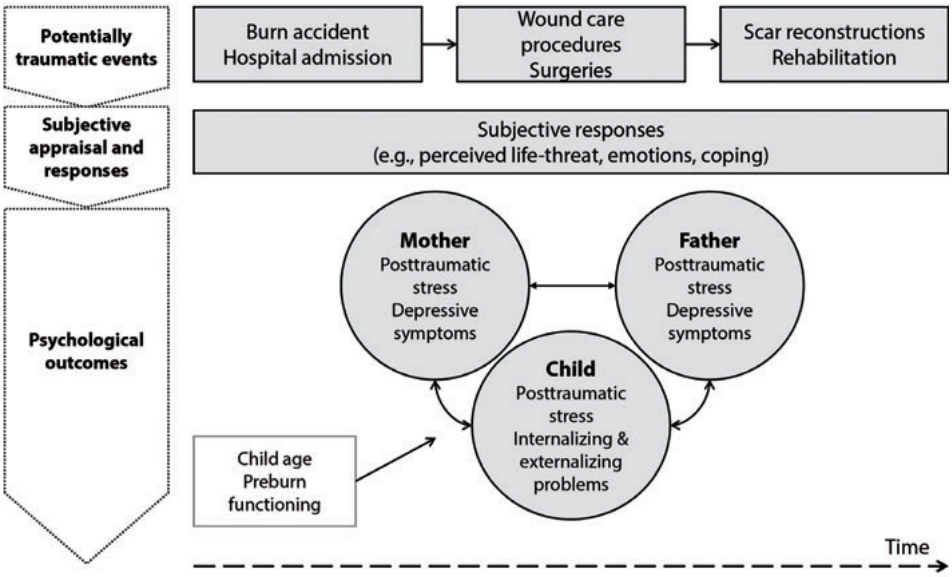

Figure 1. Schematic representation of the injury phases and potentially traumatic events, psychological constructs, and within-family associations examined in the current dissertation. This representation is an adapted version of the integrative (trajectory) model of Pediatric Medical Traumatic Stress (Kazak et al., 2006; Price et al., 2016).

Outline of this dissertation

In **Chapter 2 to 5** the results of a prospective cohort study on parental and child adjustment after burn injury in school-aged children and adolescents (8-18 years old) are presented. **Chapter 2** examines child, mother and father posttraumatic stress symptoms within the first month and three months postburn. The study focuses on the within-family associations of posttraumatic stress, as well as the role of parents' own symptoms in their observations of child posttraumatic stress. Broadening the perspective beyond child posttraumatic stress to child emotional and behavioral difficulties, **Chapter 3** focuses on child internalizing and externalizing problems 12 months postburn, and its associations with preburn functioning, and parental posttraumatic stress. In **Chapter 4,** we move from the overall family level to the couple level. We examine the course and predictors of mothers' and fathers' posttraumatic stress up to 18 months postburn, while specifically taking into account the interdependency of symptoms on the couple level. Turning to the individual parent level**, Chapter 5** focuses specifically on mother's adjustment. The chapter not only includes data on mothers of children in the age of 8 to 18 years, but also those from a cohort of mothers with children aged 0 to 4 years. The aim of this chapter is to examine a range of mothers' emotions (i.e., fear, sadness, horror, anger, guilt, and shame) related to the burn event, and its longitudinal associations with symptoms of posttraumatic stress and depression.

Chapters 6, 7, and 8 include the results of a series of qualitative studies. Semi-structured interviews with children and parents were used to gain a more in-depth understanding of experiences surrounding pediatric burns and to formulate implications for clinical care. **Chapter 6** specifically focuses on the parent's perspective of their presence or absence during child wound care procedures. In **Chapter 7,** children's own experiences after burn injury are the subject of investigation. 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 are examined in this chapter. In **Chapter 8**, a similar study is presented for parents' reflections on their child's burn injury, with specific attention to their memories and appraisals of the child's injury. **Chapter 9** presents a summary of the main findings and a general discussion of the findings.

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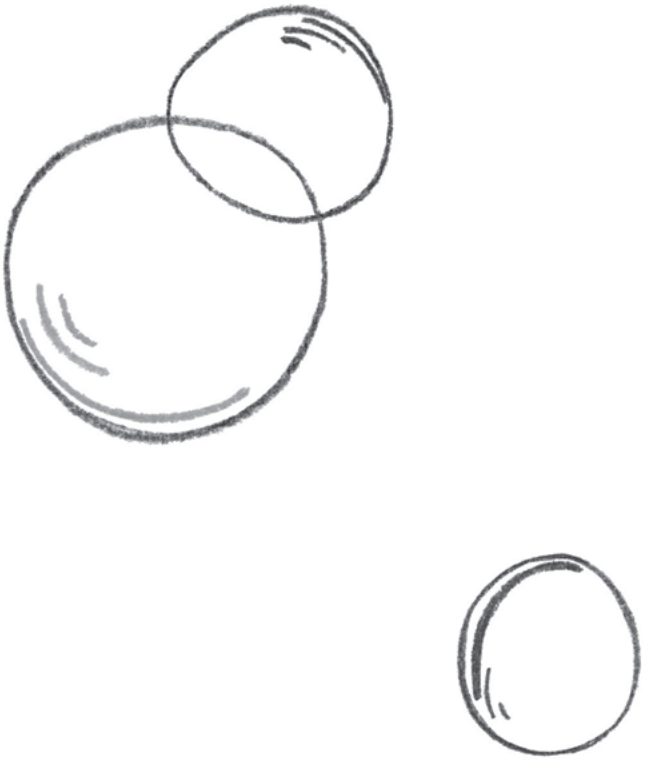
Part I

Parent and child psychological adjustment:
Longitudinal course and associations



Chapter 2

Mother, father and child traumatic stress reactions after pediatric burn: Within-family co-occurrence and parent-child discrepancies in appraisals of child stress

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2

Abstract

Aim: The current study examined occurrence and within-family associations of traumatic stress reactions after child burn injury, while in the same model addressing the role of parents' own symptoms in their reports of child symptoms. **Method:** One-hundred children (8-18 years old), and their mothers (n = 90) and fathers (n = 74) were assessed within the first month (T1) and three months (T2) postburn. Parents and children rated child traumatic stress reactions on the Children's Responses to Trauma Inventory (CRTI) and parents rated their own reactions on the Impact of Event Scale (IES). Cross-sectional associations at the two occasions were examined using a Structural Equation Model. **Results:** Occurrence of traumatic stress symptoms in the clinical range was higher in parents (T1: 24-50%; T2: 14-31%) than children (T1: 0-11%; T2: 3-5%, depending on whether children, mothers or fathers reported on symptoms). Traumatic stress symptoms of mothers at T1 and of both parents at T2 were significantly related to child self-reported symptoms. Moreover, mothers who experienced higher stress symptoms themselves gave higher ratings of their child's symptoms at both time points, while for fathers, this was only found at T2. **Conclusions:** The current study demonstrates the impact of pediatric burn injury on the family level, and shows simultaneous existence of within-family interrelatedness of traumatic stress and an influence of parents' own symptoms on their perception of child symptoms. Findings highlight the need for trauma symptom screening in all family members and for considering informants' symptoms to understand the child's functioning in particular.

Introduction

Burn events are potentially traumatizing for children and adolescents. Besides the burn event and injury itself, potential stressors include treatment-related factors such as pain, repeated wound care and skin grafting procedures. Clinically relevant acute stress reactions appear to be present in 25 to 31% of children (De Young, Kenardy, Cobham, & Kimble, 2012; Saxe et al., 2005; Stoddard et al., 2006). Although symptoms after pediatric injury generally tend to decline over time, they persist in a subgroup (Le Brocque, Hendrikz, & Kenardy, 2010b), indicating the necessity to identify children in need of psychological support.

To assess child traumatic stress reactions, both the child and its parents can be a source of information. However, child assessment is complicated because parent and child symptoms may co-occur as both can be affected by the traumatic event and parents' own symptoms may influence their observation of child symptoms (Kassam-Adams, García-España, Miller, & Winston, 2006). Evidence for the co-existence of these two phenomena was provided by a previous cross-sectional study, showing an association between maternal and child self-reported traumatic stress symptoms after war exposure, as well as a distortion in maternal reports of their child behavior, related to their own traumatic stress symptoms (Smith, Perrin, Yule, & Rabe-Hesketh, 2001). The current study aims to further unravel the complexity of underlying family systemic influences and to especially examine the role of fathers, thereby enhancing insight into the underlying interdependency and discrepancy between mothers, fathers and children.

The concept of 'relational PTSD' refers to the co-occurrence of parent and (young) children's stress symptoms after a traumatic event (Scheeringa & Zeanah, 2001). Within this model, it is assumed that the parent's symptoms exacerbate the child's symptoms and vice versa. The interrelatedness of parent and child symptoms is also emphasized within the integrative (trajectory) model of pediatric medical traumatic stress (Kazak et al., 2006; Price, Kassam-Adams, Alderfer, Christofferson, & Kazak, 2016). Indeed, several studies have shown parents' higher initial stress reactions to increase the risk of (later) child traumatic stress symptoms (Landolt, Ystrom, Sennhauser, Gnehm, & Vollrath, 2012; Nugent, Ostrowski, Christopher, & Delahanty, 2007; Saxe et al., 2005). However, research has indicated that the strength of the association between child and parent symptoms may depend on the timing of the assessments, as well as on the age of the child; with stronger relationships for younger, compared to older children (Brosbe, Hoefling, & Faust, 2011).

Over and above the actual co-occurrence of child- and parent reactions, parents' own traumatic stress symptoms potentially influence the way in which they perceive their child's reactions to the trauma. Several studies have shown that parents with more stress symptoms themselves report higher symptoms in their child, suggesting that parents with higher traumatic stress are more prone to overestimate the child's stress symptoms (Ghesquire et al., 2008; Kassam-Adams et al., 2006; Shemesh et al., 2005; Valentino, Berkowitz, & Stover, 2010). This phenomenon is suggested to be one of the explanations for the observed discrepancy between child self-reports and parental reports of child symptoms, which has been shown in various trauma populations (Kassam-Adams et al., 2006; Meiser-Stedman, Smith, Glucksman, Yule, & Dalgleish, 2007; Shemesh et al., 2005).

To fully understand traumatic stress reactions within the family, assessing both parents is essential. Women have been indicated to be more vulnerable to develop posttraumatic stress disorder (e.g., Stein, Walker, & Forde, 2000), which is supported by the observation of higher levels of stress symptoms after burn injury in mothers compared to fathers (Bakker, van der Heijden, van Son, & Van Loey, 2013). Moreover, mothers' traumatic stress symptoms generally have a stronger association with child symptoms, compared to fathers' stress symptoms (Morris, Gabert-Quillen, & Delahanty, 2012). This was confirmed in a recent study in preschool children with burns, where maternal symptoms of acute stress were associated with child acute stress, while paternal symptoms were not (Haag & Landolt, 2017). However, whether this stronger association for mothers also applies to longer term symptoms and older children with burns is unknown. Also, it is unclear whether a potential influence of parents' own symptoms on reports of child stress symptoms will be different between mothers and fathers, as no previous studies have made comparisons. A previous study in child anxiety showed that mothers' reports of child anxiety were related to mothers' depressive symptoms, while this was not the case for fathers (Krain & Kendall, 2000). This suggests that comparing mothers and fathers is relevant and might inform clinical practice regarding the potential consequences of maternal and paternal involvement in assessment of child symptoms.

The main aim of the current study was to examine associations between child (8 to 18 years old) and parent traumatic stress symptoms and the potential impact of parents' own symptoms on reports of their child's symptoms. Prior to examining these associations in one model, parent-child agreement on child stress symptoms within the first month and three months after the burn event was investigated. It was hypothesized that parent-child agreement regarding child stress symptoms would be low to moderate (Kassam-Adams et al., 2006). In the final model, a significant association between child

self-reported stress reactions and parents' stress reactions was expected (Price et al., 2016). In addition, parents with higher levels of traumatic stress were hypothesized to report more stress symptoms in their child, while accounting for the child's self-rated symptoms (Kassam-Adams et al., 2006; Shemesh et al., 2005; Smith et al., 2001). The model was examined for associations within the first month postburn. Next, data collected three months postburn were used to examine whether the model was replicated. Differences between mothers and fathers were examined exploratory. The role of child age was examined by including comparisons between children younger and older than 13 years of age.

Method

Participant recruitment and procedures

Data for this study were collected as part of a larger prospective study on child (age 8 to 18 years) and parental adjustment following pediatric burn injury. Earlier studies in this cohort examined child health-related quality of life (Pan et al., 2015), child behavioral problems (Egberts et al., 2016) and parents' traumatic stress reactions (Egberts, van de Schoot, Geenen, & Van Loey, 2017). The unique contribution of the current study is the inclusion of child posttraumatic stress reactions and the simultaneous analysis of child and parent stress reactions. From April 2007 to July 2011, data were collected in three Dutch and four Belgian burn centers. Data collected within the first month postburn (T1) and three months postburn (T2) were used for the current study. Families were eligible to participate in the study if the child had been in the hospital for more than 24 hours and the percentage total body surface area (TBSA) burned was more than or equal to 1%. Exclusion criteria included limited Dutch language proficiency, child cognitive impairment, and self-inflicted burns. Researchers at the burn centers contacted eligible families and offered oral and written information. Written informed consent was obtained from the mother and father. Children provided written (≥12 years) or oral (<12 years) assent. The researchers requested to complete the first questionnaires within the first four weeks of admission and follow-up at three months consisted of mail-out questionnaires. The study was approved by two independent ethics committees in the Netherlands and Belgium (NL18008.056.07 and B67020072060).

Of the 202 families eligible for the study, 22 (11%) declined to participate, 15 (7%) children were already discharged before the family could be approached and 19 (9%) families were not invited because the local researcher deemed their participation to be too demanding (e.g., psychiatric background, severely ill family members, involvement

of child protection services, or severe financial problems). Twenty families (10%) gave their informed consent to participate, but completed none of the questionnaires. For the purpose of this study, we selected children who completed reports of their own stress symptoms within the first month postburn and for which at least one of their parents completed reports on child symptoms, hereby excluding 26 families. This selection resulted in a sample of 100 families, with reports of 100 children, 90 mothers and 74 fathers. A comparison between the 100 participating families and non-participating families revealed no significant differences in terms of child gender ($p = .55$), number of days in the hospital ($p = .91$), percentage TBSA burned ($p = .84$), and number of surgeries ($p = .62$). However, children from participating families were younger than children from non-participating families ($M_{participating} = 12.8$, $SD = 3.0$, $M_{non\text{-}participating} = 13.8$, $SD = 3.0$; $t(184) = 2.35$, $p = .02$). From T1 to T2, 12 children (12%), 17 mothers (19%) and 10 fathers (14%) dropped out of the study. Comparing the participants that dropped out with the participants that completed measures at T2 revealed no significant differences in terms of self-reported traumatic stress symptoms at T1 ($p_{child} = .87$, $p_{mother} = .14$, $p_{father} = .33$).

Participants

The sample of 100 children consisted of 69 boys (69%) and 31 girls (31%). Sixty-three percent of the burn events occurred at home. For children under the age of 13 years, the burn event occurred at home significantly more often than for children 13 years and older ($p < .001$). In the total sample, the incidence of flame burns was highest (54%), followed by scalds (34%). Incidence of scalds was higher in younger (< 13 years) than older (≥ 13 years) children, while older children more often had flame burns ($p < .001$). Mean TBSA burned was 8.8% ($SD = 10.3$, range 1-72%). Fifty-four (54%) of the children required at least one skin grafting procedure (M number of skin grafting procedures = .96, $SD = 1.95$, range 0-16, median = 1). Length of hospital stay ranged from one to 218 days ($M = 18$ days, $SD = 29$ days, median = 12 days). Mean age of parents was 42.4 years for mothers ($SD = 6.1$, range 28-55 years) and 44.8 years for fathers ($SD = 6.6$, range 32-64 years). The majority of the parents were employed (68% of mothers and 91% of fathers). Eighty-one (81) % of the mothers and 90% of the fathers were married or living with a partner, while 19% of the mothers and 10% of the fathers reported to be single or widowed.

Measures

Child traumatic stress symptoms. Within the first month postburn and three months postburn, the child, mother and father separately filled out the Children's

Responses to Trauma Inventory (CRTI, revised version; Alisic, Eland, & Kleber, 2006). This questionnaire consists of 34 items and assesses the extent to which trauma-related responses were present in the child in the past 7 days. The items included are identical for the child- and parent versions. Items are rated on a 5-point Likert scale ranging from 1 to 5. The measure consists of 4 subscales: intrusion (7 items, e.g., repetitive, intrusive recollections of the trauma), avoidance (11 items, e.g., avoiding conversations about the event), arousal (6 items, e.g., difficulty concentrating), and other child-specific responses (10 items, e.g., feelings of guilt). Clinical relevance of symptoms was derived from clinical norm reference data, with cut-offs based on the 80th percentile (Alisic, Eland, Huijbregts, & Kleber, 2011). The cut-off value was dependent on the child's age and the informant of the CRTI (Child report, 8-12 years old = 91, 13-18 years old = 118; parent report, 8-12 years old = 100, 13-18 years old = 99). As recommended by Alisic and colleagues (2011), clinical relevance was only determined for the total CRTI score, and not for the subscales. Cronbach's alpha's for the total scale were .85 for children, .92 for mothers, and .88 for fathers within the first month postburn and .91, .92, and .93, respectively at three months postburn, indicating adequate reliability.

Parental traumatic stress symptoms. Both parents completed the Impact of Event Scale (IES; Horowitz, Wilner, & Alvarez, 1979; Sundin & Horowitz, 2002) within the first month postburn and three months postburn. The IES is a valid and psychometrically sound 15-item self-report measure used to assess two dimensions of traumatic stress reactions, namely, symptoms of intrusion and avoidance. Both the mother and father were asked to fill out the Dutch version of the IES (Brom & Kleber, 1985) by rating the frequency of symptoms they experienced specifically in relation to their child's burn event on a 4-point Likert scale (0-1-3-5). The total possible score could range from 0-75, with higher scores representing higher levels of stress. Following Dutch (van der Velden, van der Burg, Steinmetz, & van den Bout, 1992) and Australian research (Le Brocque, Hendrikz, & Kenardy, 2010a), scores ≥26 on the Total scale were considered 'clinically relevant stress symptoms.' In our sample, the IES demonstrated adequate reliability, with Cronbach's alpha of .85 and .84 for the total scale within the first month postburn, and .90 and .89 at three months postburn, for mothers and fathers, respectively.

Child- and burn characteristics. Characteristics of the child (i.e., gender and age) and the burn (i.e., percentage TBSA burned, number of skin grafting procedures, and length of stay in the hospital) were acquired from the medical file. Percentage TBSA burned is the estimated percentage body surface area affected by partial- or full-thickness burns. Within the first month postburn, parents provided information on the location of the burn event and the cause of the burn.

Statistical analyses

Prior to analyses, data were inspected for accuracy of entry and missing values, and the score distributions were examined. First, clinical relevance of stress reactions was established for the child, mother and father reports on the CRTI and the mother and father reports on the IES with the use of above-mentioned cut-off values.

To examine informant agreement, intra-class correlations (ICCs) among child, mother and father reports of child stress symptoms were calculated for the total CRTI scale and the four subscales. ICCs < .40 were interpreted as poor agreement, .40-59 as fair agreement, .60-.74 as good agreement, and ≥ .75 as excellent agreement (Cicchetti, 1994). Moreover, agreement on clinical relevance of the total symptoms score (dichotomous) was evaluated with the κ-statistic (Cohen's Kappa coefficient: Cohen, 1960). The κ-statistic was interpreted as follows: <0 poor, 0-.20 slight, .21-.40 fair, .41-.60 moderate, .61-.80 substantial, and >.81 almost perfect agreement (Landis & Koch, 1977). Lastly, difference scores were calculated by subtracting the child report score from the parent report score, to capture the size of the potential difference. For mother-father agreement, the mother report score was subtracted from the father report score. Statistical significance of mean differences was tested with paired sample *t*-tests.

Path models were used to examine the associations between traumatic stress reactions of the child, mother, and father, and to examine the relative contribution of parents' own stress symptoms to their reports of child symptoms, accounting for the child's self-reported symptoms. First, a path model with data from the first month postburn was estimated and this model was replicated with data collected three months postburn. Thereafter, the two models were combined and Wald tests were used to test for differences in strength of the coefficients between the two time points. Differences between mothers and fathers within each time point were also examined using Wald tests. A multigroup model was used to examine whether associations differed between the group of children under and above the age of 13 years. A model in which all associations were constrained to be equal across the two age groups (< 13 years vs. ≥ 13 years) was compared to a model without these equality constraints. Models were examined within a structural equation modeling framework, using Mplus 7.4 (Muthén & Muthén, 2012). As inspection of histograms and values of skewness (ranging from .07 to 1.17) and kurtosis (ranging from -1.06 to 2.93) indicated slight deviations from normality in some variables, a robust maximum likelihood (MLR) estimator was used. Dependency of the data (i.e., children, mothers and fathers are part of the same family) was taken into account in the model by using adjusted standard errors.

In the path model, full information maximum likelihood (FIML) was used to deal with missing data, hereby using all available data. As we examined a saturated model, no fit statistics were calculated. Path coefficients were tested two-sided.

Results

Child and parental stress symptoms: occurrence and correlations

Table 1 presents means, standard deviations, correlations of the measures and the number of family members with stress symptoms in the clinical range. In the first month postburn, the correlation between child self-reported stress symptoms and parents' symptoms was moderate (r = .38) for mothers and weak (r = .11) for fathers. Three months postburn, this correlation was moderate for both mothers (r = .33) and fathers (r = .39). Within-person correlations between traumatic stress symptoms at T1 and T2 were moderate to strong (Child self-reported symptoms r = .49; Mother symptoms r = .71; Father symptoms r = .58), showing an association between symptom levels in the first month and three months postburn for all family members. Child self-reported symptoms and mother-reported child symptoms were significantly higher for younger children at both time points. Also, mothers of younger children reported more symptoms themselves at T1.

At T1 and T2 respectively, 6% and 5% of the children's self-reported stress symptoms were in the clinical range. All of the children with symptoms in the clinical range were under the age of 13. Clinically relevant child stress symptoms were reported by mothers for 11% and 3% of the children, at the two time points, respectively. At T1, 90% of these children were under the age of 13, while at T2, all children were in the younger age group. Fathers reported clinically relevant symptoms in respectively 0% and 3% of the children at T1 and T2. At T2, the children with symptoms in the clinical range as reported by fathers were all younger than 13 years old. Parental reports of their own stress symptoms indicated clinically relevant symptoms in 50% of mothers (child < 13 years: 58%; child ≥ 13 years: 41%) and 24% of fathers (child < 13 years: 25%; child ≥ 13 years: 22%) at T1, and in 31% of mothers (child < 13 years: 39%; child ≥ 13 years: 22%) and 14% of fathers (child < 13 years: 19%; child ≥ 13 years: 9%) at T2.

Table 1. *Pearson correlations (top) and descriptive statistics (bottom) of child and parent traumatic stress symptoms, in different informants at two time points*

	1	2	3	4	5	6	7	8	9	10	11
Child symptoms T1											
1. Child CRTI	-										
2. Mother CRTI	.55**	-									
3. Father CRTI	.40**	.49**	-								
Child symptoms T2											
4. Child CRTI	**.49****	.31**	.25	-							
5. Mother CRTI	.41**	.50**	.37**	.69**	-						
6. Father CRTI	.29*	.29*	.52**	.59**	.75**						
Parent symptoms T1											
7. Mother IES	**.38****	.63**	.40**	.16	.34**	.18	-				
8. Father IES	**.11**	.24	.16	.26	.58**	.39**	.26*				
Parent symptoms T2											
9. Mother IES	.24*	.54**	.22	**.33****	.53**	.37**	**.71****	.37**	-		
10. Father IES	.21	.29*	.46**	**.39****	.54**	.62**	.44**	**.58****	.55**	-	
11. Age	-.21*	-.31**	-.07	-.25*	-.33**	.09	-.27**	-.07	-.21	-.29	-
M	65.30	69.28	62.53	57.22	57.65	55.23	26.69	15.88	18.84	11.22	12.79
SD	15.93	19.69	14.45	17.66	17.80	16.93	14.00	11.63	14.29	11.25	3.04
N	100	90	74	78	74	62	91	72	75	63	100
n (%) with symptoms in clinical range	6(6)	10(11)	0(0)	4(5)	2(3)	2(3)	46(50)	17(24)	23(31)	9(14)	-

Note. T1 = within first month postburn, T2 = 3 months postburn. CRTI = Children's Responses to Trauma Inventory (range 34-170), IES = Impact of Event Scale (range 0-75). Correlations in bold are addressed in text. *$p < .05$, **$p < .01$.

Cross-informant agreement on child stress symptoms

As displayed in Table 2, ICCs between child- and mother reports of child total stress symptoms as well as the four subscales were poor to fair at T1 (ranging from .38 to .56) and fair to good at T2 (ranging from .55 to .70). Father-child agreement on child symptoms could be classified as poor to fair at T1 (ICCs ranging from .17 to .49), and as poor to good at T2 (ranging from .31 to .67). ICCs between mother and father reports of child symptoms generally reflected fair agreement at T1 and good agreement at T2 (ranging from .24 to .54 and from .59 and.75, respectively).

The κ-statistics displayed in Table 2 reflect the extent of cross-informant agreement regarding scores reflecting clinically relevant stress in the child. Agreement on presence of clinically relevant symptoms varied, with κ ranging from .32 to .79. Mother-child agreement could be regarded fair at T1, and substantial at T2. Father-child agreement at T1 could not be calculated, as no fathers rated their child as experiencing symptoms

in the clinical range. At T2, father-child agreement was substantial. Likewise, mother-father agreement was substantial at T2.

As shown in Table 2, difference scores between reports of children, mothers and fathers indicated that mothers generally reported significantly higher levels of child symptoms than children and fathers at T1. There were no significant differences in level of reported child symptoms between children and fathers. At T2, differences between child and mother reports of child symptoms disappeared, as well as differences between mothers and fathers.

Path analyses

Results of the two path models are shown in Figure 1 and Table 3. At T1, the association between parental symptoms and child self-reported symptoms was significant for mothers, but not for fathers. However, the results of the Wald test showed that the strength of the relationship was not significantly different for mothers and fathers (χ^2 (1) = 2.99, p = .08). At T2, both the associations between child self-reported symptoms and mother symptoms, and between child self-reported symptoms and father symptoms were significant. The Wald test confirmed that this association did not differ in strength for mothers and fathers at T2 (χ^2 (1) = .09, p = .76). For mothers as well as fathers, associations with child self-reported symptoms did not differ between T1 and T2 (Mothers: χ^2 (1) = .20, p = .66; Fathers: χ^2 (1) = 3.15, p = .08). The association between mother and father symptoms of traumatic stress was significant at both time points.

Path coefficients indicated that mothers' stress symptoms were independently associated with their reports of child symptoms at both time points. This indicates that mothers experiencing more stress symptoms themselves, observed more symptoms in their child than accounted for by the child's self-report. For fathers, this was only the case at T2. The results of the Wald test showed that these coefficients differed significantly between mothers and fathers at T1, but not at T2 (T1: χ^2 (1) = 9.68, p = .002; T2: χ^2 (1) = 2.05, p = .15). Also, for fathers, this relationship was stronger at T2 than T1 (χ^2 (1) = 10.74, p = .001), while for mothers, the association was stronger at T1 than T2 (χ^2 (1) = 4.43, p = .04). Although not an association of main interest, at T1, it was found that fathers reported more stress symptoms in their child in case mothers reported higher stress (p = .002).

Table 2. *Mean level of child traumatic stress symptoms (left), and cross-informant agreement (right)*

	Child traumatic stress symptoms						Cross-informant agreement								
	Child report		Mother report		Father report		Child-mother			Child-father			Mother-father		
	M	*SD*	*M*	*SD*	*M*	*SD*	ICC	κ	Δ	ICC	κ	Δ	ICC	κ	Δ
Within first month postburn															
Total stress symptoms	65.3	15.9	69.3	19.7	62.5	14.4	.54	.32	4.5*	.40	-	-1.9	.48	-	-7.8**
Intrusion	12.9	4.4	14.6	5.2	13.4	4.1	.46		1.7**	.49		.7	.51		-1.3*
Avoidance	21.1	6.0	21.7	7.2	19.4	5.8	.38		.6	.17		-1.7	.54		-3.3**
Arousal	11.3	3.9	12.1	4.3	10.7	3.2	.50		.7	.30		-.1	.24		-1.1
Other child-specific responses	20.1	5.9	21.0	6.2	19.0	5.3	.56		1.1	.41		-.9	.42		-2.2**
Three months postburn															
Total stress symptoms	57.2	17.8	57.6	17.8	55.2	16.9	.69	.65	.7	.59	.79	-1.8	.75	.66	-1.3
Intrusion	10.9	3.9	11.2	4.4	11.6	4.2	.59		.3	.31		.9	.67		.6
Avoidance	18.9	6.7	18.2	6.6	17.5	6.5	.57		-.6	.41		-1.5	.66		-1.0
Arousal	11.0	4.2	11.3	4.5	10.4	3.9	.55		.3	.46		-.5	.59		-.4
Other child-specific responses	16.4	6.1	16.9	5.6	15.8	5.5	.70		.7	.67		-.7	.72		-.5

Note. ICC = intra-class correlation, κ = Cohen's Kappa coefficient for agreement on clinical relevance of symptoms (dichotomous), Δ = mean difference between reports of two informants (child report subtracted from the parent report, and mother report subtracted from the father report, respectively).
*$p < .05$, **$p < .01$.

An additional multigroup analysis investigated whether the relations in the model between parents and children differed across age groups (< 13 years vs. ≥ 13 years). The results revealed that at both time points the associations between the variables in the model were not different for younger compared to older children (T1: χ^2 (10) = 14.49, p = .15; T2: χ^2 (10) = 10.91, p = .36); parent and child symptom interrelatedness and the influence of parents' own stress reactions on their report of child symptoms did not depend on child age.

The two models explained 50% of the variance in mother-reported child symptoms at T1 and 59% at T2. For fathers, explained variance was 30% at T1 and 55% at T2.

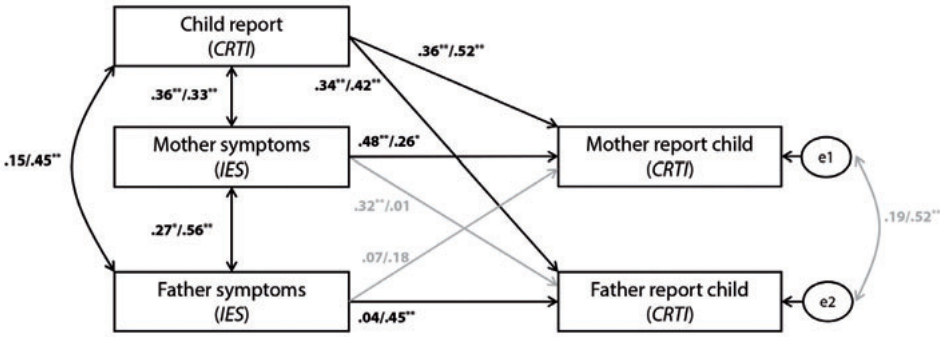

Figure 1. Path model representing associations between parent traumatic stress and (parent report of) child traumatic stress. Standardized coefficients are shown, with values for T1 (within first month postburn) on the left and for T2 (three months postburn) on the right. Bold lines represent main associations of interest. CRTI = Children's Responses to Trauma Inventory, IES = Impact of Event Scale.

*p < .05, **p < .01.

Table 3. *Parameter estimates for the path models*

	Within first month postburn (n = 100)					Three months postburn (n = 82)				
	B	SE	p_B	CI_B	β	B	SE	p_B	CI_B	β
Child report CRTI										
→ Mother report CRTI	.44	.11	<.001	[.23 – .65]	.36	.52	.10	<.001	[.32 – .72]	.52
→ Father report CRTI	.31	.11	.004	[.10 – .52]	.34	.42	.11	<.001	[.20 – .64]	.42
↔ Mother symptoms (IES)	79.06	23.58	.001	[32.85 – 125.28]	.36	81.00	29.24	.006	[23.70 – 138.30]	.33
↔ Father symptoms (IES)	27.97	21.09	.190	[-13.36 – 69.31]	.15	89.46	33.53	.008	[23.74 – 155.19]	.45
Mother symptoms										
→ Mother report CRTI	.66	.12	<.001	[.42 – .91]	.48	.32	.13	.015	[.06 – .58]	.26
↔ Father symptoms (IES)	44.01	19.59	.025	[5.61– 82.41]	.27	89.92	22.41	<.001	[45.99 – 133.84]	.56
Father symptoms										
→ Father report CRTI	.05	.16	.752	[-.26 – .36]	.04	.69	.18	<.001	[.34 – 1.03]	.45

Note. CRTI = Children's Responses to Trauma Inventory, IES = Impact of Event Scale. → reflect regression coefficients, ↔ reflect covariance between two constructs. CI = 95% confidence interval

Discussion

This study examined co-occurrence of child, mother, and father traumatic stress reactions after child burn injury. In the same model the potential impact of parents' own stress symptoms on their ratings of child symptoms was examined, while accounting for stress symptoms as reported by the child. The study showed that parent and child traumatic stress reactions were related and that, after having taken into account these associations, parental stress reactions were associated with parents perceiving more stress symptoms in their child.

Depending on the informant of child symptoms, 0 to 11% of the children were indicated to have traumatic stress symptoms in the clinical range. These rates are in line with findings after child accidental injury (Daviss et al., 2000; Kassam-Adams & Winston, 2004), but low compared to findings after burn injury by Saxe and colleagues (2005), reporting that 31% of the children could be diagnosed with acute stress disorder. Higher mean burn size in the latter sample possibly explains the discrepancy with rates in the present study. Similar to previous studies (e.g., Landolt, Vollrath, Ribi, Gnehm, & Sennhauser, 2003), the present study revealed high occurrence of parental stress symptoms in the clinical range compared to rates in their children, emphasizing the impact pediatric burn injury can have on parents.

The present study indicates that perspectives of mothers, fathers and children on child traumatic stress symptoms differ. Consistent with the study of Kassam-Adams & colleagues (2006), parent-child agreement on presence of stress symptoms in the child was generally low in the first month after the burn event and moderate to good three months postburn. This finding is in line with previous studies (Meiser-Stedman et al., 2007; Schreier, Ladakakos, Morabito, Chapman, & Knudson, 2005) and suggests that parent and child views on child traumatic stress reactions converge over time. A possible explanation is that all family members initially have to get used to the unfamiliar, stressful and demanding (hospitalization) situation. In this period, physical care for the wounds may dominate, children and parents may need time to recognize child stress reactions and may use different reference situations to judge these reactions. After discharge, old as well as new family routines may characterize daily life, resulting in better opportunities to judge the child's behavior.

Within the first month postburn, mothers in the present study were found to overreport child symptoms relative to the child's report, while this was not found for fathers. This may be explained by a higher prevalence of mothers', compared to fathers', traumatic stress reactions. The findings for mothers contrast two previous studies that

found parents to generally underreport child symptoms (Meiser-Stedman et al., 2007; Schreier et al., 2005). A potential explanation of these contrasting results is that earlier studies on parent-child agreement have not differentiated between reports of mothers and fathers and have not included information on (potentially different) prevalence rates of mothers' and fathers' own traumatic stress. Findings of the current study imply that reports by mothers and fathers should not be assumed to be interchangeable.

As hypothesized, parental symptoms of traumatic stress were related to child self-rated symptoms, indicating a shared experience of symptoms within the family. Especially mothers' traumatic stress symptoms were associated with child symptoms within the first month postburn, which is in line with findings from a meta-analysis (Morris et al., 2012), while three months postburn, associations with child symptoms were also found for fathers. Finding no association between paternal and child symptoms shortly after the burn event is consistent with recent findings in young children and their parents (Haag & Landolt, 2017). Concurrent associations between child and parent traumatic stress after pediatric (burn) injury have been reported previously (Daviss et al., 2000; Saxe et al., 2005). The co-occurrence of symptoms within the family that we observed in the longer term fits a relational perspective on PTSD (Scheeringa & Zeanah, 2001). Although this relational model focuses on trauma reactions in young children and their parents, our study indicated that similar mechanisms may apply to the age group of the current study. Mechanisms explaining co-occurrence of symptoms assumed in the model include dysfunctional parent-child relationship patterns, such as unresponsive, overprotective or reenacting patterns. For example, parents' traumatic stress reactions have been related to more self-reported coaching of avoidant child coping (Kichline, Kassam-Adams, Weiss, Herbers, & Marsac, 2017). Alternatively, the association between child and parent symptoms may be explained by a shared genetic vulnerability (Koenen, Nugent, & Amstadter, 2008).

After controlling for the co-occurrence of symptoms within the family, the present study also showed that parents with higher stress symptoms themselves perceived more stress in their children independent of the child's own reported stress levels, a finding supported by previous studies (Kassam-Adams et al., 2006; Smith et al., 2001). This effect was found for mothers at both occasions and for fathers at three months postburn, but not within the first month postburn. However, father reports of child symptoms were related to the mothers' symptoms at this occasion. Overall, our findings indicate that parents with higher stress symptoms are more prone to report elevated stress in their child. Possible explanations are parents with more stress symptoms having difficulty to differentiate their child's reactions from their own (Kassam-Adams et al.,

2006) or parents' symptoms biasing them to recall more negative information in terms of child problems (De Los Reyes & Kazdin, 2005). In sum, the current findings suggest that parent's own traumatic stress is one of the explaining factors of observed parent-child discrepancies in reports of child symptoms.

The differences between mothers and fathers that were observed for relationships with (parent- and child reported) child traumatic stress may be explained by differential involvement of mothers and fathers in their child's hospital care. Similar to the potential explanation put forward by Haag and colleagues (2017), clinical evidence suggests that mothers are generally more often involved in their child's care during hospitalization, for example by being present during child wound care. However, as no data were collected regarding parental involvement during hospitalization and after discharge in the current study, this is a relevant topic to be examined in future studies.

Overall, children below 13 years of age appeared to experience higher levels of traumatic stress than adolescents above 13 years of age. These findings are in line with previous studies reporting more stress symptoms in younger children in the acute aftermath of injury (Kassam-Adams & Winston, 2004; Le Brocque et al., 2010b). Results of a review suggest that age differences may be most pronounced for immediate symptoms and do not apply to chronic posttraumatic stress (Brosbe et al., 2011). Because the current study did not describe measurements beyond three months postburn, it is unclear whether age differences dissolve by that time. Results further showed that mothers, but not fathers, experienced higher levels of symptoms within the first month postburn when their child was younger. In general, the age differences found support the assumption that the developmental period in which pediatric injury takes place is important to consider when examining psychological responses in families (Kazak et al., 2006; Price et al., 2016). Despite this, the current study found no significant differences between the two age groups in terms of relationships between child and parent symptoms. Also, no age differences were found regarding parents reporting more symptoms in their child when they experienced more symptoms themselves. Thus, overall, age differences were primarily found in level of child symptoms, while age did not appear to have an effect on associations of posttraumatic stress symptoms within the family.

The findings have to be interpreted in light of the study's limitations. First, with respect to external validity, the results only apply to the first month and three months postburn and do not automatically generalize to later time points. Second, to minimize the burden of the study, no information was obtained from structured diagnostic interviews, which limits generalizations beyond questionnaire scores to clinical

diagnosis of PTSD. Moreover, the instrument used to assess parental symptoms only covered two symptom clusters of the updated diagnosis of PTSD. Third, no information on subclinical levels of child stress symptoms could be provided, as appropriate norm data were not available for the CRTI. Fourth, the low rate of clinically relevant child traumatic stress reactions at T2 needs replication in another sample to rule out that the strong parent-child agreement is a chance result. Fifth, because some families were not invited to participate in the study (for example because of severe psychiatric problems in one of the parents) this may have resulted in an underestimation of traumatic stress responses. Finally, non-participation was higher in families of older teenagers, which limits generalizability to this age group.

Results of the present study highlight the co-occurrence of traumatic stress symptoms within families coping with the consequences of child burn injury, while at the same time showing evidence for parents' observation of stress reactions in their child being associated with their own stress reactions. In international guidelines, it is currently recommended to use multiple informants in the assessment of child traumatic stress symptoms. The findings of the present study are in line with these recommendations and emphasize the importance of including the child's self-report when they are capable of providing this. To distinguish between relational influences of traumatic stress in family members and potential overreporting of child traumatic stress by parents who experience stress reactions themselves, professionals should consider the parents' reaction to the injury and include them in a therapeutic plan if wanted and indicated.

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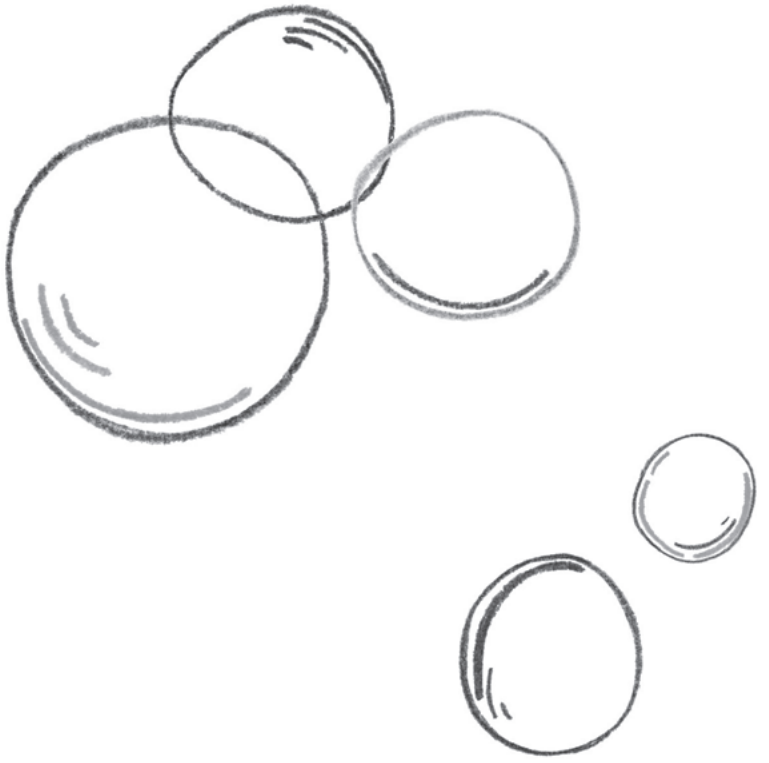

Chapter 3

Child and adolescent internalizing and externalizing problems 12 months postburn: The potential role of preburn functioning, parental posttraumatic stress, and informant bias

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3

Abstract

Adjustment after pediatric burn injury may be a challenge for children as well as their parents. This prospective study examined associations of internalizing and externalizing problems in children and adolescents 12 months postburn with preburn functioning, and parental acute- and chronic posttraumatic stress symptoms (PTSS) from different perspectives. Child, mother, and father reports of 90 children (9-18 years), collected within the first month and 12 months postburn, were analyzed. Results indicated that overall, child and parental appraisals of pre- and postburn behavioral problems were not significantly different from reference data. Rates of (sub)clinical postburn behavioral problems ranged from 6 to 17%, depending on the informant. Pre- and postburn behavioral problems were significantly related, but only from the parents' perspective. Path models showed an association between parental PTSS 12 months postburn and parental reports of child internalizing problems, as well as a significant indirect relationship from parental acute stress symptoms via PTSS 12 months postburn. Notably, no associations between parental PTSS and child reports of postburn behavioral problems were found. In conclusion, parental observations of child externalizing problems appear to be influenced by their perspectives on the child's preburn functioning, while parental observations of internalizing problems are also related to long-term parental PTSS. However, these factors seem of no great value in predicting behavioral problems from the child's perspective, suggesting substantial informant deviations. To optimize adjustment, clinical burn practice is recommended to adopt a family perspective including parent perception of preburn functioning and parental PTSS in assessment and intervention.

Introduction

Adjustment after pediatric burn injury may be a challenge for children and adolescents, as well as their parents. Burn events are often traumatic in nature, the wounds are extremely painful, and deep dermal burns inevitably cause disfiguring scars. Children need to adjust to their changed physical appearance and may feel dissatisfaction with appearance (Pope, Solomons, Done, Cohn, & Possamai, 2007). At the same time, they may have to cope with reactions in their social environment and possible stigmatizing behaviors (Lawrence, Rosenberg, Mason, & Fauerbach, 2011). As a consequence, children could develop internalizing (i.e., symptoms of depression and anxiety) and externalizing (i.e., symptoms of anger and aggression) problems. Adjustment might be especially difficult in (early) adolescence, a period in which more emphasis is placed on outer appearance and social acceptance. Although internalizing and externalizing problems after burn events in children have been a regular topic of previous research, to date, prospective long-term studies for school-aged children and adolescents are lacking.

Earlier cross-sectional studies in school-aged children and adolescents with burns have reported elevated levels of internalizing problems during hospitalization and shortly after this phase (Liber, List, Van Loey, & Kef, 2006; Pardo, García, Marrero, & Cía, 2008), as well as elevated levels of externalizing problems (Pardo, García, & Gómez-Cía, 2010). The few cross-sectional studies on long-term behavioral problems (i.e., at least 1 year after the burn event), have examined children from a wide range of ages at burn injury. These studies generally showed no differences between burn-injured children and the normative population (Blakeney et al., 1993; Landolt, Grubenmann, & Meuli, 2000; Rosenberg et al., 2007; Willebrand et al., 2011). Also, specifically in young children (i.e., 0-4 years), cross-sectional as well as prospective studies indicate that the levels of internalizing and externalizing problems in the long term do not deviate substantially from normative groups (Bakker et al., 2014; Graf, Schiestl, & Landolt, 2011; Kent, King, & Cochrane, 2000). Nevertheless, a proportion of children (3-13%) is indicated to experience clinically significant behavioral problems, but factors that play a role in the development of internalizing and externalizing problems are not well understood.

In the literature on burns, inconsistent findings emerge regarding the role of preburn functioning and burn severity in determining postburn outcomes. Some studies in adults find evidence for a role of burn severity in psychological outcomes (McKibben, Bresnick, Wiechman Askay, & Fauerbach, 2008; Van Loey et al., 2013), while other studies suggest that postburn problems are mainly the consequence of a history of preburn psychopathology (Öster & Sveen, 2014). In children, mainly cross-sectional

studies on long-term internalizing and externalizing problems are available, from which the role of preburn functioning cannot reliably be derived. To our knowledge, only one study on child postburn behavioral problems included appraisals of preburn behavior (Meyer, Robert, Murphy, & Blakeney, 2000). This study examined toddlers with large burns and found that postburn rated internalizing and externalizing problems did not differ from retrospective accounts of preburn behavior. More general, a meta-analysis on risk factors of psychopathology following accidental trauma has pointed to pretrauma psychopathology as one of the most important and consistent predictors (Cox, Kenardy, & Hendrikz, 2008). Regarding burn severity, the majority of long-term studies have reported that burn size is not related to total behavioral problems (Blakeney et al., 1993; Landolt, Grubenmann, & Meuli, 2002; Willebrand et al., 2011). These studies may suggest that most children are able to overcome the consequence of burns irrespective of the burn size and could suggest a role of the family in the child's adjustment process.

Trauma research indicates that parental posttraumatic stress symptoms (PTSS) are interrelated with the child's adjustment (De Young, Kenardy, & Cobham, 2011; Scheeringa & Zeanah, 2001), both in young and in older children, and across a variety of traumatic events, including burn injuries (Alisic, Jongmans, van Wesel, & Kleber, 2011; Bakker et al., 2014; Landolt, Ystrom, Sennhauser, Gnehm, & Vollrath, 2012). It is assumed that parents experiencing PTSS possibly are less available to support their child in the posttraumatic period, which may affect the child's adjustment. Moreover, parental avoidance symptoms, such as not talking about the trauma and avoidance of trauma-related stimuli, could have a negative impact on the child (Ostrowski, Christopher, & Delahanty, 2007). As a consequence, children may not be able to confront and resolve their own anxieties, hereby maintaining psychological symptoms (McFarlane, 1987). Mothers often experience adverse outcomes after a burn event to their child, particularly PTSS (Bakker, van der Heijden, van Son, & Van Loey, 2013; De Young, Hendrikz, Kenardy, Cobham, & Kimble, 2014). Studies indicate that fathers may also experience these negative outcomes (Bakker et al., 2013; McGarry et al., 2013), but research on paternal adjustment after pediatric burn injury is scarce. In addition, as most burn studies have focused on parental PTSS and child outcomes of pre-school children, there is little evidence concerning the interrelatedness of parents' PTSS and postburn functioning of older children and adolescents.

Another explanation for a relationship between parental PTSS and child adjustment may lie in a possible observational bias as a consequence of posttraumatic stress. Research has indicated that parents' own responses to a traumatic event appear to influence their assessment of child symptoms (Smith, Perrin, Yule, & Rabe-Hesketh,

2001). Compared to child self-report, highly distressed parents tend to overestimate PTSS in their child (Kassam-Adams, García-España, Miller, & Winston, 2006). In burn research, a prospective study on 1-year postburn behavioral problems in young children showed that both mothers' and fathers' acute stress symptoms predicted higher levels of child postburn internalizing and externalizing problem behavior (Bakker et al., 2014). As most studies, including the latter, have used the parent as the only informant, it is not clear whether this reflects informant bias or is due to the mutually influencing parent-child interactions. Studies including child reports may add to this currently insufficiently understood association. Furthermore, parental PTSS may reduce and it is not clear how this change may affect parental behavioral observation of the child's behavioral problems.

The present study will examine the associations between appraisals of preburn functioning, parental PTSS and internalizing and externalizing problems (i.e., behavioral problems) 12 months postburn in children and adolescents (age 9-18 years). Moreover, it is examined whether these associations are different across informants of postburn behavioral problems (children, mothers, and fathers). First, pre- and postburn behavioral problems in our sample will be compared to data from the normative population. Our first hypothesis is that our sample will, on average, not deviate substantially from these reference data (Blakeney et al., 1993; Willebrand et al., 2011). Next, relationships between preburn behavioral problems, parental PTSS, and child postburn behavioral problems will be examined. The hypothesized model is displayed in Figure 1. Direct relationships of parental PTSS within the first month postburn and PTSS 12 months postburn with child behavioral problems will be studied, as well as an indirect (i.e., mediational) relationship between parental PTSS within the first month postburn and child behavioral problems through parental PTSS 12 months postburn. Our second set of hypotheses concerns these relationships. A significant positive relationship between pre- and postburn behavioral problems is anticipated (Cox et al., 2008). It is hypothesized that parents' own PTSS within the first month postburn will be directly related to observing behavioral problems in the child (Bakker et al., 2014), as well as through parental PTSS 12 months postburn. Direct relationships between parental PTSS 12 months postburn and parental observations of postburn behavioral problems in the child are hypothesized to be significant (Kassam-Adams et al., 2006; Smith et al., 2001). However, no significant associations between parental PTSS (at both time points) and children's self-reported behavioral problems are expected (Kassam-Adams et al., 2006).

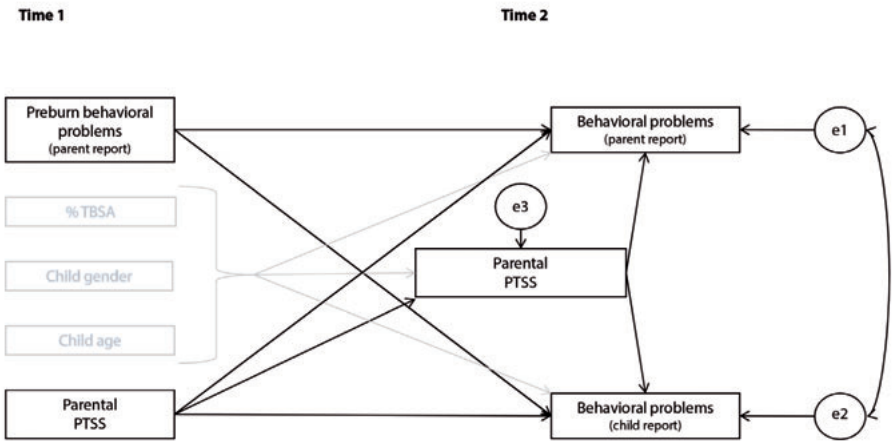

Figure 1. Hypothesized model on the associations between preburn behavioral problems, parental PTSS and behavioral problems 12 months postburn.

Method

Procedure

This study is part of a larger prospective study on child (age 8-18 years) and parental adjustment following a pediatric burn event. This cohort has been described in another study, focused on health-related quality of life (Pan et al., 2015). The study was approved by two independent ethics committees in the Netherlands and Belgium. From April 2007 to July 2011, data were collected in three Dutch and four Belgian burn centers. The current study used data collected within the first month postburn (T1) and at 12 months postburn (T2). Researchers at the burn centers contacted eligible families during admission and requested to complete the first questionnaires within the first 4 weeks postburn. They explained the study purpose and offered additional written information. Written informed consent was obtained from the mother, father, and child. Families were eligible to participate if the child had been in the hospital for more than 24 hours and the total burned surface area (TBSA) was more than or equal to 1%. Exclusion criteria were insufficient Dutch language proficiency and cognitive impairment in the child.

A total of 202 families were eligible for the larger study. For the purpose of this paper, we selected children who, at 12 months postburn, had the minimum age (11 years) to fill out the Youth Self Report (Achenbach, 1991b). A total of 52 children were not in the appropriate age range, leaving 148 children eligible for this study. Of these, 16 families declined to participate in this study, ten families gave their informed consent to

participate but dropped out within the first month postburn, 13 children were already discharged before the family could be approached, and 11 families were not invited because their participation was deemed inappropriate (e.g., psychiatric background, multi-problem families, or severely ill family members). In eight families, parents had incomplete data on child preburn functioning and/or their own PTSS. Thus, for the present study, we used data of 90 families that all gave informed consent and from which at least one of the parents provided information on preburn functioning as well as their own PTSS at T1 or T2. We compared the 90 participating families with nonparticipating families and found no significant differences in terms of child gender ($p = .80$), age ($p = .63$), length of stay in the hospital ($p = .42$), percentage TBSA ($p = .35$), number of surgeries ($p = .68$) and percentage deep burns ($p = .86$).

Participants

Eighty-five mothers and 65 fathers of 90 children were included in final analyses. Demographic and burn characteristics of the children are presented in Table 1. As can be seen, 56% of the children required at least one surgery.

The mean age of participating mothers was 43.1 years (SD = 5.6, range 28-55 years). The mean age of participating fathers was 45.9 years (SD = 6.2, range 33-64 years). The majority of the parents were employed (75% of mothers and 91% of fathers) and had a partner (87% of mothers and 89% of fathers).

In between the two studied time points, of the 90 families, 39 children, 30 mothers, and 32 fathers dropped out. However, reports of families with (partially) missing data at T2 were not excluded in further analyses. Comparisons between families that participated at T1 and T2 and families that dropped out revealed no differences in terms of child age (Mothers: $p = .17$, Fathers: $p = .12$), gender (Mothers: $p = .90$, Fathers: $p = .32$), percentage TBSA (Mothers: $p = .94$, Fathers: $p = .94$), preburn behavioral problems (Mothers: $p = .52$, Fathers: $p = .19$) and parental PTSS at T1 (Mothers: $p = .77$, Fathers: $p = .64$).

Table 1. *Sample demographic and burn characteristics of included children (n = 90)*

	M	SD	Range
Child age (years)	13.9	2.4	9.5-17.8
TBSA (%)	10.0	12.3	1-72
Length of stay in hospital (in days)	19.4	29.7	1-180
Number of surgeries	1.2	2.6	0-16
	n	%	
Child gender (boys)	65	72	
Burn type			
Flame/fire	56	62	
Scald	23	26	
Contact	4	4	
Chemical/electrical	6	7	
Other	1	1	
Site of accident			
At home (in- or outside)	53	59	
Somewhere else (in- or outside)	37	41	

Measures

Child behavioral problems. Within the first month postburn, both parents completed the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997), a measure that has been previously used as a brief behavioral screening questionnaire (Goodman, Ford, Simmons, Gatward, & Meltzer, 2000). The SDQ consists of 25 items. Parents were asked to retrospectively report on the functioning of their child prior to the burn event. Because the hospitalization phase is often a demanding period for parents, using a brief questionnaire seemed more convenient than using an extensive and time-consuming questionnaire. Parents were asked to rate behavioral items on a 3-point scale ranging from 0 (not true) to 2 (very true). Items of the SDQ fall within five scales; Conduct Problems, Inattention-Hyperactivity, Emotional Symptoms, Peer Problems and Prosocial Behavior. The Total Difficulties scores comprises the sum of these scales, excluding the last. For the present study, the Total Difficulties score was used as a predictor variable. Scores higher than 14 on the total scale were referred to as (sub)clinical scores. The reliability and validity of the SDQ are in general satisfactory (Goodman, 2001). In our sample, Cronbach's alpha for the total SDQ-score was .84 for mother reports and .83 for father reports. SDQ reference data were derived from a British sample consisting of children in between 11 and 15 years old (Meltzer, Gatward, Goodman, & Ford, 2000), as there were no appropriate Dutch or Belgian reference data available.

At 12 months postburn, both parents completed the Dutch version of the Child Behavior Checklist (Achenbach, 1991a) . Parents rated behavioral items on a 3-point scale ranging from 0 (not true) to 2 (very true or often true). Children filled out the related YSR (Achenbach, 1991b), containing the same items as the CBCL. The CBCL and accompanying YSR are extensively validated instruments with adequate reliability and validity (Achenbach, 1991b, 1991a). In our sample, Cronbach's alpha for the internalizing symptoms scale was .84 for mothers, .84 for fathers, and .92 for children (YSR). For the externalizing symptoms scale, coefficients were .90 for mothers, .86 for fathers, and .87 for children. For the CBCL and YSR, *T* scores were used to represent child postburn behavioral problems. Dutch CBCL and YSR reference data were derived from the Dutch manual (Verhulst & van der Ende, 2013), which were collected as part of multicultural reference data (Achenbach & Rescorla, 2007).

Parental PTSS. The Impact of Event Scale (IES; Horowitz, Wilner, & Alvarez, 1979; Sundin & Horowitz, 2002) was used to assess parental PTSS within the first month postburn and 12 months postburn. This questionnaire assesses two dimensions of traumatic stress, namely symptoms of intrusion and avoidance. Both parents completed the Dutch version of the IES at both time points (Brom & Kleber, 1985). The IES consists of 15 items. Parents were asked to rate the frequency of symptoms they had experienced specifically in relation to their child's burn event on a 4-point Likert scale (0-1-3-5). The total possible score ranged from 0 to 75, with higher scores representing higher levels of stress. Scores higher than 26 on the total scale were referred to as 'clinically significant stress'. In our sample, Cronbach's alpha for the total IES was .86 (T1) and .87 (T2) for mothers and .86 (T1) and .90 (T2) for fathers.

Child and burn characteristics. Characteristics of the child (i.e., gender and age) and the burn (i.e., percentage TBSA, number of surgeries during initial hospitalization and length of stay in the hospital) were reported from the medical file. TBSA is the estimated percentage body surface area affected by second- and third-degree burns. The number of surgeries reflects the amount of skin grafting procedures the child has undergone. Parents provided information within the first month postburn on the place of the burn event (i.e., inside or outside the home) and the cause of the burn (e.g., hot fluid, flame, or contact with hot object).

Statistical analyses

First, data were inspected for typing errors and missing values. Next, normality of the data was examined, and means, standard deviations, and intercorrelations among variables were calculated.

Second, prevalence of clinically significant parental PTSS was described and paired sample *t*-tests were used to compare parental PTSS at T1 and T2. To answer our first hypothesis, pre- and postburn behavioral problems were compared to reference data (Meltzer et al., 2000; Achenbach & Rescorla, 2007), with one-sample *t* -tests.

Third, paths models were used to estimate direct and indirect associations among the constructs (Figure 1) within a structural equation modeling framework, using Mplus 6.11 (Muthén & Muthén, 2010). Four separate structural models were examined, because the relatively small sample size did not permit including all variables in a single model. The first two models included mother and child reports of internalizing and externalizing problems, respectively. Likewise, two separate models were fitted for father and child reports of internalizing and externalizing problems. Direct effects of preburn behavioral problems and parental PTSS within the first month postburn on postburn behavioral problems were modeled. The indirect (mediational) effect of parental stress within the first month postburn via parental stress symptoms 12 months postburn was examined: the total effect of the independent variable PTSS within the first month postburn, on the dependent variable behavioral problems, was subdivided into its direct effect on the dependent variable and its indirect effect on the dependent variable through the proposed mediator PTSS 12 months postburn. Covariates included child age, gender, and percentage TBSA. Postburn parent and child reports of behavioral problems were allowed to correlate. Because the sample size was too small for the relatively large amount of parameters, model constraints had to be imposed. Based on previous research and after checking the correlation matrix, specific (nonsensical) correlations between independent variables were constrained to zero. These included the correlations between parental PTSS at T1 and T2 and preburn behavioral problems, child age and preburn behavioral problems, child age and percentage TBSA, and preburn behavioral problems and percentage TBSA. All continuous independent variables (i.e., child age, percentage TBSA, preburn behavioral problems, and parental PTSS) were centered using the grand mean, and the dichotomous predictor child gender was labelled 0–1 (0 = boy).

As recommended by Preacher and Hayes (2008), we employed a bootstrapping method (with n = 5000 bootstrap resamples) to assess the indirect effects and to control for nonnormally distributed data. Results of the path model were displayed using bootstrap bias-corrected 95% confidence intervals (CI). Point estimates of effects were considered significant in case zero was not contained in the confidence interval. Relationships were tested two-sided.

Missing data at T2 were estimated using full-information maximum likelihood (FIML). With this default method in Mplus, all available information is used to estimate missing data. As a consequence, we were able to include data from the total sample of 90 families. We assessed model fit with the χ^2 statistic, the comparative fit index (CFI), the Tucker Lewis Index (TLI) and the root-mean-square of approximation (RMSEA). CFIs and TLIs above .90 (Kline, 2011) and RMSEAs less than .08 indicate a good fit and were used as the criteria for evaluating model fit beyond the χ^2 statistic.

Results

Descriptive statistics and correlations

Table 2 shows the means, standard deviations, and intercorrelations of the variables. All variables were approximately normally distributed (skewness range -.20 to 1.57; kurtosis range: -1.03 to 2.28), with the exception of percentage TBSA, which was positively skewed (skewness: 3.20) and had a high peak (kurtosis: 11.31).

The correlation between maternal and paternal reports of child behavioral problems at T1 was .55. For internalizing and externalizing problems at T2, these correlations were .65 and .75, respectively. These large correlations indicate that parental agreement on child behavior problems was high. Correlations between child-reported and mother-reported internalizing and externalizing problems were .35 and .62, respectively. For child-father agreement, these correlations were .47 (internalizing problems) and .63 (externalizing problems).

Prevalence of parental PTSS and child behavioral problems

In the first month postburn, 47% of the mothers reported clinically significant PTSS in relation to their child's burn event. For fathers, this was 27%. One year postburn, 27% of the mothers and 8% of the fathers reported clinically significant PTSS. For mothers and fathers, the reduction in stress symptoms from T1 to T2 was significant: $M_{mothersT1}$ = 25.15 , SD = 14.78, $M_{mothersT2}$= 16.25, SD = 12.20; t (54) = 6.18, $p < .001$; $M_{fathersT1}$ = 15.00 , SD = 12.90, $M_{fathersT2}$= 8.75, SD = 10.81; t (35) = 2.97, p = .005.

Mothers and fathers reported total preburn behavioral problems on the SDQ in the (sub)clinical range in 27% and 25% of the children, respectively. Regarding postburn behavioral problems, CBCL reports of mothers and fathers indicated that, respectively, 16% and 17% of children had externalizing problems in the (sub)clinical range. For internalizing problems, these percentages were 15-6%. Finally, 12% of children themselves reported postburn externalizing problems in the (sub)clinical range and

16% reported internalizing problems in this range. The levels of agreement for the presence or absence of internalizing problems in the (sub)clinical range were 87% for mothers and children, 90% for fathers and children, and 84% for mothers and fathers. For externalizing problems, these percentages were 87%, 83%, and 84%, respectively.

Compared to reference data, preburn behavioral problems in our sample were not significantly different (mother reports: p =.11, Cohen's d = .18; father reports: p = .19, Cohen's d = .17). Regarding postburn behavioral problems, using the CBCL and YSR, in general, no significant differences between our sample and reference data were found and, on average, effect sizes indicated only small differences (internalizing problems, mother reports: p = .13, Cohen's d = -.20, child reports: p = .09, Cohen's d = -.27; externalizing problems, mother reports: p = .73, Cohen's d = .05, father reports: p = .73, Cohen's d = -.06 child reports: p = .27 Cohen's d = -.16). One medium difference (d = -.40) was found for fathers, who reported significantly less internalizing problems in their child compared to parents from reference data: $M_{reference}$ = 6.95, SD = 5.80, $M_{fathersT2}$ = 4.82, SD = 4.83; t (32) = -2.54, p =.02.

Path analyses

All four models showed adequate fit to the data, which is shown in Table 3. The results of the four path analyses are presented in Tables 4 and 5. Maternal reports of preburn behavioral problems were positively associated with their own reports of child internalizing problems 12 months postburn, although the association was at the borderline of significance (Table 4). For fathers, the association was significant (Table 5). In contrast, self-reported postburn internalizing problems by the child were not associated with preburn behavioral problems reported by mothers or fathers. This same pattern of results was obtained for externalizing problems.

Appraisals of PTSS within the first month postburn were associated with appraisals of PTSS 12 months postburn for mothers as well as fathers. Maternal reports of their PTSS within the first month postburn were not directly associated with their reports and child reports of internalizing and externalizing problems. However, maternal PTSS 12 months postburn had a significant positive relationship with their own reports of child internalizing problems. Paternal reports of their own PTSS within the first month postburn were associated with reporting less internalizing problems in their child. In contrast, their PTSS 12 months postburn had a positive relationship with their reports of internalizing problems. There were no significant direct relationships between mothers' or fathers' PTSS 12 months postburn and parental reports of child externalizing problems and child reports of internalizing and externalizing problems.

Table 2. *Intercorrelations and descriptive statistics (n = 90)*

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. Preburn behavioral problems M	-													
2. Preburn behavioral problems F	.55**	-												
3. PTSS 1 month postburn M	.11	.07	-											
4. PTSS 1 month postburn F	-.07	-.08	.20	-										
5. PTSS 12 months postburn M	.08	.14	.70**	.40*	-									
6. PTSS 12 months postburn F	-.02	.16	.47**	.44**	.52**	-								
7. Externalizing problems M	.50**	.39*	-.13	-.14	.10	.13	-							
8. Externalizing problems F	.70**	.61**	-.14	-.28	.09	.12	.75**	-						
9. Externalizing problems C	.24	.03	-.16	-.13	-.05	.11	.62**	.63**	-					
10. Internalizing problems M	.30*	.28	.28*	.13	.45**	.30	.30*	.23	-.07	-				
11. Internalizing problems F	.40*	.59**	.11	-.27	.35*	.26	.42*	.53**	.26	.65**	-			
12. Internalizing problems C	.09	-.15	.07	.13	.12	.15	.21	.11	.44**	.35*	.47*	-		
13. Child age	-.09	-.01	-.24*	-.12	-.23	-.15	-.09	-.03	-.15	-.13	-.15	-.19	-	
14. Percentage TBSA	.09	-.16	.17	.13	.09	-.09	-.19	-.18	-.27	-.05	-.27	-.26	.12	-
M	9.31	9.00	25.48	15.85	16.25	8.66	49.58	49.03	47.22	50.53	47.34	47.63	13.88	9.95
SD	5.94	6.04	14.34	12.45	12.20	10.53	10.18	10.03	10.13	8.92	9.72	11.03	2.43	12.26

Note. M = Mother report; F = Father report, C = Child report.
PTSS = Posttraumatic stress symptoms, TBSA = Total burned surface area
*$p < .05$, **$p < .01$.

In both parents, PTSS 12 months postburn significantly mediated the effect of PTSS within the first month postburn on their reports of child internalizing problems. No significant indirect effects were found for externalizing problems. In addition, no significant indirect effect of maternal or paternal PTSS within the first month postburn via PTSS 12 months postburn on child reports of internalizing and externalizing problems was found.

Child age and gender were not significant predictors of postburn behavioral problems. Moreover, no significant effects were found for the percentage TBSA in the models using father and child reports of internalizing and externalizing problems. However, a lower percentage of TBSA was associated with more externalizing problems reported by the mother, as well as with child self-reported internalizing and externalizing problems (in models 1 and 2). As this finding was unexpected, data were inspected to explain the relationships found. Two children with high percentages TBSA were identified (e.g., 59 and 72% TBSA; two outliers which were found earlier) that had low to moderate ratings on all measures of behavioral problems. To check if these outliers possibly influenced the results, analyses for models 1 and 2 were repeated without the two outliers (results are not displayed, but are available upon request), which resulted in nonsignificant parameters in two of the three relationships. Therefore, the relationships found seemed to be especially due to the influence of two children with high percentages TBSA and low ratings of behavioral problems.

Preburn behavioral problems, parental PTSS 1 and 12 months postburn, percentage TBSA, child gender, and child age explained 13 to 52% of variance in the four path models. Percentages were higher for parent reported problems, compared to child reports, which can be seen in Tables 4 and 5.

Table 3. *Model fit information for four path models*

		CFI	TLI	RMSEA	χ^2	df	*p*
Model 1	Mother- and child reports of internalizing problems	.98	.92	.06	6.31	5	.28
Model 2	Mother- and child reports of externalizing problems	.98	.94	.05	6.25	5	.28
Model 3	Father- and child reports of internalizing problems	1.00	.99	.02	5.11	5	.40
Model 4	Father- and child reports of externalizing problems	1.00	1.00	.01	5.05	5	.41

Table 4. *Relationship of preburn behavioral problems, maternal posttraumatic stress symptoms (PTSS) and covariates with mother- and child reported behavioral problems 12 months postburn*

	Model 1 Internalizing problems								Model 2 Externalizing problems							
	Mother reports				Child reports				Mother reports				Child reports			
	B	CI	SE	β	B	CI	SE	β	B	CI	SE	β	B	CI	SE	β
Direct effects																
Preburn behavioral problems	**0.50**	**0.00, 1.04**[a]	.27	**.34**	0.27	-0.46, 1.05	.38	.15	**1.02**	**0.56, 1.48**	.24	**.57**	0.48	-0.20, 1.17	.35	.27
PTSS 1 month postburn	0.02	-0.20, 0.19	.10	.03	-0.06	-0.34, 0.25	.15	-.07	-0.16	-0.41, 0.04	.11	-.22	-0.15	-0.42, 0.17	.15	-.21
PTSS 12 months postburn	**0.29**	**0.06, 0.53**	.12	**.39**	0.14	-0.32, 0.57	.22	.15	0.23	-0.04, 0.52	.14	.26	0.13	-0.26, 0.50	.19	.15
Percentage TBSA	-0.07	-0.22, 0.04	.07	-.10	**-0.19**	**-0.50, -0.04**	.14	**-.22**	**-0.20**	**-0.33, -0.06**	.07	**-.24**	**-0.21**	**-0.43, -0.07**	.10	**-.26**
Child gender[b]	1.81	-5.43, 7.31	3.13	.09	3.25	-5.96, 12.55	4.74	.13	-3.42	-9.35, 2.23	2.97	-.14	-4.88	-11.44, 1.96	3.35	-.21
Child age	0.00	-0.91, 1.12	.51	.00	-0.67	-2.48, 1.06	.92	-.15	-0.64	-1.59, 0.29	.48	-.14	-0.98	-2.28, 0.31	.67	-.23
PTSS T1 → PTSS T2	**0.54**	**0.36, 0.68**	.08	**.64**	**0.54**	**0.36, 0.68**	.08	**.64**	**0.53**	**0.36, 0.68**	.08	**.64**	**0.53**	**0.36, 0.68**	.08	**.64**
Indirect effects																
PTSS T1 → PTSS T2 → behavioral problems	**0.16**	**0.04, 0.32**	.07	**.25**	0.07	-0.16, 0.32	.12	.10	0.12	-0.02, 0.30	.08	.16	0.07	-0.14, 0.27	.10	.10
Explained variance		30%				13%				44%				24%		

Note. CI = Bootstrap bias-corrected two-sided 95% confidence interval. Effects that are statistically significant are written in bold.
TBSA = Total burned surface area
[a] p =.06
[b] 0 = boy, 1 = girl.

Table 5. *Relationship of preburn behavioral problems, paternal PTSS and covariates with father- and child reported behavioral problems 12 months postburn*

	Model 3 Internalizing problems								Model 4 Externalizing problems							
	Father reports				Child reports				Father reports				Child reports			
	B	CI	SE	β	B	CI	SE	β	B	CI	SE	β	B	CI	SE	β
Direct effects																
Preburn behavioral problems	**0.79**	**0.21, 1.26**	.27	**.50**	-0.30	-1.05, .56	.42	-.17	**0.84**	**0.08, 1.37**	.32	**.53**	0.02	-0.80, .90	.44	.01
PTSS 1 month postburn	**-0.38**	**-0.79, -0.12**	.16	**-.50**	-0.05	-0.66, 0.41	.27	-.06	-0.23	-0.70, 0.10	.20	-.30	0.00	-0.55, 0.39	.23	-.01
PTSS 12 months postburn	**0.31**	**0.03, 0.68**	.16	**.35**	0.18	-0.52, 0.69	.31	.18	0.16	-0.27, 0.43	.16	.18	0.16	-0.44, 0.60	.25	.17
Percentage TBSA	0.07	-0.31, 0.40	.19	.09	-0.15	-0.73, 0.33	.24	-.16	0.03	-0.37, 0.66	.24	.03	-0.20	-0.65, 0.54	.28	-.23
Child gender[a]	6.45	-0.11, 11.95	3.09	.31	5.22	-5.30, 15.21	5.27	.23	0.81	-9.11, 8.07	4.25	.04	-4.83	-15.13, 3.34	4.62	-.22
Child age	-0.61	-2.04, 0.60	.66	-.15	0.75	-1.60, 2.64	1.06	.17	-0.52	-2.00, 0.98	.77	-.13	0.13	-1.89, 1.94	.95	.03
PTSS T1 → PTSS T2	**0.41**	**0.16, 0.75**	.15	**.47**	**0.41**	**0.16, 0.75**	.15	**.47**	**0.40**	**0.16, 0.76**	.15	**.47**	**0.40**	**0.16, 0.76**	.15	**.47**
Indirect effects																
PTSS T1 → PTSS T2 → behavioral problems	**0.13**	**0.02, 0.43**	.09	**.16**	0.07	-0.19, 0.39	.14	.08	.06	-0.07, 0.26	.08	.08	0.06	-0.15, 0.33	.12	.08
Explained variance		52%				14%				36%				16%		

Note. CI = Bootstrap bias-corrected two-sided 95% confidence interval. Effects that are statistically significant are written in bold.
TBSA = Total burned surface area
[a] 0 = boy, 1 = girl.

Discussion

This study included child, mother, and father reports of postburn behavioral problems, hereby providing an encompassing family perspective on postburn adjustment. Results showed that overall, pre- and postburn behavioral problems were within normal limits. Depending on the informant, rates of (sub)clinically significant postburn internalizing and externalizing problems ranged from 6 to 17%. Parents and children displayed rather similar perspectives on the presence or absence of (sub)clinical behavioral problems, with mother-child agreement in 87% of the cases for internalizing and externalizing problems and father-child agreement in, respectively, 90 and 83% of the cases. Findings further showed that postburn internalizing and externalizing problems were related to preburn behavioral functioning, but only if parents reported on postburn behavioral problems. Additionally, higher parental stress symptoms 12 months postburn were associated with more child internalizing problems as reported by mothers and fathers, but not as reported by children. In both parents, an indirect relationship was found from PTSS within the first month postburn via PTSS 12 months postburn to reporting internalizing problems in their child. Results of this study emphasize the use of a family systems perspective in research and clinical practice regarding pediatric burns.

As hypothesized using results of prior studies (Blakeney et al., 1993; Willebrand et al., 2011), children and adolescents in our sample were not different from reference samples with regard to preburn behavioral problems and postburn internalizing and externalizing problems. As we only examined the long-term outcome, we cannot rule out the possibility that children and adolescents experienced transient internalizing and externalizing problems during or shortly after the period of hospitalization. Previous research has reported elevated symptoms during these periods (Liber et al., 2006; Pardo et al., 2010, 2008). Furthermore, we did not include measures of child acute and posttraumatic stress symptoms, while it has been shown before that a considerable part of children and adolescents experience these symptoms after burn injury (Landolt, Buehlmann, Maag, & Schiestl, 2009; Saxe et al., 2005). However, overall, the results of this study indicate that, on average, children and adolescents are not at risk to experience elevated levels of internalizing and externalizing problems 12 months after burn injury, which is a positive finding.

The inclusion of appraisals of preburn functioning in this study provides additional information about the adjustment of children and adolescents after burn injury. As hypothesized, our results showed that preburn behavioral problems were predictive of postburn internalizing and externalizing problems, from the parents' perspective. As

proposed (Cox et al., 2008), pretrauma psychological problems may continue to place children at a disadvantage with regard to their ability to cope and recover from the stressful event, hereby maintaining or increasing psychological problems. However, the role of preburn adjustment was not unequivocal in this study, as it was not predictive of child reports of postburn behavioral problems. In our study, parents appraised the preburn adjustment of the child, while child reports could have provided different views. Future studies are needed to investigate whether a similar relationship would be found for child-reported pre- and postburn behavioral problems.

This study showed that burn severity was not related to postburn behavioral problems in the models using father and child reports. This concurs with previous child studies that found no relation between burn size and postburn behavioral problems (Blakeney et al., 1993; Landolt et al., 2002; Willebrand et al., 2011). However, in the current study, a larger percentage TBSA was related to less behavioral problems in the models using mother and child reports. The counterintuitive finding was primarily due to two children with high percentages TBSA and low scores on behavioral problems. Percentage TBSA is only one aspect of burn severity; previous studies have shown a negative impact of visible scarring (Willebrand et al., 2011) or poor hand functioning (Baker, Russell, Meyer, & Blakeney, 2007) on postburn outcomes. However, in general, the results of the present study support the idea that larger burn size does not necessarily implicate a higher risk of postburn adjustment problems.

Conform our hypothesis, we found significant associations between parental PTSS 12 months postburn and parental reports of internalizing problems in their child. Different mechanisms may explain this relationship. A first possibility is that parents' own levels of stress diminish their capacity to be responsive to the child's needs, which may have an adverse impact on the child (Scheeringa & Zeanah, 2001). However, as these findings not held for child self-reports, it may be more likely that parental mental health affects the way in which parents interpret the behavior of their offspring. Previous studies have indicated that parental acute and posttraumatic stress reactions influence their assessment of child symptoms (Kassam-Adams et al., 2006; Pan et al., 2015; Shemesh et al., 2005; Smith et al., 2001). Parents with higher PTSS might be more prone to perceive internalizing problems in their child, because they may have difficulty in differentiating their child's reactions from their own (Kassam-Adams et al., 2006). As PTSS fall more within the spectrum of internalizing syndromes, this idea is supported by not finding significant associations between parental PTSS and reports of child externalizing problems in this study. The presence of an association between parental PTSS and reports of internalizing problems, but not externalizing problems,

might also be due to the child's internalizing problems being more difficult to observe (Achenbach, McConaughy, & Howell, 1987), and therefore more prone to observational bias resulting from parental PTSS.

Although parental posttraumatic stress within the first month postburn (i.e., more acute stress) was not directly related to parent reports of child behavioral problems at 12 months, there was an indirect relationship of early PTSS via PTSS 12 months postburn to parental reports of child internalizing problems measured at 12 months. In concordance with previous studies, levels of parental PTSS at 1 and 12 months postburn were significantly related and suggest the possibility of chronification of PTSS (Landolt et al., 2012). The observed indirect nature of the relationship between early PTSS and parental reports of internalizing problems might indicate that only parents with chronic PTSS (in contrast to transient PTSS) are more prone to perceive higher internalizing problems in their child. Still, other studies found parental acute stress symptoms to be directly related to reports of young children's 12 months postburn behavioral problems (Bakker et al., 2014) and PTSS of school-aged children after a medical traumatic event (Landolt et al., 2012). Beyond the aforementioned relationships, in the present study, a negative association was found between paternal initial PTSS and fathers' reports of child postburn internalizing problems. As no previous study has reported this finding, an explanation for this relationship is highly speculative. In spite of this unexpected result, the indirect effect found in this study suggests that parents' higher acute stress symptoms that are not transient may be regarded a risk factor for long-term PTSS and consequent higher ratings of child postburn internalizing problems.

This multicenter study has a number of strengths, including the prospective design, the inclusion of fathers, the assessment of preburn functioning, and the relatively large sample size compared to other child burn studies. However, several limitations need to be considered too. First, we could only use information from two time points. Therefore, conclusions about directionality of effects cannot be drawn. For example, it is possible that children's postburn internalizing problems contribute to parental PTSS, as parents struggle to deal with their protective feelings and guilt (Scheeringa & Zeanah, 2008). However, as we found no significant relationships with child reports of internalizing problems, this explanation appeared less likely. Second, it could be argued that parental PTSS may be a result of burn injury in parents themselves. However, as the incidence of injury in other family members (not specifying which family member was injured) was only 8% in the present sample, this could not explain the high prevalence of parental PTSS (i.e., 47% in mothers and 27% in fathers within the first month postburn). We therefore assume that parental traumatic stress symptoms

are mainly the consequence of perceived threat to the child's life, witnessing the burn event or parental emotions related to appraisals about the trauma (Bakker et al., 2013). Last, as in most burn studies, the absolute sample size in this study was small, which may limit generalizability of the results. Future research is warranted to replicate the findings. As a consequence of the small sample size, there was also limited statistical power to investigate more parameters in this study and to investigate the maternal, paternal, and child reports in a single model. Attempts were made to include all parameters in a single model, but model fit was inappropriate. However, in the model concerned, nonsignificant equality constraints between fathers and mothers indicated no overall differences.

To increase the generalizability of our findings, future research is needed, especially regarding the relative contribution of preburn functioning to postburn outcomes as this was a vulnerability factor in this study. Further studies could also include pretrauma measures of resilience, such as prosocial behavior, personality characteristics, and positive family functioning. Furthermore, future studies are warranted to examine the mechanism explaining the relationship between parental PTSS and child postburn outcomes.

Results from this study may have implications for clinical burn practice. First, appraisals of preburn behavior shortly after the burn injury appear to be predictive of postburn problems from a parental perspective. This suggests that high-risk children may be identified in an early phase by the use of screening and that these children and their families may be followed up thereafter. However, the lack of evidence for the role of preburn behavior as perceived by parents, as well as the small total amount of variance explained in child self-reports of postburn behavioral problems, suggests that more insight is needed into determinants of the childs' own appraisal of postburn problems. Aspects such as social support (Bamum, Snyder, Rapoff, Mani, & Thompson, 1998), coping style, and personality (Liber, Faber, Treffers, & Van Loey, 2008) may be important in this respect. Second, this study points to the role of chronic parental PTSS. Although parental acute stress symptoms in general are high and symptoms may largely decrease with time (Bakker et al., 2013), a substantial amount of parents continue to experience clinically significant stress symptoms, as was shown again in the present study. Monitoring these symptoms in the aftermath of a pediatric burn event seems important for parental well-being but also for its impact on (the perception of) child postburn behavioral problems. Last, this study points to the role that choice of informants plays in assessing postburn adjustment. In the assessment of behavioral problems, no one's informant report can be used as a 'gold standard' (De Los Reyes &

Kazdin, 2005). This implicates that, when possible, reports of multiple informants should be included, as they all provide valuable information. Possible discrepancies should be discussed and incorporated in determining treatment goals and decisions.

Overall, the results of this study suggest that child behavioral problems 12 months postburn as perceived by parents are associated with parental appraisals of child preburn problems as well as parental chronic PTSS. Therefore, we recommend clinical burn practice to use a family perspective, by specifically including parents in assessment and intervention.

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Chapter 4

Parents' posttraumatic stress after burns in their school-aged child: A prospective study

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4

Abstract

Objective: This prospective study examined the course and potential predictors of parents' posttraumatic stress symptoms (PTSS) after burn injury in their child (age 8 to 18 years). **Method:** 111 mothers and 91 fathers, representing 118 children, participated in the study. Within the first month after the burn event and subsequently at 3, 12, and 18 months postburn, both parents completed the Impact of Event Scale (IES). Parental emotions related to the burn event and appraisal of threat to the child's life were assessed, which were investigated in a multilevel regression model. **Results:** Within the first month postburn, 48% of the mothers and 26% of the fathers reported clinically significant PTSS (IES ≥ 26), which decreased to respectively 19% and 4% 18 months postburn. Symptoms of intrusion were mainly individually experienced, whereas parents within a couple were more similar in terms of their avoidance symptoms. The perceived life threat and feelings of guilt and anger linked to the burn event were significantly related to parental PTSS, especially in mothers. **Conclusions:** The results indicate that a burn event to a child has a severe (acute) psychological impact on parents and that clinical levels of PTSS may persist in a subgroup of parents. The findings underline the need to incorporate parent support in burn care, especially for mothers with a strong emotional response during the first months after the burn event.

Introduction

A pediatric burn event severely disrupts the life of families involved. Witnessing the child's burn trauma or exposure to child distress and pain during hospitalization may be very distressing for parents. In the acute aftermath of a pediatric burn event, parental posttraumatic stress symptoms (PTSS) appear to be relatively common. Research has shown that 25 to 50% of parents experience clinically relevant PTSS levels within the first months postburn (Bakker, van der Heijden, van Son, & Van Loey, 2013; De Young, Hendrikz, Kenardy, Cobham, & Kimble, 2014; Hall et al., 2006). Previous studies in parents of young children (0 to 4 years old) showed that initial symptoms largely decline as time goes by (Bakker et al., 2013; De Young et al., 2014). However, up to 18% of mothers and 6% of fathers still experience clinically significant PTSS 18 months after the burn event (Bakker et al., 2013). So far, no longitudinal investigations have specifically examined the course of PTSS in parents of school-aged children and adolescents. Moreover, it is unknown whether associated factors with PTSS established in parents of young children, are similar in parents of older children. Establishing these factors will improve early identification of parents who are in need of professional support.

Parental appraisal of threat to the child's life seems important in explaining parental PTSS after pediatric injury, such as traffic-related injuries (Kassam-Adams, Fleisher, & Winston, 2009) or burns (Bakker et al., 2013). Within the integrative (trajectory) model of pediatric medical traumatic stress, the interpretation of medical events has been referred to as one of the most powerful predictors of parental traumatic stress (Price, Kassam-Adams, Alderfer, Christofferson, & Kazak, 2016). Moreover, people's emotions after trauma are dependent on the way they appraise the trauma (Beck, 1976). Specifically, the parental emotions of guilt and anger have been shown important in pediatric burns. Parents may feel responsible for their child's injury or feel they have failed in protecting their child (Mason, 1993). Consequent guilt feelings are experienced by a considerable number of parents (Mason, 1993; Rivlin & Faragher, 2007). In turn, these feelings have been associated with parental PTSS (Bakker et al., 2013; De Young et al., 2014; Fukunishi, 1998). The same holds for feelings of anger (Bakker et al., 2013), although less research has focused on this parental emotion in relation to pediatric burns.

The developmental period in which pediatric trauma takes place, is considered essential to understand the psychological consequences within the family (Kazak et al., 2006; Price et al., 2016). Although in the majority of child medical trauma studies, child age has not been shown associated with levels of parents' PTSS (e.g., Landolt, Vollrath,

Ribi, Gnehm, & Sennhauser, 2003; Le Brocque, Hendrikz, & Kenardy, 2010), differences in the role of parents' appraisal and emotions after burn injury may be expected between parents of young (i.e., infants, toddlers and pre-schoolers), and school-aged children and adolescents. Whereas young children typically receive scald burns in the presence of adults and at home, school-aged children have a higher risk of sustaining flame burns, which are generally more severe (Vloemans et al., 2011). Moreover, as school-aged children are less often supervised by their parents, feelings of direct responsibility and guilt are expected to be less prevalent in their parents. However, in case others are present at the burn event, parents may attribute more responsibility to these people, which could be accompanied by externalizing emotions, such as anger (Neumann, 2000). Thus, depending on the appraisal regarding one's responsibility for the burn event, feelings of guilt and anger might act differently in shaping subsequent PTSS of parents of school-aged children and adolescents, versus younger children.

In addition to parents' appraisal and emotions, other factors associated with parents' PTSS identified in earlier studies comprise higher burn severity (Bakker et al., 2013; Hall et al., 2006; Rizzone, Stoddard, Murphy, & Kruger, 1994) and a greater number of invasive medical procedures (De Young et al., 2014). With regard to child gender, one previous study showed that parents of girls reported more intrusion and avoidance symptoms (Bakker et al., 2013), while another study found this was only the case for avoidance (McGarry et al., 2013).

In research on pediatric medical trauma, mothers are more often the subject of investigation, compared with fathers. It has been frequently demonstrated that women are more vulnerable to develop posttraumatic stress disorder (PTSD) than men after a traumatic event (Stein, Walker, & Forde, 2000). Women display higher levels of negative threat appraisal and appear to use more avoidant and emotion-focused coping (Tamres, Janicki, & Helgeson, 2002), that increase the risk of PTSD (Olff, Langeland, Draijer, & Gersons, 2007). However, the role of fathers after trauma should also be considered and findings from mothers should not automatically be generalized to parents in general (Phares, Lopez, Fields, Kamboukos, & Duhig, 2005). Moreover, it is valuable to study parental PTSS within the parental dyad, as parents are part of the same family and thus share certain characteristics. In addition, vulnerability factors in one parent may influence the other. Therefore, dependency of parents' reactions should be taken into account when studying their psychological symptoms.

Most previous studies on parental PTSS after a pediatric burn event have not differentiated between symptoms, although distinct symptom clusters might be differentially related to its predictors (Schell, Marshall, & Jaycox, 2004). Especially

when examining symptoms within couples, a distinction may be relevant. Mothers and fathers may have different intrusive images about the burn event (Bakker et al., 2013). Particularly, intrusions may be associated with high levels of emotions such as guilt and anger (Holmes, Grey, & Young, 2005), that subsequently induce and maintain avoidance and PTSS (e.g., Creamer, Burgess, & Pattison, 1992). Symptoms of avoidance may be more identical within couples than intrusion symptoms, because they include a behavioral component, such as avoiding talking about the event. Moreover, intrusion and avoidance symptoms have been shown not to develop in a unified way, with avoidance being more enduring, compared with symptoms of intrusion (McFarlane, 2000). Therefore, differentiating between the symptom clusters may reveal relevant distinctions in terms of course and interdependence of symptoms, as well as different relationships with predictors.

The aim of the current study was to examine the course of PTSS in parents of children aged 8 to 18 years and to identify individual and shared parent factors that were associated with this course. The first hypothesis of the current study was that parental symptoms of intrusion and avoidance would decrease over time. Second, it was expected that, throughout the entire study period, mothers would show higher symptoms of intrusion and avoidance than fathers. The third hypothesis was that parental feelings of guilt and anger, and perceived threat to the child's life within the first month postburn would be associated with higher levels of PTSS, but that associations would be stronger for mothers. Fourth, symptoms of avoidance were hypothesized to be more similar *within* couples, compared with symptoms of intrusion, which were expected to show less similarity within couples. Shared couple factors expected to be significantly related to parental PTSS were child gender (girls) and percentage total body surface area (TBSA; higher) burned. No significant associations with child age were expected.

Method

Procedure

This study is part of a large prospective study on child (age 8 to 18 years) and parental adjustment following a pediatric burn event. Earlier articles on this cohort report on behavioral problems (Egberts et al., 2016) and health-related quality of life (Pan et al., 2015) of the child. A study with the same design was conducted earlier in a group of young children (age 0 to 4 years) and their parents (e.g., Bakker et al., 2013). Two independent ethics committees in the Netherlands and Belgium approved the current

study. From April 2007 to July 2011, families were enrolled in three Dutch and four Belgian burn centers. The current study used data collected within the first month after the burn event (T1) and subsequently at 3 (T2), 12 (T3), and 18 months postburn (T4). Families were eligible to participate if the child had been in the hospital for more than 24 hours and the TBSA burned was more than or equal to 1%. Exclusion criteria included limited Dutch language proficiency and child cognitive impairment. During admission, researchers at the burn centers contacted eligible families and requested to complete the first questionnaires within the first four weeks postburn. They explained the study purpose and offered additional written information. Written informed consent was obtained from the mother and father. Children provided written (≥12 years) or oral (<12 years) assent. Following discharge from the hospital, follow-ups consisted of mail-out questionnaires. In case families did not return the questionnaires, they were contacted by telephone to remind them to return the questionnaires. Although there was no guarantee that parents completed the questionnaires separately, to prevent parents from influencing one another, parents were instructed to complete the measures separately, questionnaires were sent in separate envelops, parents had their own return envelope, and the questionnaires were marked 'mother' or 'father' in conspicuously coloured labels.

Of the 202 eligible families, data from 118 families, from which at least one parent per family completed the PTSS measure on at least one study occasion, were used. Twenty-two families declined to participate in the study, 28 families gave their informed consent to participate but did not complete a measure on parental PTSS, 15 children were already discharged before the family could be approached, and 19 families were not invited because their participation was deemed inappropriate (e.g., psychiatric background, severely ill family members, or families with prolonged socioeconomic and psychosocial problems). The 118 participating families did not differ from the other 84 eligible families in terms of child gender ($p = .59$), length of stay in the hospital ($p = .26$), percentage TBSA burned ($p = .32$), number of surgeries ($p = .40$), and percentage deep burns ($p = .51$). However, children from non-participating families were older than children from participating families ($M = 12.9$, $SD = 3.0$ vs. $M = 13.9$, $SD = 3.1$; $t\ (197) = 2.2$, $p = .03$).

Participants

Data from 111 mothers and 91 fathers, including 84 couples representing 118 children were included in descriptive analyses. Mothers had a mean age of 42.1 years ($SD = 5.9$, range 28 to 55 years). The mean age of fathers was 44.7 years ($SD = 6.4$, range 30 to

64 years). The majority of the parents, 93% of mothers and 86% of fathers, was born in the Netherlands or Belgium. The education level of the mothers and fathers was categorized as low (primary education, technical and vocational training until the age of 16; 37% of mothers, 30% of fathers), middle (technical and vocational training until the age of 18; 35% of mothers, 29% of fathers), or high (technical or vocational training for ages 18 and older or university; 28% of mothers, 41% of fathers). The majority of the parents was employed (70% of mothers and 93% of fathers) and had a partner (82% of mothers and 91% of fathers).

Of the children, 70% were boys. Children were, on average, 12.9 years old (*SD* = 3.0, range 7.9 to 17.8 years). Fifty-six percent of the burn injuries were flame burns (e.g., resulting from a barbecue- or firework accident), 33% scald burns, 11% were other types of burns (e.g., electrical, chemical, or contact). Most burn accidents occurred at home (62%), either inside or outside. The average TBSA affected was 9.6% (*SD* = 11.8%), with a range of 1% to 72%. The mean length of hospital stay was 20.1 days (*SD* = 32.5, range 1 to 218 days). Fifty-four percent of the children required at least one skin grafting procedure during the initial hospitalization (*M* = 1.1, *SD* = 2.5, range 0 to 16).

For the final multilevel analysis, only parents that provided information on the predictors in the model could be included. The availability of data for this sample is described in the missing data analyses of the Results section.

Measures

Parental PTSS. The Impact of Event Scale (IES; Horowitz, Wilner, & Alvarez, 1979; Sundin & Horowitz, 2002) was used to assess parental PTSS. This questionnaire assesses two dimensions of traumatic stress, namely symptoms of intrusion and avoidance. Both parents completed the Dutch version of the IES (Brom & Kleber, 1985) at all four time points. The IES consists of 15 items. Parents were asked to rate the frequency of symptoms they had experienced specifically in relation to their child's burn event on a 4-point Likert scale (0 = not at all, 1 = rarely, 3 = sometimes, 5 = often). The total possible score ranged from 0 to 75, with higher scores representing higher levels of stress. Based on Dutch (Van der Velden, Van der Burg, Steinmetz, & Van den Bout, 1992) and Australian (Le Brocque et al., 2010) research, scores ≥26 on the Total scale were considered 'clinically significant stress symptoms.' In the present study, the subscales Intrusion (range 0 to 35) and Avoidance (range 0 to 40) were used as the dependent variables. In our sample, Cronbach's alpha for the Total Scale, Intrusion subscale and Avoidance subscale of the IES ranged from .85 to .90, from .78 to .89, and from .75 to .86 for mothers and fathers at the four time points.

Parental appraisal and emotions related to the burn event. Within the first month postburn, both parents reported their subjective appraisal of the life-threatening nature of the injury (yes/no) through a single item: "At any time, did you think your child would not survive the burn event?" Psychometric properties of this item were not assessed, but previous studies have supported the validity of the measure (e.g., Kassam-Adams et al., 2009). Items assessing parents' emotions were developed for the purpose of the present study. In contrast to measuring trait emotions, emotions directly related to the burn event were assessed with the question, "To what extent do the following emotions apply when you think about the accident that caused the burn?" The emotions of guilt and anger were evaluated in the present study. Answers were rated on a 5-point Likert scale ranging from 0 (not at all) to 4 (a lot). The choice for the use of single items was driven by the demanding nature of the hospitalization phase for parents, hereby minimizing the burden of the study.

Child- and burn characteristics. Characteristics of the child (i.e., gender and age) and the burn (i.e., percentage TBSA affected, number of skin grafting procedures during initial hospitalization and length of stay in the hospital) were derived from the medical file. Percentage TBSA affected is the estimated percentage body surface area affected by partial- or full-thickness burns. Within the first month postburn, parents provided information on the place of the burn event (i.e., inside or outside the home) and the cause of the burn (e.g., hot fluid, flame or contact with hot object).

Statistical analyses

First, descriptive statistics for parental PTSS, and emotions and appraisal related to the burn event were calculated, as well as correlations between the constructs. For these statistics, all available data from the complete sample of 118 families were used. To examine the course and predictors of parental PTSS, multilevel regression analysis was used. In the data, there was a three-level hierarchy. The lowest level comprises the four measurement moments; time (first level), which are nested within an individual parent (second level), with parents nested in a couple (third level). Predictors included varied only at one of the levels. On the individual parent level (second level) predictors comprised parental gender, and appraisal and emotions related to the burn event. Predictors that varied on the couple level (third level) were child and burn characteristics, such as child age and percentage TBSA burned. Separate multilevel regression analyses were performed for the symptom clusters Intrusion and Avoidance. Analyses were conducted in Mplus 7.4 (Muthén & Muthén, 2012). As some of the variables were non-normally distributed, a robust maximum likelihood (MLR) estimator was used.

In multilevel analysis, missing data on the outcome level is allowed for, by using a missing conditionally at random assumption. This assumption allows the probability of missing data to depend on observed data (Enders, 2010; Hox, 2010). To assess the reasonableness of this assumption, missing data analyses were performed. Next, in the multilevel analyses, a full information maximum likelihood (FIML) estimator was used to estimate missing data, with the use of all available data. With the inclusion of the observed variables related to the probability of missingness in the multilevel model, FIML leads to unbiased parameter estimates for cases with and without missing data (Hox, 2010).

In the first step of the multilevel analyses, for both symptom clusters separately, the course of symptoms in mothers and fathers was examined in a model with time (coded as 0, 3, 12, and 18 months). Moreover, to test for a possible nonlinear course of symptoms, a quadratic term was added to the model. Based on these models, intraclass correlations were calculated to define the proportion of the variance at each level. Next, predictors at the individual parent level were entered into the model (i.e., parent characteristics), followed by the predictors at the couple level (i.e., child characteristics). To examine whether mothers and fathers varied in their course of symptoms, random slopes for the time variable were added at the individual parent and the couple level, respectively. In case a decrease in model deviance provided evidence for random slopes, it was examined whether predictors at the specified level could explain this variation, by including interactions between time and these predictors. In a last step, interactions between parental gender and appraisal/emotions were tested exploratory, to examine whether associations between appraisal/emotions and parental PTSS would be different for mothers and fathers.

In multilevel models, predictor variables are assumed to be random variables. However, in the present analyses, this assumption was violated for the variable parental gender. This variable cannot be regarded a random variable, because when a father is included in the analyses, corresponding to the value 0, the other value is automatically 1 (a mother). After adding the variable parental gender to the Intrusion model, the variance of intrusion symptoms increased, instead of decreased, which is a known feature (Snijders & Bosker, 1994). Therefore, no explained variance estimates could be derived for the third level of the Intrusion model.

Results

Prevalence of parental PTSS

Means and standard deviations of parental PTSS, and the percentage of mothers and fathers with clinically significant PTSS (IES Total ≥ 26) at the four measurement moments are displayed in Table 1. Prevalence of clinically significant PTSS was especially high within the first month postburn. The correlations between mothers' and fathers' symptoms of intrusion were small to moderate, namely .14, .37, .26 and .14 at the four subsequent measurement moments, respectively. For symptoms of avoidance, correlations were small to large, namely .26, .51, .53 and .55.

Table 1. *Means (M), standard deviations (SD) and percentage of mothers and fathers with clinically significant posttraumatic stress symptoms*

	1st month	3 months	12 months	18 months
Mothers	*n* = 108	*n* = 89	*n* = 69	*n* = 69
IES – Total, *M* (*SD*)	26.0 (14.0)	18.5 (14.1)	15.7 (11.7)	13.6 (11.4)
IES – Intrusion	15.9 (8.6)	10.9 (7.9)	9.7 (7.0)	8.1 (6.3)
IES – Avoidance	10.1 (7.8)	7.6 (7.7)	5.9 (5.9)	5.5 (6.6)
% of mothers with IES ≥ 26	48%	29%	25%	19%
Fathers	*n* = 84	*n* = 73	*n* = 48	*n* = 51
IES – Total	16.0 (11.9)	11.2 (11.3)	8.9 (10.3)	6.9 (8.5)
IES – Intrusion	9.8 (7.7)	6.5 (6.6)	5.5 (5.8)	4.4 (5.0)
IES – Avoidance	6.2 (6.3)	4.6 (6.1)	3.4 (5.7)	2.5 (4.5)
% of fathers with IES ≥ 26	26%	14%	6%	4%

Note. Total *n* = 111 mothers and 91 fathers, from 118 families. The sample size (*n*) refers to participating mothers and fathers at each time point separately. IES = Impact of Event Scale.

Parental emotions, appraisal, and PTSS

Within the first month postburn, the majority of parents (57% of the mothers and 59% of the fathers) reported at least some level of anger (a minimum score of 1 on a 0 to 4 scale). For feelings of guilt, this was 45% of the mothers and 46% of the fathers. Within couples, mean guilt feelings within the first month postburn were not significantly different for mothers (*M* = .8, *SD* = 1.2), compared to fathers (*M* =.8, *SD* = 1.2). Likewise, feelings of anger did not differ between mothers (*M*= 1.1, *SD* = 1.3) and fathers (*M* =1.2, *SD* = 1.3). Of the mothers, 13% had perceived their child's life to be in danger. For fathers, this was 8%. This difference was not statistically significant (χ^2 (1) = 1.33, *p* = .25). In Table 2, associations between parental feelings of guilt and anger, perceived life

threat, and parental PTSS at the four measurement moments are displayed. Correlations between parental PTSS and emotions and appraisal appear to be higher in mothers than in fathers.

Table 2. *Associations between parental guilt feelings, anger, and perceived threat as assessed within the first month postburn and posttraumatic stress symptoms of intrusion and avoidance at all four time points*

	1st month	3 months	12 months	18 months
Mothers	*n* = 105-106	*n* = 87	*n* = 68	*n* = 68
Intrusion – guilt feelings	.31**	.26*	.22	.33*
Intrusion – anger	.32**	.24*	.25*	.18
Intrusion – perceived threat	.24*	.27*	.27*	.24
Avoidance – guilt feelings	.30**	.35**	.13	.31*
Avoidance – anger	.35**	.25*	.27*	.10
Avoidance – perceived threat	.35**	.31**	.26*	.29*
Fathers	*n* = 79	*n* = 67	*n* = 45	*n* = 47
Intrusion – guilt feelings	.26*	.07	.10	.02
Intrusion – anger	.04	-.04	.08	-.02
Intrusion – perceived threat	.23*	.26*	.21	.08
Avoidance – guilt feelings	.17	.01	.03	.06
Avoidance – anger	-.03	.02	.18	.03
Avoidance – perceived threat	-.04	.18	.23	.02

Note. Total *n* = 111 mothers and 91 fathers, from 118 families. The (range of the) sample sizes (*n*) refer(s) to the number of participating mothers and fathers at each time point separately. Sample sizes differ from those reported in Table 1, due to missing data on parental guilt feelings, anger and perceived threat. *$p < .05$, **$p < .01$.

Missing data analyses

The selection of parents that completed at least one IES and provided complete information on the predictors included in the multilevel model resulted in a sample of 104 mothers and 76 fathers, from 108 families. Table 3 displays the proportion of parents that completed the IES at each time point, as well as the proportion of couples in which both parents completed the measure per time point. By the use of FIML, available information from all 108 families could be used in the analyses.

To assess the reasonableness of the missing conditionally at random assumption, analyses of variance and chi-square difference tests were conducted to examine possible differences between couples in which both parents completed questionnaires at all time points (*n* = 34 families), couples in which both parents participated but both

parents dropped out during the study (n = 30), and couples in which only one parent participated from the start or in which one of the parents dropped out (n = 44). No differences between these families were found in terms of child age (p = .85), child gender (p = .83), percentage TBSA burned (p = .98), number of surgeries (p = .86) or location of the accident (p = .59). Moreover, a comparison between the three groups revealed no differences regarding a combined mean PTSS score of mothers and fathers at T1 (p = .33).

To assess possible differences within the group of mothers and the group of fathers as a function of missing data, parents with partially missing data were compared with parents who completed all measures in terms of self-reported measures at T1. Mothers with complete data did not differ from mothers with partially missing data in terms of intrusion and avoidance at T1 and anger. However, mothers with partially missing data reported significantly higher feelings of guilt at T1, compared with mothers with complete data: $M_{complete}$ = .6, SD = .9, $M_{missing}$ = 1.2, SD = 1.5; t (70) = 2.27, p = .03. For fathers, no differences were found regarding intrusion and avoidance at T1, and feelings of anger or guilt. However, more fathers with complete data had perceived their child's life to be in danger, compared with fathers with partially missing data: χ^2 (1) = 6.87, p = .009. By including the variables that were related to the missingness in the multilevel model, the use of FIML resulted in unbiased parameter estimates.

Table 3. *Number of parents that completed the Impact of Event Scale (IES) per time point*

	Mothers (n = 104)	Fathers (n = 76)	Couples[a] (n = 72)
Within first month	102 (98%)	74 (97%)	70 (97%)
3 months	85 (82%)	62 (82%)	57 (79%)
12 months	66 (64%)	42 (55%)	39 (54%)
18 months	66 (64%)	44 (58%)	41 (57%)
All time points[b]	59 (57%)	37 (49%)	34 (47%)

Note. Total n = 108 families, for which complete information regarding predictors included in the multilevel model was available.
[a] Number and percentage of couples of whom both the mother and the father completed the IES.
[b] Number and percentage of mothers, fathers, and couples that completed the IES at all time points.

Multilevel analyses

Unexplained variance. Intraclass correlations were calculated in a model with time and the quadratic term as predictors. In the model with intrusion symptoms, 32%

of the variance was located at the time level, 61% at the individual parent level and 7% at the couple level. This indicates that intrusions are mainly individually experienced symptoms that show little overlap within a parent couple. For avoidance, 44% of the variance was located at the time level, and the amount of variance located at the individual parent- and couple level was similar to each other (both 28%), indicating that symptoms of avoidance are experienced individually and show resemblance within a couple. Thus, there was a larger overlap in avoidance symptoms than intrusion symptoms between two parents within one couple.

Course of parental PTSS. Over time, parental symptoms of intrusion and avoidance decreased. There was a significant positive quadratic term for both types of symptoms, indicating a nonlinear effect of time. Figure 1 displays the course of intrusion and avoidance symptoms for mothers and fathers (estimated means). The existence of random slopes in intrusion and avoidance indicates that parents from the same couple did not have the same course of symptoms over time. However, between couples, the course of symptoms for mother-father dyads did not consistently differ.

Explanatory variables. Results of the final models for symptoms of intrusion and avoidance are displayed in Table 4. For intrusion, gender of the parent had a significant effect: mothers reported higher levels of symptoms throughout the study period, compared with fathers. Guilt feelings within the first month postburn were related to higher intrusion across both parents. The effect of anger was only present for mothers and not for fathers (interaction effect $B = 1.12$). Parents who had perceived their child's life to be in danger, reported more symptoms of intrusion over the four time points. At the couple level, more severe burns were related to more symptoms of intrusion. The effects of child gender and location of the accident were not significant. The only significant variable explaining differences in intrusion within couples was gender of the parent; mothers decreased more than fathers, indicating that the difference between mothers and fathers became smaller over time.

Similar to symptoms of intrusion, mothers reported higher levels of avoidance symptoms than fathers. More feelings of guilt were associated with higher avoidance across mothers and fathers. The effects of anger and perceived threat on avoidance symptoms were present in mothers but not in fathers (interaction effects $B_{anger} = .92$; $B_{threat} = 3.31$). Mothers with higher anger levels and mothers who had perceived their child's life to be in danger, experienced more avoidance. At the couple level, parents of girls reported more symptoms of avoidance. Moreover, when the accident had occurred within the home, more avoidance was reported by parents. The individual differences in

the course of avoidance symptoms (i.e., the random slope) could be partially explained by feelings of anger; there was an initial effect of anger, that diminished as time passed.

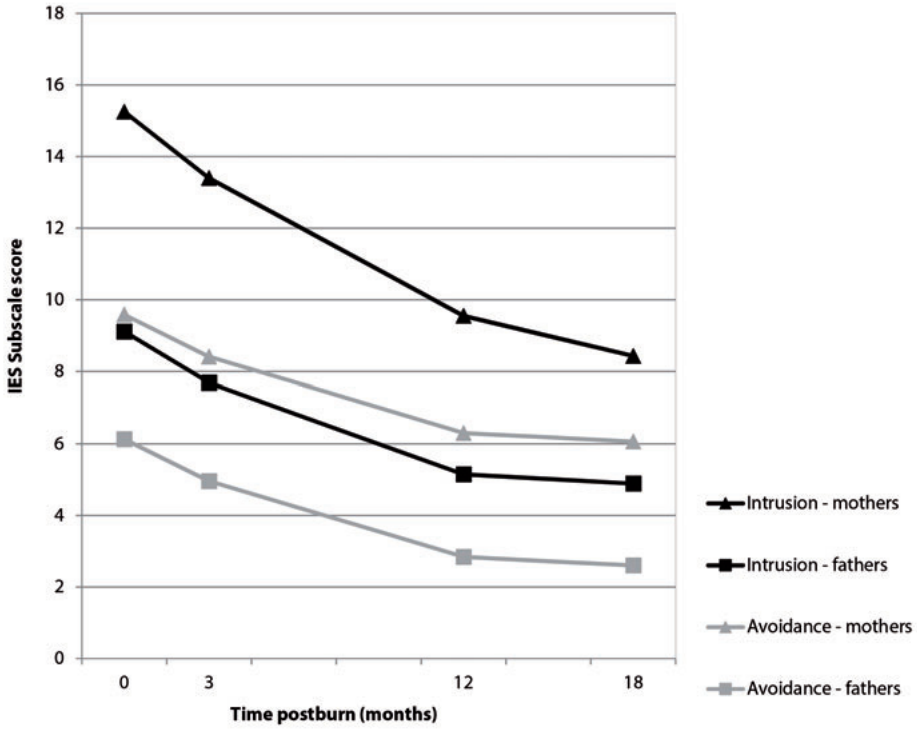

Figure 1. Longitudinal course of intrusion and avoidance symptoms of mothers and fathers, as assessed with the Impact of Event Scale (IES). Estimated means are based on a model with time, time squared, and parent gender.

Table 4. *Multilevel regression analyses: Predictors of parental intrusion and avoidance symptoms*

	Intrusion		Avoidance	
	B	*SE*	*B*	*SE*
Time level				
Intercept	9.42***	2.35	3.48*	2.41
Time[a]	-.54***	.12	-.36***	.13
Time squared	.02***	.01	.01**	.01
Individual parent level				
Parent gender (male = 0, female = 1)	4.80***	1.20	1.98***	.78
Feelings of guilt	1.36***	.39	.58**	.34
Feelings of anger	.08	.47	.31	.46
Perceived threat (no = 0, yes = 1)	2.12*	1.47	1.24	1.34
Parent gender x Feelings of guilt	-	-	-	-
Parent gender x Feelings of anger	1.12**	.53	.92**	.46
Parent gender x Perceived threat	-	-	3.31**	1.88
Couple level				
Child gender (boy = 0, girl = 1)	.99	.92	1.92**	1.01
Child age	-.22*	.16	-.03	.16
% TBSA	.12***	.03	.01	.04
Accident at home (no = 0, yes = 1)	-.50	1.00	1.95***	.83
Time interaction variables				
Time x Parent gender	-.13**	.06	-	-
Time x Feelings of anger	-		-.04*	.02
Explained variance				
At individual parent level	25 % (of initial 61 %)		19 % (of initial 28 %)	
At couple level	*n.a.*[b]		20 % (of initial 28 %)	
Of random slopes at parent level	14 %		14 %	

Note. Total $n = 104$ mothers and 76 fathers, from 108 families. Sample sizes differ from those reported in Table 1 and 2, due to parents from 10 families having incomplete information on predictors. *SE* = standard error; TBSA = total body surface area; n.a. = not applicable. [a] Random at individual parent level. [b] Explained variance could not be calculated, as explained in text. *$p < .10$, **$p < .05$, ***$p < .01$ (all tested one-sided).

Discussion

The present study examined the course and predictors of PTSS in parents after a burn event to their school-aged child. This is the first study to investigate this in a cohort of 8 to 18-year-old children. Results show that a substantial amount of parents experience serious traumatic stress symptoms in the first 18 months after their child's burn injury, with higher prevalence briefly after the incident and in mothers. Initial feelings of guilt and anger, as well as appraisal of threat to the child's life were shown to be related to a higher level of parental PTSS over time, especially in mothers. Moreover, although symptoms of intrusion were mainly individually experienced, parents within a couple were more similar in terms of their avoidance symptoms.

In the first month after the burn event, 48% of the mothers and 26% of the fathers experienced clinically significant PTSS. After 18 months, 19% of the mothers and 4% of the fathers experienced clinically relevant symptoms. On average, symptoms decreased over time. Prevalence rates were comparable to prospective studies in parents of preschool children (Bakker et al., 2013; De Young et al., 2014) and school-aged children and adolescents (Hall et al., 2006). It seems that most parents recover from initial symptoms or can be regarded resilient, which is in line with the conceptual model for pediatric medical traumatic stress (Kazak et al., 2006; Price et al., 2016). In congruence with a previous study in a younger cohort (Bakker et al., 2013), there was a higher prevalence of clinically relevant stress symptoms in mothers, compared to fathers. However, in both cohorts, the acute impact of the child's burn injury appears to be large in both parents, with high levels of PTSS in the first month postburn for mothers as well as fathers, whereas only mothers are indicated to be more at risk of persistent PTSS up to 18 months postburn.

In line with the cognitive model of PTSD (Ehlers & Clark, 2000), results of this study emphasize the relevance of parental appraisal and emotions after a pediatric burn event. Overall, whether the parent had perceived their child's life to be at risk during the acute phase was identified as a risk factor for later PTSS. This finding is supported by previous research (e.g., Bakker et al., 2013; Kassam-Adams et al., 2009) and fits within the conceptual model for pediatric medical traumatic stress (Kazak et al., 2006; Price et al., 2016). Although parents of older children appear to experience lower guilt feelings compared with parents of younger children (Bakker et al., 2013), higher initial guilt feelings were related to higher levels of PTSS, which was in line with previous studies (Bakker et al., 2013; De Young et al., 2014; Fukunishi, 1998). Negative self-blame coping strategies that may be part of guilt might increase the risk of PTSS in parents (Franck et

al., 2015). Anger was related to higher PTSS in mothers, and not in fathers, which was an unexpected finding, as it is well established that anger is related to later PTSS (e.g., Mayou, Ehlers, & Bryant, 2002). Although feelings of guilt and anger may be part of the posttraumatic stress response, previous studies have found that these emotions do not merely reflect overlap with the posttraumatic symptom clusters. For example, after removal of the anger item from a PTSD instrument, the association between anger and PTSD did not considerably decrease (Novaco & Chemtob, 2002). Also, a recent review suggested that guilt may be trauma-specific, rather than a feature of low mood, which is also a common symptom after trauma (Pugh, Taylor, & Berry, 2015). In sum, parents' early subjective appraisal and emotional responses were related to PTSS. Although parents' feelings of anger and guilt might to some degree be regarded normal or rational reactions to the child's burn injury, the relevance of these emotions is reflected by their associations with PTSS. This indicates that attention should be paid to the occurrence of initial guilt and anger responses in identifying parents at risk. However, more research is warranted to study the course of these emotions, in order to unravel the dynamics important for effective prevention or intervention.

The differentiation between symptoms of intrusion and avoidance was indicated to be informative in the present study, as results suggested a different nature of symptoms, as well as unique relationships with parent- and child factors. Intrusions were indicated to be more individually experienced symptoms that decreased with time, whereas avoidance appeared more similar within a couple of parents and more stable across the studied time interval, in agreement with findings in parents of younger children (Bakker et al., 2013). Parents may avoid talking about the trauma or may hide emotions from their partner. This active avoidant pattern has been described in couples after a traumatic event in one of the partners (Goff et al., 2006), or after the loss of a child, with parents avoiding to confront the other partner with his or her own grief, to not upset the other parent (Stroebe et al., 2013). In the present study, the overlap in avoidance symptoms in parents could be partially explained by factors that were shared within a couple. In case the burn accident occurred at home, parents reported more avoidance. This might be explained by parents more often being confronted with reminders of the event at home, which cause distress and avoidance strategies. Moreover, parents of girls experienced more avoidance, which has been reported previously (Bakker et al., 2013; McGarry et al., 2013). This finding might be tentatively explained by parents' perceptions of the impact of burn scars being different for girls and boys or by preburn or postburn gender-specific modelling and reinforcement processes (i.e., socialization theory). In a qualitative study, parents of girls described being concerned regarding

the long-term meaning of their daughters' scar, whereas parents of boys described their sons as being 'proud of their scar' (McGarry et al., 2015). Although avoidance was unrelated to burn severity, higher burn severity was related to more parental symptoms of intrusion, which is in line with previous studies finding an (indirect) association with parental PTSS (Bakker et al., 2013; Bakker, Van Loey, van Son, & van der Heijden, 2010; Hall et al., 2006; Rizzone et al., 1994). Results may have clinical implications in that the more interdependent nature of symptoms of avoidance call for interventions and family support at the couple- or family level, whereas treatment of intrusions should be more individually focused.

Prevalence rates of parental PTSS were comparable to a previous study in younger children (Bakker et al., 2013), although in the present study, less variance was explained by the total model (see supplementary material for a more detailed comparison to the study of Bakker and colleagues: http://dx.doi.org/10.1037/hea0000448.supp). This suggests that additional predictors must be considered to explain the similar severity of symptoms in parents of older children, which is an area of further study. Furthermore, in addition to taking into account other vulnerability factors such as parents' trauma history (McGarry et al., 2013) and preburn parent or child psychological problems (Le Brocque et al., 2010) in explaining parent PTSS, future research could aim to specifically examine the factors that explain why the majority of parents do not develop clinically significant PTSS in the long-term. As resilience appears to be the most common response pattern after potential trauma, followed by recovery (Bonanno, 2004), research might focus on factors that determine resilience and recovery pathways in parents after child burn injury. For example, parental emotional expression and cognitive reappraisal may help to mitigate the initial posttraumatic stress response. Also, interpersonal processes within the parental dyad should be taken into account (e.g., Compas et al., 2015).

Strengths of the present study include the prospective design, the inclusion of fathers, and, in analysis, the taking account of couples that as a dyad share and evoke similar experiences. However, some limitations of this study need to be addressed. First, although the sample size was large compared with other child burn studies, a larger sample size would have allowed stronger conclusions. This could, however, not be obtained within a reasonable study period of 5 years, as the incidence of burns in the age group under study is low (D'Souza, Nelson, & McKenzie, 2009), and the refusal rate to participate was rather high. Although the 84 eligible families that declined participation did not differ from the 118 included families regarding burn characteristics, older teenagers more often refused to participate, which may limit generalizability of the results to the older teenagers. Moreover, families that did not participate may differ

from participating families on variables that were not measured, such as psychosocial functioning. Thus, a selection bias may still be present. Second, although analyses using FIML corrected for observed differences in mothers' feelings of guilt and fathers' perceived life threat between parents with and without missing data, other unmeasured variables may be associated with the probability of missing data. Third, posttraumatic stress symptoms were assessed with a self-report questionnaire, which prevents drawing inferences regarding the proportion of parents that meet diagnostic criteria for PTSD. Moreover, the instrument used in the current study only covers two symptom clusters of the updated diagnosis of PTSD in the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; American Psychiatric Association, 2013). For example, no data were collected on parental hyperarousal, although these symptoms have been indicated to be important in predicting subsequent severity in other posttraumatic stress symptom clusters (Schell et al., 2004). Moreover, assessment of the current two symptoms did not allow differentiation of PTSS within the first month postburn from symptoms of acute stress disorder, as dissociative symptoms were not assessed. Last, although this study acknowledged the interdependency of parental reactions, psychological reactions of the child itself were not included in the present model. Studies on so-called 'relational PTSD' (Scheeringa & Zeanah, 2001) have, however, emphasized the mutual influence of symptoms in parents and children.

The results of this study highlight the role of parents' initial emotional response in adjustment after pediatric burn injury and underscore the importance of attending to the needs of parents in pediatric burn care. In pediatric psychology studies, parents specific emotional responses have not often been the subject of investigation, although the present study showed they are prospectively associated with parents' traumatic stress. Whether targeting the initial emotional response and appraisal already in an early phase can reduce the risk of long-term parental PTSS should be examined in future studies. Interventions such as imagery exposure and imagery rescripting might be promising, as they have been shown to be able to change feelings of guilt, followed by a decrease in symptoms of posttraumatic stress (Oktedalen, Hoffart, & Langkaas, 2015). In sum, the integration of parents in psychosocial aftercare of pediatric burn injury is recommended, even in the treatment of school-aged children and adolescents, who generally become more independent of their parents as they grow older.

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Chapter 5

Mothers' emotions after pediatric burn injury: Longitudinal associations with posttraumatic stress- and depressive symptoms 18 months postburn

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Abstract

Background: A child's burn injury is an emotional experience for parents. The aim of this study was to examine the longitudinal relationships of mothers' trauma-related emotions with symptoms of posttraumatic stress and depression 18 months postburn. **Methods**: Data from two cohort studies (including children aged 0-4 and 8-18 years old) were combined, resulting in a sample of 296 mothers. Mothers reported intensity of burn-related emotions within the first month (T1) and 12 months postburn (T2). The Impact of Event Scale (IES) and the depression subscale of the Hospital and Anxiety Depression Scale (HADS-D) were administered at T1 and 18 months postburn (T3). Longitudinal associations between emotion variables and symptoms of posttraumatic stress and depression were examined in two path models. **Results**: Based on two Exploratory Factor Analyses (EFA), emotion variables were combined in two factors: basic emotions (fear, sadness, horror, and anger) and self-conscious emotions (guilt and shame). Path analyses indicated that persistence of basic emotions (from T1 to T2) was related to persistence of posttraumatic stress- and depressive symptoms. Self-conscious emotions showed associations with posttraumatic stress- and depressive symptoms during the first month and were longitudinally related to depressive, but not posttraumatic stress, symptoms. **Conclusions**: The current study clarifies the role of mothers' basic and self-conscious emotions in relation to the maintenance of posttraumatic stress and depressive symptoms after a child's burn injury. We discuss potential clinical implications.

Introduction

Serious burn injury in a child may evoke strong emotions in parents and places them at risk of developing symptoms of posttraumatic stress disorder (PTSD). DSM-IV (American Psychiatric Association, 2000) diagnostic criteria for PTSD included not just exposure to a traumatic event, but also intense emotions of fear, helplessness, and horror at the time. Later studies have shown that a broader range of emotions experienced in response to trauma (such as anger, guilt, shame, and disgust) is associated with subsequent PTSD symptoms (Brewin, Andrews, & Rose, 2000; Engelhard, Olatunji, & Jong, 2011; O'Donnell, Creamer, McFarlane, Silove, & Bryant, 2010). DSM-5 (American Psychiatric Association, 2013) no longer includes this criterion, but does acknowledge the wide range of emotions implicated in PTSD.

This enhanced insight as shown in changed DSM criteria points at the usefulness of investigating a broader range of peritraumatic (i.e., at the time of the trauma) and posttraumatic emotions, and their development over time. As theorized by Ehlers and Clark (2000), emotions may be triggered by cognitive (re)appraisals of the trauma and its aftermath, which likely change over time. However, most studies that included multiple trauma-related emotions assessed emotions once (Brewin et al., 2000; O'Donnell et al., 2010). Studies including repeated assessments of emotions mainly involved intervention studies in patients with PTSD (e.g., Øktedalen, Hoffart, & Langkaas, 2015; Resick, Nishith, Weaver, Astin, & Feuer, 2002; Stapleton, Taylor, & Asmundson, 2006), focused on trait emotions (Feeny, Zoellner, & Foa, 2000; Lommen, Engelhard, van de Schoot, & van den Hout, 2014), or only assessed them in the first days after the traumatic event (e.g., Amstadter & Vernon, 2008). Therefore, scientists have recommended more longitudinal research to examine changes in emotions and PTSD over time (McLean & Foa, 2017; Pugh, Taylor, & Berry, 2015). These studies may reveal who recovers and who is at risk of chronic PTSD symptoms. Furthermore, as depressive symptoms often co-occur with posttraumatic stress after trauma (e.g., O'Donnell, Creamer, & Pattison, 2004), it is relevant to study trauma-related emotions in relation to depressive symptoms as well. The few available studies indicate that sadness, anger, guilt and shame are associated with depressive symptoms (Kubany et al., 1995; Marx et al., 2010; Rizvi, Kaysen, Gutner, Griffin, & Resick, 2008).

Pediatric burn injury is a potentially traumatic event for parents, leading to symptoms of posttraumatic stress (Bakker, Van Loey, van Son, & van der Heijden, 2010; De Young, Hendrikz, Kenardy, Cobham, & Kimble, 2014; Hall et al., 2006) and depression (De Young et al., 2014; Phillips & Rumsey, 2008). Although levels of traumatic stress

and depression typically decrease after the acute phase (De Young et al., 2014), a considerable number of parents experience long-term symptoms (Bakker et al., 2010; Phillips & Rumsey, 2008). Qualitative research suggests that parents experience a range of trauma-related emotions such as fear, sadness, anger, and guilt (Egberts et al., submitted; McGarry et al., 2015). Research has mainly focused on trauma-related guilt, and has demonstrated that it is commonly reported by mothers (Bakker et al., 2010) and is associated with concurrent and later PTSD symptoms (Bakker et al., 2010; De Young et al., 2014; Hawkins, Centifanti, Holman, & Taylor, in press). Furthermore, general guilt but not burn-specific guilt, has been related to parental depression cross-sectionally (Sveen & Willebrand, 2018). Studying the longitudinal associations between a broader range of burn-related emotions and long-term posttraumatic stress and depressive symptoms is valuable, because this may indicate which parents are at risk and whether different emotions play a differential role in maintaining these symptoms.

The present study examined intensity of mothers' emotions related to their child's burn injury and its longitudinal associations with symptoms of posttraumatic stress and depression. The focus is on mothers because women are more at risk of developing posttraumatic symptoms than men (Stein, Walker, & Forde, 2000). To increase the sample size and generalizability, the study combines two previous cohorts of younger and older children. The aims of the study were: 1) to examine the presence and intensity of mothers' negative emotions (i.e., fear, sadness, horror, anger, guilt, and shame) in relation to their child's burn injury within the first month (T1) and at 12 months postburn (T2), 2) to investigate a potential underlying structure of these emotions, and 3) to examine the relationships between mothers' emotions at T1 and T2 and posttraumatic stress- and depressive symptoms 18 months postburn (T3) while controlling for symptoms at T1.

Method

Procedure and participant recruitment

The combined data from two prospective cohort studies on parental symptoms of PTSD and depression following a pediatric burn event were used (Bakker, van der Heijden, van Son, & Van Loey, 2013; Egberts, van de Schoot, Geenen, & Van Loey, 2017). The first cohort concerned children in the age of 8 months to 4 years old, whereas the second cohort comprised children aged 8 to 18 years old. The research questions of the current study were answered using the combined data, although participant characteristics are reported for each cohort separately. The study was approved by two ethics committees in the Netherlands and Belgium. Between April 2007 and July 2011,

families were enrolled in three Dutch and four Belgian burn centers. The current study used data on mothers' adjustment, collected within the first month after the burn event (T1), and subsequently at 12 (T2) and 18 months postburn (T3). Families were eligible to participate if the child had been admitted to the hospital for more than 24 hours and the child's total body surface area (TBSA) burned was more than or equal to 1%. Families were excluded in case of insufficient Dutch language proficiency or child cognitive impairment. During admission, researchers at the burn centers contacted eligible families, explained the study purpose, and offered additional written information. Parents and children (>12 years old) provided written informed consent.

Participants

Of the 515 eligible families, 55 families of the first cohort and 22 families of the second cohort declined to participate in the study, 26 children (first cohort) and 15 children (second cohort) were already discharged before the family could be approached, and 16 (first cohort) and 19 (second cohort) families were not invited because their participation was deemed inappropriate (e.g., psychiatric background, severely ill family members, involvement of child protection services, or severe financial problems). Thirty-two (first cohort) and 34 (second cohort) mothers gave their informed consent to participate but did not complete the emotion measure at T1. In total, data from 296 mothers, who completed the emotion measure at T1, could be used (*n* first cohort = 184, *n* second cohort = 112). Table 1 displays the characteristics of the two cohorts.

Measures

Emotions related to the burn event. At T1 and T2, mothers' burn-related emotions were assessed through self-reports on the question "To what extent do the following emotions apply when you think about the accident that caused the burn?". The emotions of fear, sadness, horror, anger, shame, and guilt were used in the current study and comprised single items. Answers were rated on a 5-point Likert scale (0 = not at all, 1 = a little, 2 = somewhat, 3 = quite a lot, 4 = a lot).

Table 1. *Mother- and child characteristics within the two cohorts*

	M		*SD*		Range	
	Young cohort	*Older cohort*	*Young cohort*	*Older cohort*	*Young cohort*	*Older cohort*
Child age (years)	1.79	12.91	.92	2.96	.59 - 4.67	7.85 - 17.80
TBSA (%)	7.47	9.36	6.52	11.43	1 - 45	1 - 72
Length of stay in hospital (in days)	11.18	18.67	10.47	27.35	1 - 55	1 - 180
Number of surgeries	.52	1.09	.85	2.44	0 - 5	0 - 16
Mother age (years)	31.85	42.07	5.28	5.89	20 - 45	28 - 55
	n		%			
	Young cohort	*Older cohort*	*Young cohort*	*Older cohort*		
Child gender (boys, girls)	121,63	77,34	66, 34	70,30		
Burn type						
Flame/fire	7	64	4	57		
Scald	166	35	90	31		
Contact	9	6	5	5.5		
Chemical/electrical	2	6	1	5.5		
Other	0	1	0	1		
Site of accident						
At home (in- or outside)	147	70	80	62.5		
Somewhere else (in- or outside)	37	42	20	37.5		

Posttraumatic stress symptoms. The Impact of Event Scale (IES; Horowitz, Wilner, & Alvarez, 1979; Sundin & Horowitz, 2002) was used to assess mothers' posttraumatic stress symptoms at T1 and T3. This valid and psychometrically sound 15-item questionnaire assesses symptoms of intrusion and avoidance, two dimensions of traumatic stress. The Dutch version of the IES (Brom & Kleber, 1985) was used. Mothers were asked to rate the frequency of symptoms they had experienced specifically in relation to their child's burn event on a 4-point Likert scale (0-1-3-5). The total possible score ranged from 0 to 75, with higher scores representing higher levels of stress. A cut-off score of 26 was used to indicate 'clinically relevant stress symptoms' (Le Brocque, Hendrikz, & Kenardy, 2010; van der Velden, van der Burg, Steinmetz, & van den Bout, 1992). The IES demonstrated adequate reliability at both time points, with Cronbach's alpha of .85 at T1 and .88 at T3 for the Total scale.

Depressive symptoms. The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) was used to assess mothers' depressive symptoms. The HADS consists of a 7-item subscale for anxiety (HADS-A) and a 7-item subscale for

depression (HADS-D). A literature review of the HADS has indicated appropriate sensitivity, specificity and concurrent validity (Bjelland, Dahl, Tangen, & Neckelmann, 2002). Mothers' reports on the validated Dutch version of the HADS-D (Spinhoven et al., 1997) completed at T1 and T3 were used for the current study. Items were rated on a 4-point Likert scale (ranging from 0 to 3), with a total possible sum score for depressive symptoms ranging from 0 to 21 and higher scores indicating higher levels of depressive symptoms. A cut-off score of 8 was used to indicate clinically relevant depressive symptoms or 'possible caseness', since this score has been shown to achieve an optimal balance between sensitivity and specificity when using the HADS-D as a screening instrument (Bjelland et al., 2002). The Cronbach's alpha of the HADS-D was .88 at T1 and .85 at T3, indicating adequate reliability.

Child- and burn characteristics. Characteristics of the child (i.e., gender and age) and the burn (i.e., percentage TBSA affected, number of skin grafting procedures during initial hospitalization and length of stay in the hospital) were derived from the medical file. Percentage TBSA affected is the estimated percentage body surface area affected by partial- or full-thickness burns. Parents provided information on the burn type and the site of the accident at T1.

Data analysis

Drop-out analysis. Of the 296 mothers who completed the emotion measure at T1, 204 (69%) completed all relevant measures at T2 and T3. These mothers were compared to the 92 mothers with missing data at T2 and/or T3. Mothers with complete data did not differ significantly in terms of posttraumatic stress- and depressive symptoms at T1 ($p = .21$ and $p = .74$, respectively), or the T1 emotions of fear ($p = .56$), sadness ($p = .28$), horror ($p = .48$), shame ($p = .63$), and guilt ($p = .74$). However, mothers with missing data reported somewhat higher levels of anger at T1, compared to mothers with complete data: $M_{complete} = 1.20$, $SD = 1.40$, $M_{missing} = 1.64$, $SD = 1.51$; t (165) = -2.39, $p = .02$. No differences between the two groups were found in terms of child gender ($p = .77$), age ($p = .15$), or burn severity ($p = .61$).

Statistical analysis. First, presence, intensity, and mean levels of mothers' emotions in relation to the burn event were calculated and compared between T1 and T2, prevalence of clinically relevant levels of posttraumatic stress- and depressive symptoms were described, and correlations between mothers' emotions, posttraumatic stress- and depressive symptoms were calculated.

Second, two exploratory factor analyses (EFA), at T1 and T2, respectively, were conducted in SPSS (version 24) to be able to summarize the six emotion items

according to their underlying structure. The goal was to reduce correlated emotions to interpretable factors that could be used in further analyses. A direct oblimin (oblique) rotation was used to allow for a correlation between the factors. Determination of the number of factors and the interpretation of the factors was based on eigenvalue criteria (>1), the scree plot, the factor loadings, and theoretical grounds. Next, emotion factors were calculated by averaging the emotion items that loaded on the factor.

Third, associations between mothers' emotions, posttraumatic stress- and depressive symptoms were examined in two path models (Figure 1). Separate path models were estimated in which posttraumatic stress and depressive symptoms at T3, respectively, were used as outcome measures. Analyses were conducted in Mplus 7.4 (Muthén & Muthén, 2012). Bayesian estimation with weakly informative priors (based on the possible range of parameter values) was used for both path models, because of the complexity of the models relative to the sample size (van de Schoot, Winter, Ryan, Zondervan-Zwijnenburg, & Depaoli, 2017). In estimating the models, the steps of the WAMBS-Checklist were followed (Depaoli & van de Schoot, 2017). A detailed report of these steps applied to the current data, including the exact prior specifications, inspection of convergence, and a sensitivity analysis will be made available via the Open Science Framework. The posterior predictive *p* value (ppp-value) was used to estimate the model fit, with values around .50 indicating a well-fitting model.

Results

Descriptive statistics, prevalence, and correlations

Figure 2 displays the intensity of mothers' emotions at both time points. Sadness and fear were the emotions most commonly reported; most mothers reported at least some level (≥ 1 on a 0-4 scale) of these emotions at T1 and T2 (Sadness T1: 96%, T2: 88%; Fear T1: 84%, T2: 73%). At least some level of anger, horror, or guilt was present in approximately 50% of the mothers (Anger T1: 59%, T2: 49%; Horror T1: 52%, T2: 49%; Guilt T1: 65%, T2: 54%). For shame these percentages were 41% (T1) and 34% (T2). Mean levels (see Table 2) of all emotions decreased from T1 to T2 (p_{fear} <.001; $p_{sadness}$ <.001; p_{horror} =.035; p_{anger} =.025; p_{shame} =.001; p_{guilt} <.001).

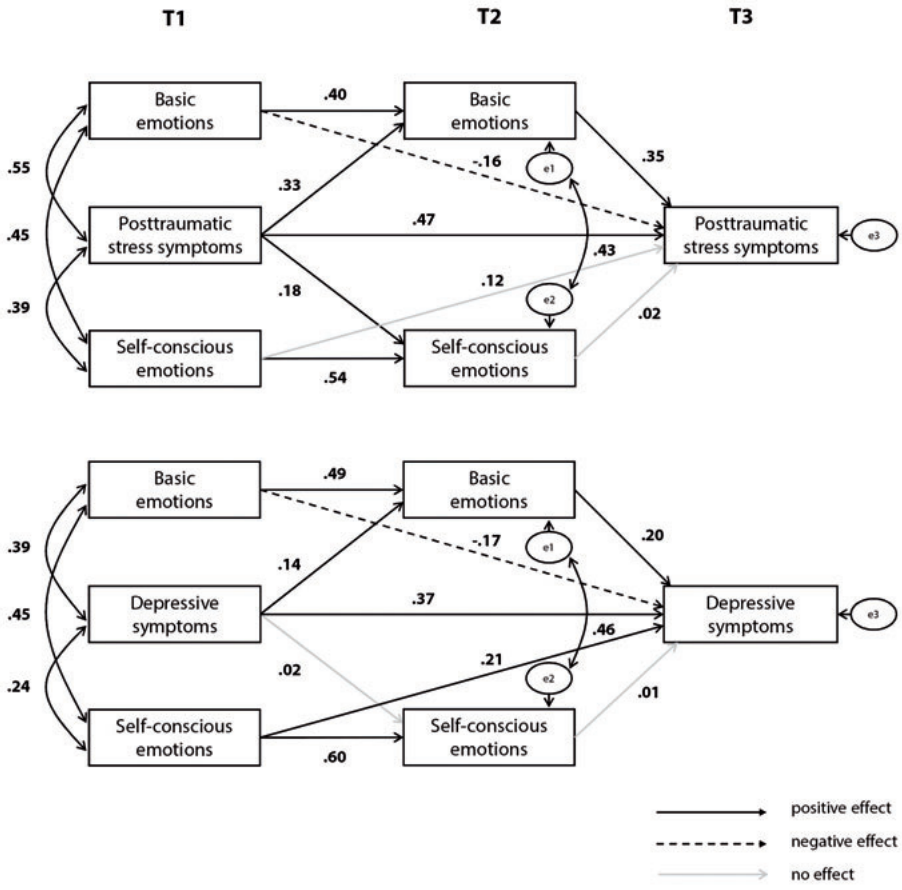

Figure 1. Results of two path models representing the longitudinal associations between the summarizing emotion variables (basic and self-conscious emotions) and posttraumatic stress symptoms/depressive symptoms. Standardized coefficients are shown. The shape of the lines indicates the direction of effects. Lines in grey represent parameters for which the 95% Credibility Interval contained the value of zero, indicating no effect. T1 = within the first month postburn, T2 = 12 months postburn, T3 = 18 months postburn.

Based on the pre-determined cut-off of the IES, 49% of the mothers reported clinically relevant levels of posttraumatic stress at T1, which decreased to 18% at T3. Based on the HADS-D cut-off, the prevalence of clinically relevant levels of depression was 31% at T1 and 7% at T3. At T1, 24% of the mothers had clinically relevant levels of both posttraumatic stress and depression, which decreased to 6% at T3.

The correlations between symptoms of posttraumatic stress and depression at the same time point were large (.61 at T1, .56 at T3). Table 2 shows the bivariate correlations between mothers' emotions at T1 and T2, and symptoms of posttraumatic stress and depression at T1 and T3. With a few exceptions, both concurrent and longitudinal correlations of emotions with posttraumatic stress and depression were significant. Both concurrently and longitudinally, most emotions showed higher correlations with posttraumatic stress than depressive symptoms.

Exploratory Factor Analysis

Table 3 displays the factor loadings of the six emotions at both time points. Based on the scree plot, eigenvalue criteria, and factor loadings resulting from the two EFAs, a two-factor solution was chosen at T1 and T2. The factor structure was similar across the two time points. The first factor comprised fear, sadness, horror, and anger, and was termed 'basic emotions' (cf. Tracy & Robins, 2004). This factor explained 34% of the variance at T1 and 43% at T2. The second factor included shame and guilt, and was termed 'self-conscious emotions' (cf. Tracy & Robins, 2004), and explained 31% of the variance at T1 and 36% at T2. The correlation of the two factors was .52 at T1 and .48 at T2.

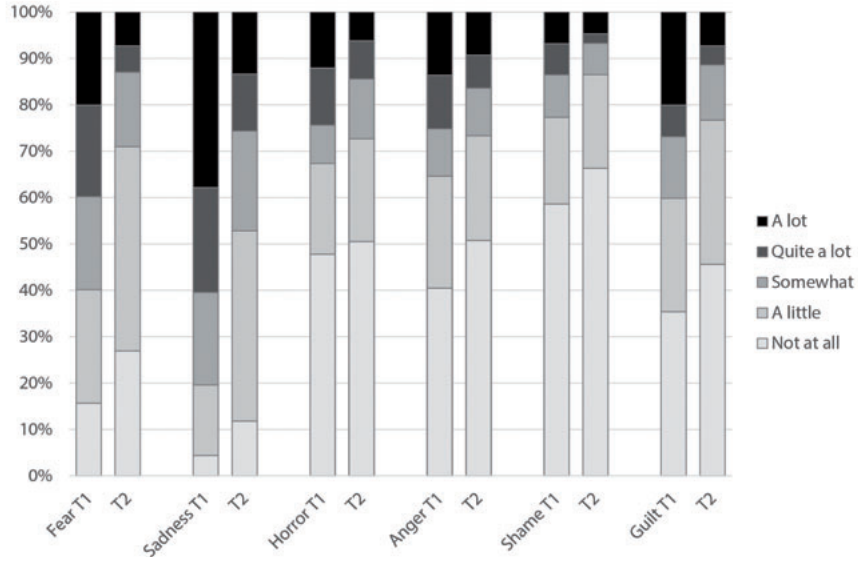

Figure 2. Frequency of mothers' burn-related emotions within the first month (T1) and 12 months postburn (T2).

Table 2. *Means (M) and standard deviations (SD) of mothers' emotions at T1 and T2, and Pearson correlations with symptoms of posttraumatic stress and depression at T1 and T3*

	M (SD)		Posttraumatic stress				Depression			
			T1		T3		T1		T3	
Emotions	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2
Fear	2.04 (1.37)	1.22 (1.13)	.44**	.40**	.30**	.40**	.31**	.27**	.16	.35**
Sadness	2.74 (1.23)	1.74 (1.22)	.44**	.45**	.31***	.46**	.36**	.26**	.11	.13
Horror	1.21 (1.45)	.97 (1.24)	.32**	.42**	.16*	.41**	.21**	.22**	.08	.22**
Anger	1.34 (1.45)	1.02 (1.32)	.43**	.48**	.24**	.52**	.29**	.34**	.19**	.28**
Shame	.84 (1.24)	.59 (1.03)	.31**	.37**	.23**	.36**	.18**	.15*	.24**	.26**
Guilt	1.52 (1.52)	.96 (1.18)	.40**	.37**	.34**	.36**	.26**	.14	.35**	.20**
n			280-285	192-193	192-194	184-185	282-287	193-195	188-190	179-180

Note. T1 = within first month postburn, T2 = 12 months postburn, T3 = 18 months postburn. Total *n* = 296 mothers. The range of the sample sizes (*n*) refers to the number of mothers for whom data was available at each time point. *$p < .05$, **$p < .01$

Table 3. *Factor loadings and Eigenvalues for the six emotions after two Exploratory Factor Analyses (EFA) with oblimin rotation*

	Component loadings			
	T1		T2	
	Component 1	Component 2	Component 1	Component 2
Fear	**.71**	.06	**.73**	.07
Sadness	**.80**	.09	**.64**	.19
Horror	**.44**	.13	**.83**	.09
Anger	**.55**	.20	**.65**	.23
Shame	.00	**.86**	.16	**.67**
Guilt	.03	**.74**	.08	**.99**
	Eigenvalues			
	2.06	1.85	2.60	2.18

Note. T1 = within first month postburn, T2 = 12 months postburn. Total *n* = 285 at T1 and 191 at T2.

Path analyses

Results of the two path models are shown in Figure 1 and Table 4. The model explained 48% of the variance for posttraumatic stress, and 26% for depressive symptoms at T3.

In the model with *posttraumatic stress symptoms* at T3 (top of Figure 1), strong path coefficients were found relating higher initial (T1) basic emotions and higher initial posttraumatic stress symptoms via higher basic emotions at T2 with more posttraumatic stress symptoms at T3. Moreover, the direct path between posttraumatic stress symptoms at T1 and T3 was strong. Thus, higher initial basic emotions and posttraumatic stress symptoms are associated with higher long-term posttraumatic stress symptoms, especially if initial emotions persist. Taking account of other levels and relationships in the model, *higher* initial basic symptoms at T1 were directly associated with lower posttraumatic stress at T3. For self-conscious emotions at T1 and T2, no associations with posttraumatic stress at T3 were found. Within the same time point (T1), posttraumatic stress symptoms showed positive associations with both basic- and self-conscious emotions.

In the model with *depressive symptoms* at T3 (bottom of Figure 1), a similar pattern was observed for the relationship between basic emotions and depressive symptoms; higher basic emotions at T1 were related to more depressive symptoms at T3 via higher basic emotions at T2. Higher depressive symptoms at T1 were related to higher symptoms at T3. Accordingly, higher initial basic emotions and depressive symptoms are longitudinally related to long-term depressive symptoms, if basic emotions persist. Similar to the posttraumatic stress model, lower basic emotions at T1 were directly related to higher depressive symptoms at T3, when taking into account the other relationships. Furthermore, higher self-conscious emotions at T1 were longitudinally related to more depressive symptoms at T3, whereas no association was observed between self-conscious emotions at T2 and depressive symptoms at T3. Positive concurrent relationships between the constructs were observed, with higher depressive symptoms at T1 associated with higher basic- and self-conscious emotions at T1.

Table 4. *Parameter estimates for the posttraumatic stress symptoms path model and the depressive symptoms path model*

	PTSS				Depressive symptoms			
	Posterior				Posterior			
	B	*SD*	CI_B	β	*B*	*SD*	CI_B	β
PTSS/Depressive symptoms T3 predicted by								
PTSS/Depressive symptoms T1	**.42**	**.06**	**.30, .54**	**.47**	**.25**	**.05**	**.16, .34**	**.37**
Basic emotions T1	**-1.96**	**.85**	**-3.65, -.30**	**-.16**	**-.50**	**.26**	**-1.01, .00**	**-.17**
Basic emotions T2	**4.29**	**.93**	**2.45, 6.11**	**.35**	**.62**	**.28**	**.10, 1.17**	**.20**
Self-conscious emotions T1	1.17	.73	-.25, 2.61	.12	**.52**	**.22**	**.10,.94**	**.21**
Self-conscious emotions T2	.18	.93	-1.62, 1.99	.02	.04	.28	-.52, .60	.01
Basic emotions T2 predicted by								
Basic emotions T1	**.39**	**.06**	**.27, .51**	**.40**	**.48**	**.06**	**.36, .59**	**.49**
PTSS/Depressive symptoms T1	**.02**	**.01**	**.01, .03**	**.33**	**.03**	**.01**	**.00, .06**	**.14**
Self-conscious emotions T2 predicted by								
Self-conscious emotions T1	**.45**	**.05**	**.36, .54**	**.54**	**.48**	**.04**	**.40, .57**	**.60**
PTSS/Depressive symptoms T1	**.01**	**.01**	**.00, .02**	**.18**	.00	.01	-.02, .03	.02
Within-time associations								
Basic emotions T1 ↔ PTSS/Depressive symptoms T1	**8.08**	**1.02**	**6.24, 10.23**	**.55**	**1.83**	**.31**	**1.28, 2.48**	**.39**
Self-conscious emotions T1 ↔ PTSS/Depressive symptoms T1	**6.93**	**1.15**	**4.80, 9.33**	**.39**	**1.39**	**.36**	**.72, 2.14**	**.24**
Basic emotions T1 ↔ Self-conscious emotions T1	**.59**	**.09**	**.44, .77**	**.45**	**.59**	**.09**	**.43, .77**	**.45**
Basic emotions T2 ↔ Self-conscious emotions T2	**.27**	**.05**	**.18, .38**	**.43**	**.31**	**.06**	**.22, .44**	**.46**

Note. CI = 95% Credibility Interval, parameters are printed in bold in case zero was not contained in the CI. T1 = within first month postburn, T2 = 12 months postburn, T3 = 18 months postburn. PTSS = Posttraumatic stress symptoms. Ppp-value is .50 for the posttraumatic stress model and .46 for the depressive symptoms model

Discussion

The current study demonstrated that mothers varied in their experiences of emotions in reaction to their child's burn injury. Mothers' emotions related to their child's trauma were categorized into basic emotions (fear, sadness, horror, and anger) and self-conscious emotions (guilt and shame). Persistence of basic emotions in the first year after burn injury was related to long-term posttraumatic stress- and depressive symptoms. Initial self-conscious emotions were longitudinally related to long-term depressive symptoms but not posttraumatic stress.

Within the first month postburn, 31% of the mothers reported clinically relevant levels of depressive symptoms and 49% reported posttraumatic stress in the clinical range. Eighteen months postburn these rates were 7 and 18%, respectively. Nearly all mothers who reported clinically relevant levels of depressive symptoms 18 months postburn also reported posttraumatic stress symptoms in the clinical range, indicating that depressive symptoms occurred in the context of posttraumatic stress. This is consistent with the inclusion of the negative alterations in cognitions and mood cluster in the DSM-5 PTSD criteria (American Psychiatric Association, 2013) and with research that suggests symptoms of posttraumatic stress and depression show less differentiation in the long-term and reflect a more general chronic traumatic stress reaction (Breslau, Davis, Peterson, & Schultz, 2000; O'Donnell et al., 2004).

The classification of basic and self-conscious emotions derived from the factor analysis shows close resemblance with the theoretical distinction between more "basic" emotions and self-conscious emotions (cf. Tracy & Robins, 2004). Shortly after the burn event, sadness (96%) and fear (84%) were almost universal, in line with studies reporting that sadness was the most dominant emotion in relation to the trauma (Berntsen & Rubin, 2007; Hathaway, Boals, & Banks, 2009). Guilt and shame occurred in about half of the mothers in the first month after the injury. Overall, the intensity of all emotions decreased over time. However, the presence of a subgroup of mothers with persisting high levels of emotions highlights the potentially profound long-term emotional impact of pediatric burn injury.

The results of the current study suggest that it is particularly the persistence of basic emotions that places mothers at risk of developing chronic symptoms of posttraumatic stress and depression; rather than intense initial emotions as such. These longitudinal findings extend previous studies that have shown cross-sectional relations between trauma-related emotions and symptoms of posttraumatic stress and depression, or that have only assessed these emotions once (Brewin et al., 2000;

Kubany et al., 1995; Lancaster, Melka, & Rodriguez, 2011; Marx et al., 2010; O'Donnell et al., 2010; Rizvi et al., 2008). Initial high levels of emotions may not be indicative of long-term risk if the intensity of these emotions dissipates with time, or if they occur in the absence of early high posttraumatic stress- and depressive symptoms, as was shown by a negative association between basic emotions and long-term posttraumatic and depressive symptoms while adjusting for the other relations in the model. Clinically, this suggests that parents with high levels of basic emotions should be monitored at a later time, to determine whether these emotions persist.

Initial high levels of self-conscious emotions were associated with an increased risk of later depressive symptoms. The high degree of stability of this type of emotions observed in the present study suggests a more trait-like nature of these emotions. Self-conscious emotions encompass self-evaluative processes and have a higher cognitive complexity than basic emotions (Tracy & Robins, 2004). A qualitative study indicated a discrepancy between cognitive and affective components of guilt in parents' reflections on the responsibility for the burn event (Egberts et al., submitted), that may be subject of rumination. Rumination (a passive and repetitive focus on symptoms of distress) has consistently been shown related to depressive symptoms (Nolen-Hoeksema, Wisco, & Lyubomirsky, 2008). Thus, self-conscious emotions may induce, fuel or maintain depressive symptoms through rumination. In addition, the results suggest that the presence of early posttraumatic stress symptoms may influence the maintenance of self-conscious emotions. The results indicate that to prevent a chronic course of depressive symptoms, preventive interventions should not only attend to basic emotions but also to early posttraumatic stress and parental feelings of guilt and shame.

A first limitation of this study might be that with the use of an aggregated set of negative burn-related emotions, no conclusions can be drawn about aspects of single emotions, such as whom the emotion was directed to. Second, posttraumatic stress and depressive symptoms were assessed by using self-report questionnaires instead of diagnostic interviews. As a consequence, the number of mothers that met diagnostic criteria for PTSD or Major Depressive Disorder is unknown. In addition, the posttraumatic stress measure used in the current study only covered two of the four symptom clusters of the DSM-5 PTSD criteria (American Psychiatric Association, 2013), and did not include the cluster comprising negative alterations in cognitions and mood (although the HADS-D might have been representative for the symptoms in this cluster). Therefore, the results should be replicated using the PTSD criteria reported in DSM-5. Finally, participating mothers might have received psychological treatment throughout

the course of the study, potentially impacting their psychological symptoms and burn-related emotions, but this was not registered.

The current study shows how basic and self-conscious emotions are related to posttraumatic stress- and depressive symptoms 18 months after a traumatic event. The results indicate that initial high levels of basic emotions that persist increase the risk of chronic posttraumatic stress and of depressive symptoms that co-occur with posttraumatic stress. Over and above these relationships, self-conscious emotions are indicated to contribute to long-term depressive symptoms. The results suggest the usefulness of screening and monitoring of parents who experience high levels of emotions initially. The presence of trauma-related emotions may complicate psychological symptoms after trauma, and a decrease of persisting trauma-related emotions can be a complementary goal in the treatment of both posttraumatic stress and depressive symptoms.

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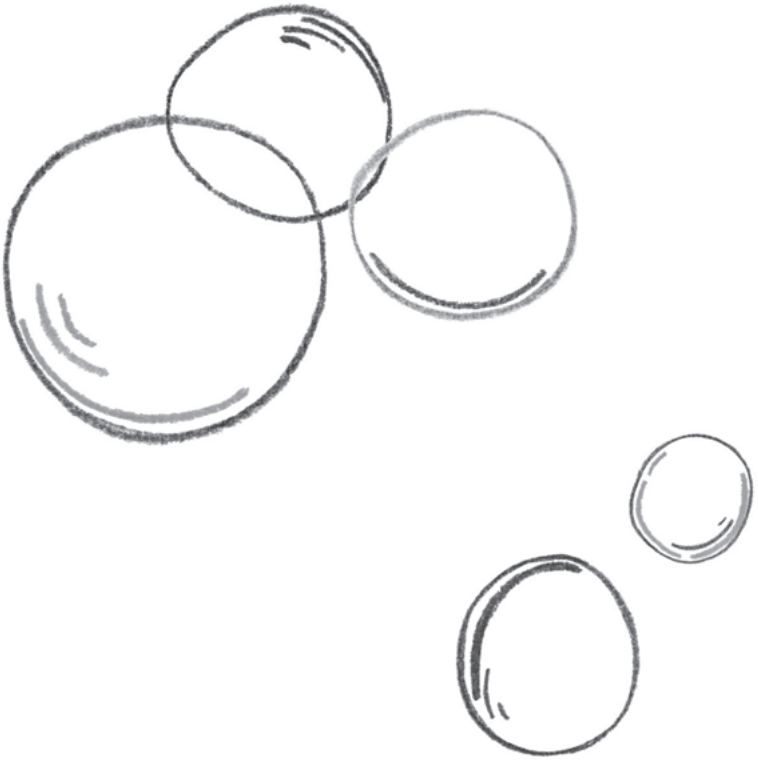
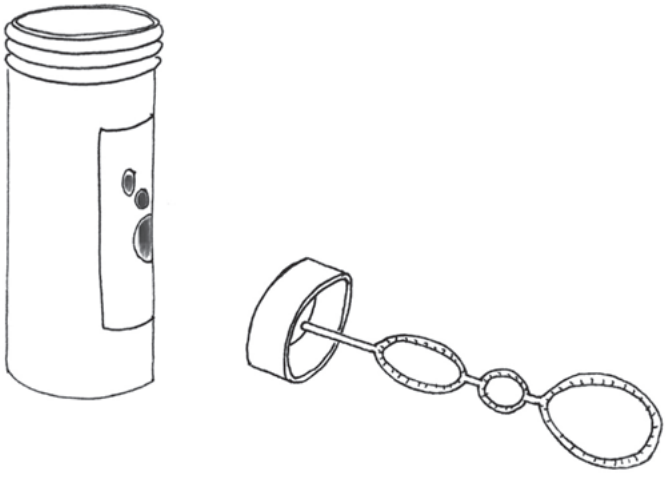
Part II

Parent and child reflections on the burn accident and hospitalization: Implications for care





Chapter 6

Parental presence or absence during pediatric burn wound care procedures

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Author contributions: ME drafted the paper; AdJ, HH, RG and NvL critically revised the paper; ME and NvL analyzed the data; ME collected the data; ME, AdJ, HH and NvL formulated research questions and developed the design

Abstract

Aim: Differing views on benefits and disadvantages of parental presence during their child's wound care after burn injury leave the topic surrounded by controversies. This study aimed to describe and explain parents' experiences of their presence or absence during wound care. **Method:** Shortly after the burn event, 22 semi-structured interviews were conducted with parents of children (0-16 years old) that required hospitalization in one of the three Dutch burn centers. Eighteen of these parents also participated in follow-up interviews three to six months after discharge. Interviews were analyzed using grounded theory methodology. **Results:** Analyses resulted in themes that were integrated into a model, summarizing key aspects of parental presence during wound care. These aspects include parental cognitions and emotions (e.g., shared distress during wound care), parental abilities and needs (e.g., controlling own emotions, being responsive, and gaining overall control) and the role of burn care professionals. **Conclusion:** Findings emphasize the distressing nature of wound care procedures. Despite the distress, parents expressed their preference to be present. The abilities to control their own emotions and to be responsive to the child's needs were considered beneficial for both the child and the parent. Importantly, being present increased a sense of control in parents that helped them to cope with the situation. For parents not present, the professional was the intermediary to provide information about the healing process that helped parents to deal with the situation. In sum, the proposed model provides avenues for professionals to assess parents' abilities and needs on a daily basis and to adequately support the child and parent during wound care.

Introduction

Offering parents the possibility to be with their child and to participate in care is recognized as an important aspect of pediatric hospital care (Coyne & Cowley, 2007). Parents express the wish for participation in their child's care and expect to be involved (Power & Franck, 2008). However, ways in which parents want to be involved are likely to differ depending on the nature of the pediatric illness or injury, the type of care concerned, and individual child and parent characteristics. Attending the wound care of their child with burns may be an additional stressor for parents on top of the burden of the burn incident and its consequences. However, parents may have good reasons to want to be present and support their child. In-depth research on parent experiences of their participation in wound care procedures after pediatric burn injury may elucidate under which circumstances parent participation leads to optimal outcomes for child and parent.

Potential benefits that have been described for parental presence during injections and other medical procedures include lower distress and higher satisfaction in parents, and prevention of child separation anxiety (Piira, Sugiura, Champion, Donnelly, & Cole, 2005). For burn wound care, presumed benefits include the opportunity for parents to comfort their child and model adaptive coping strategies. Nurses can also teach parents how to conduct wound care themselves, thereby stimulating adequate recovery after discharge (Doctor, 1994; George & Hancock, 1993).

Besides the assumed advantages of participation of parents in burn wound care procedures, it can also be distressing. Within the integrative model of pediatric medical traumatic stress, invasive procedures such as wound care have been described as events that may elicit traumatic stress reactions in both the child and its parents (Kazak et al., 2006; Price, Kassam-Adams, Alderfer, Christofferson, & Kazak, 2016). Empirically, parents have described observing pain and distress reactions in their children as the most difficult part of burn injury (Rimmer et al., 2015) and wound care in particular (Smith, Murray, McBride, & McBride-Henry, 2011). Stoddard and colleagues (2006) found an association between the child's pain during hospitalization and parents' acute stress symptoms. In a study of De Young and colleagues (De Young, Hendrikz, Kenardy, Cobham, & Kimble, 2014), 18% of the parents qualified wound care as the most traumatic part of burn injury, while for 15% of the parents, this was the actual burn injury and the wound care. Similarly, in a qualitative study, wound care procedures were described as a source of trauma for parents (McGarry et al., 2015). Therefore, participation might be

inappropriately stressful to parents and potentially associated with parental traumatic stress reactions.

When weighing the appropriateness of parental presence during wound care, besides invasiveness of the procedure and anticipated pain and emotions of the child, parental capabilities to participate are considered to be important (Doctor, 1994; George & Hancock, 1993; Stoddard et al., 2002). These capabilities may relate to the parent's emotional state. For example, child preoperative anxiety has been shown lower in the presence of a calm parent, but not in the presence of an overly anxious parent (Kain, Caldwell-Andrews, Nelson, Mayes, & Maranets, 2006). It is well documented that in the acute aftermath of pediatric burn injury, parents have to deal with their own stress reactions and emotions related to the burn event, such as guilt (Bakker, Van Loey, van der Heijden, & van Son, 2012; De Young et al., 2014). This potentially impacts their decision and perceived ability to participate in wound care. Little research has, however, specifically addressed the role of parental capabilities and emotions in participation during wound care.

Given the differing views on the benefits and drawbacks of parent participation in their child's wound care, it is not surprising that different policies on parental presence exist in clinical practice. When considering parents' presence, parental views on their preferences and role during wound care are essential. Recently, Morley and colleagues (2017) have described mothers' experiences regarding their young child's wound care. The study showed that mothers experienced a sense of duty to be present during wound care, related to their feelings of responsibility associated with being a parent. Findings also highlighted the need for appropriate support of mothers during dressing changes. These insights into the phenomenon of parental presence during wound care call for more studies in the wider parent population.

The present study aimed to increase our understanding of parents' experiences of their presence or absence during wound care, with the inclusion of a larger sample, and a wider child age range, with data of fathers and of parents that were present and those that were absent during wound care. Ultimately, the goal was to develop an integrative model describing the aspects that are important for professionals in burn care when considering parental presence or absence during wound care.

Method

Participants and procedure

The present study that is focused on the perspective of parents is part of a larger qualitative study on parental presence during wound care. Another study will offer an in-depth evaluation of nurses' and child life specialists' perspectives on parental presence and will address nursing interventions (de Jong, Egberts, Hofland, & Van Loey, 2017). To obtain the sample described in the current manuscript, parents were recruited from the three burn centers in the Netherlands between December 2014 and June 2016. In two of these burn centers, parents are offered the possibility to be present during their child's wound care procedures, while in one center parents are not present. In all centers, child life specialists are often present during wound care. While nurses primarily focus on the wound care, the child life specialist is only concerned with the child's and parent's wellbeing. In the burn center that does not offer parents the possibility to be present, the child life specialist partially takes over the parental role, in terms of distracting, comforting, and guiding the child through the procedure.

Parents of children under the age of 19 years were eligible to participate if their child required hospitalization for a burn injury and had at least undergone one wound care procedure. Parents were approached by a local researcher while they were still in the hospital. The researcher explained the purpose of the study and provided additional written information. Written informed consent was provided by all parents. To achieve variation in demographic- and child characteristics (i.e., child age, gender, burn severity, burn type), purposeful sampling was used. Child- and burn characteristics were obtained from the medical file and parents completed a questionnaire for socio-demographic information. After 3 to 6 months, the interviewer contacted parents that participated in the first interview, to ask whether they still would like to participate in a follow-up interview.

In total, parents of 22 children participated in the study. Data saturation (i.e., the point were no new themes emerged) was reached after 18 interviews. To confirm this, four subsequent interviews were conducted. In 8 families, both parents were involved in the interview, while 14 interviews were conducted with the mother only. Follow-up interviews were conducted with 18 of the 22 families (11 mothers, 1 father, 6 couples). Table 1 shows child- and burn characteristics of the sample. The mean age of participating parents was 32.9 (ranging from 23 to 54) years for mothers and 38.5 (ranging from 30 to 46) years for fathers. Educational level of the parents was classified as low (19% of the parents), middle (39% of the parents) or high (42% of the parents).

The majority of the parents were in a relationship (86%) and most of the parents were currently employed (81%). Eighty-four percent of the parents were born in the Netherlands.

The study was conducted according to the principles of the Declaration of Helsinki (revision, Fortaleza, Brasil, 2013). The Institutional Review Board of the Faculty of Social and Behavioural Sciences of Utrecht University approved the study (FETC15-085).

Table 1. *Child- and burn characteristics (n = 22)*

	M	SD	Median	Range
Child age (years)	6.5	5.8	3.2	0-16
TBSA (%)	9.0	7.1	7.7	3-34
Length of stay in hospital (in days)	15.6	10.7	11	4-50
	N	%		
Child gender (boys)	11	50		
≥ 1 surgery during initial hospitalization	11	50		
Burn type				
Scald	16	73		
Flame/fire	5	23		
Electrical	1	4		

Note. TBSA = estimated percentage total body surface area affected by partial- or full-thickness burns.

Data collection

In the first wave of data collection, semi-structured, face-to-face interviews were conducted in the burn center during hospitalization, with the exception of four interviews that were conducted shortly after discharge at the participants' home or in the burn center in case of check-up contacts. In the second wave of data collection, follow-up interviews were conducted at the families' home or in the burn center. Interviews were carried out by a trained female researcher/psychologist (first author), except for one interview that was conducted by a trained psychologist from one of the burn centers. Interviews were digitally recorded. Mean duration of the interview was 62 minutes (range: 31-106 minutes) in the first wave, and 57 minutes (range: 41-78 minutes) in the second wave.

Topics within the interview guide of the first wave concerned the experience of being present or absent during child wound care procedures, for example in terms of having a choice to be present, reasons to be present or absent (i.e., 'Why did you decide to be present/absent?' and 'Which benefits does being present have?'), preparation,

and the child's reaction. Also, the parents' role (i.e., 'Can you describe your role during wound care?'), thoughts and feelings during the procedures (i.e., 'Can you describe the thoughts that you had during wound care?') were addressed. The interview guide of the second wave was partially focused on the way parents looked back on the wound care procedures. Questions were open-ended and follow-up questions were asked to obtain a more in-depth understanding of the area of interest. In both data collection waves, first, two pilot interviews were carried out, to ensure the interview guides were workable and elicited appropriate information in terms of the study's goal. In line with the constant comparison method, based on the analyses of information obtained within the first interview phases, new topics and questions were added to the interview guide. During all interviews, the interviewer recorded field notes on relevant non-verbal cues as well as environmental factors that were important in interpreting the interview information.

Data analysis

Recorded interviews were transcribed verbatim and names were replaced by pseudonyms. Interview transcripts were imported in the software program MAXQDA 12 (2016). A grounded theory methodology including thematic analysis was used (Glaser & Strauss, 1967). Grounded theory is an inductive and systematic methodology that is used to construct theory grounded in qualitative data. As part of this methodology the constant comparison method (Boeije, 2010) was used, whereby information from new interviews was compared with existing codes to identify similarities and differences. Following Strauss and Corbin (Strauss & Corbin, 2007) interview fragments were coded using respectively open, axial and selective coding. In the open coding process, the interviews were read line-by-line and fragments were extracted and assigned a code that summarized the meaning of the fragment. Axial coding was used to group and merge codes, and to reveal connections between the categories. In the selective coding process, the core categories and the final integrative model were established. The first five interviews were coded independently by the first and last author (researchers in psychology), after which differences were discussed until consensus was reached. Subsequent interviews were coded by the first author and discussed in detail with the last author. The second and third author (researchers in nursing) reviewed all transcripts. The analyses were continuously discussed within the research team. Throughout the process, memos were written and diagrams were drawn, which helped in constructing the final integrative model.

Results

Seven themes were identified from the interviews, that were grouped under two overarching categories (see Table 2). Each of the themes is discussed in detail below. In addition, the way parents looked back on the wound care procedures three to six months after discharge is addressed and finally, an integrative model summarizing central aspects of parental presence is presented.

Table 2. *The two overarching categories and the seven identified themes*

Cognitive-emotional impact of burn event and wound care
1. Burn event-related distress
2. Shared distress
3. The child's best interest
Parental abilities and needs
4. Controlling own emotions
5. Being responsive
6. Gaining overall control
• Information provision and understanding the situation
• Perception of meaningful contribution
7. Child- and parent- focused care

Cognitive-emotional impact of burn event and wound care

1. Burn event-related distress

All parents described having experienced emotional reactions such as shock, fear, guilt, sadness and helplessness when witnessing or being informed about their child's burn injury. These emotions could extend into the period of hospitalization, although experienced to a lesser extent. Also, vivid memories of the burn event were reported, sometimes occurring in the form of intrusions or flashbacks.

2. Shared distress

Wound care procedures were distressing for children as well as parents. Children displayed pain and anxiety during wound care. Parents mainly described sadness, anxiety, feelings of guilt and powerlessness. In parents, emotions were elicited by witnessing their child's reaction to the procedure. This made parents to sympathize deeply with their child's suffering: *'It's difficult to describe, but it hurts you too. As a parent, as a father, it hurts me too of course'* [Father of a 10-year-old boy]. Feelings of powerlessness were experienced as a consequence of the inability to take away the

pain from their child. Parents explicitly mentioned that if they had the opportunity to take over their child's pain, they would do so. During the interviews in the first wave, several parents started to cry when discussing this topic. Observing the child's pain also evoked thoughts about the parent's responsibility for the child's accident, accompanied by feelings of guilt.

Parental fear and anxiety were primarily evoked by observing the wounds and thinking about the consequences of the injury. Parents described it was intense, dramatic and disruptive to see the wounds. Initially, the wounds looked ugly and severe and stressed the gravity of the situation. During wound care, alongside the distress related to the wound care itself, many parents experienced feelings of uncertainty and worries about the future and the treatment: *'Will this get better, without an operation? Because you don't want your child to have an operation, that she has a skin transplant, and so on.'* [Mother of a 4-year-old girl]. Over time, distress reactions during wound care were reported to decrease for the child and parent; this process occurred faster in some parents than others. Habituation to the situation, the progress in wound healing, predictability of the procedures and decrease of pain were seen as contributing to this decrease.

Parents of children in the burn center that did not admit parents during wound care commonly experienced distress, prior, as well as during wound care procedures. Parents stated that the moment the nurses entered the room wearing a mask, a cap and protective clothing, the (young) child's fear and anguish became apparent. This also marked the upcoming moment the parent had to leave the room, further increasing distress in the child. Signs of separation anxiety were observed by parents, as they described that the child became sad, got upset, started crying, and stretched out their arms when they left the room. For some parents, the period of wound care was tense as they had difficulty taking their mind off from what was happening with their child. One parent initially reported worst-case scenarios to come up in her mind particularly during the wound care procedures: *'It was a nightmare. Especially the first time I was afraid the whole wound care she would be screaming hysterically and be in a lot of pain'* [Mother of a 1-year-old girl]. On the other hand, other parents were able to use this period to relax to some extent, to do some phone calls, or to have a little walk. Similar to the centers in which parents were present during wound care, parents reported their distress to decrease over time.

3. The child's best interest

When parents were offered the possibility to be present during wound care, a decisive factor was whether presence or absence was considered to be in the child's best interest. Most often, being present during wound care was described as 'natural' or 'obvious', or as a responsibility associated with the parental role. Most parents emphasized the necessity to 'put your child before yourself'. This involved not thinking about possible negative consequences for the parent, but only about perceived benefits for the child: *'Well yes, of course it's not nice to watch your child while she undergoes something uncomfortable, but at the same time that doesn't weigh up against leaving her alone there. That wouldn't be an option for me'* [Mother of a 1-year-old girl].

Some parents more deliberately weighed advantages and disadvantages in deciding on their presence or absence. As a result, a minority of parents concluded their (initial) absence during wound care to be in the child's best interest. This was driven by the parent's own emotional state or the anticipated reaction of the child: *'Of course I did it for him as well as for myself, because I didn't know if I could take it. And for the nurse too, I thought if I stay now, my son's going to put up a fight. And well, it'll be really difficult to care for the wound'* [Mother of a 4-year-old boy]. Yet, deciding not to be present could lead to an internal conflict. Guilt and feelings of letting down their child were present when the parent felt the child's need for their presence or the duty to be present, but at the same time felt unable to offer this. Regardless of the parents' decision, all parents appreciated the possibility to be present during wound care.

Parents that were not admitted to the wound care expressed their understanding for the hospital policy. They were told that being present during their child's wound care procedures would be very distressing and it would be potentially traumatic to see the wounds and see their child suffer. Moreover, by being absent, the child would not associate the parent with the pain experienced during wound care, resulting in the parent continuing to be 'a safe haven'. Although it often felt unnatural for parents to leave their child prior to the wound care, given the natural tendency to provide emotional support to their child, parents trusted the health care providers in knowing the policy was in the child's and family's best interest.

Parental abilities and needs

4. Controlling own emotions

Control of parents' own emotions was considered essential for presence during wound care. Parents emphasized the need to set aside their emotions, hide their emotions from their child or not get carried away by their child's emotions. Parents described 'staying

strong' for their child and 'flipping the switch'. This was deemed necessary to meet the needs of the child during the procedures: *'…the first few days you switch off your emotions for his sake. And you block them out like, now my own feelings I'm going to put to one side because I've got to be there for him.'* [Mother of a 3-year-old boy]. Moreover, parents' own expression of distress was thought to affect their child's distress reactions and vice versa. Expression of parents' own emotions was deemed unhelpful, because the child would use their parent as a point of reference, thereby increasing child distress. Staying calm would therefore contribute to the child's emotion regulation too. Another unhelpful element of expressing their own emotions during wound care was that health care professionals would have to pay attention to the parent instead of the child, thereby delaying the procedure.

Several strategies of emotion control were mentioned by parents. A strong focus on the child, instead of the wounds and the procedures was argued to be helpful, as well as a practical mode in which parents focused on specific acts, instead of their thoughts: *'Just the focus only on her so that she can be in the silence with you. So just let everything happen around her and don't focus on all those people and things around her'* [Mother of a 1-year-old girl]. Also, a focus on positive outcomes and the positive contribution of wound care to their child's health helped parents to control their own emotions. Other parents described acceptance of their emotions, focusing on the 'here and now', or avoiding to look at the wounds. However, despite holding in their emotions during wound care, parents emphasized the need to express their emotions at another time and place: *'I know already in the evening that the wound care is planned for tomorrow. Even though I don't sleep well and can really feel that I'm tired, that I've almost run out of steam, that I've just got to do it for Laura. What I say, I think that when I'm home again I'm going to have a cry. Also because I've got to lie down on the bed for a bit to recover'* [Mother of a 2-year-old girl].

Sometimes, parents could not control their own emotions. Especially in the first days of hospitalization, some parents initially chose not to be present during wound care, because they felt overwhelmed by their emotions or had flashbacks of the burn event. Therefore, parents felt it was in their child's best interest if they were absent during wound care. When the other parent was able to take up the role in wound care, parents felt more confident about this decision. A minority of parents that chose to be present, experienced a physical (e.g., fainting) or emotional 'breakdown' during wound care: *'But if she starts crying while they're caring for her wound, then I'm going to as well. That's it really, you try the whole time to be strong and when she starts to cry, I cry with her. Then I can't say: now come on Karen, try to think about the beaches. Then I've forgotten all*

about them too, those beaches. Then I think: now, we won't be on those beaches for a while.' [Mother of a 16-year-old girl].

The theme emotion control also became apparent in parents not present, as they expressed their understanding for the hospital policy because they assumed some parents would not be capable to be present during wound care. However, this was immediately followed by the statement this did not apply to their own situation: *'… there are enough people that are just scared of hospitals, who are scared of the whole medical world. Yes I can imagine if your child ends up there, that it's twice as bad. […] It doesn't have that effect on me, but I've seen around me that it happens. […] But I'm not an unstable parent.'* [Mother of a 14-year-old boy].

5. Being responsive

Identifying the child's needs and being responsive (i.e., adequately address the child's needs) were central to the parental role during wound care. Parents identified the child's need of safety, predictability, comfort, and distraction from pain, and tried to address these needs.

The familiarity of the parent to the child in a new and possibly frightening environment was thought to contribute to the child's feelings of safety, which was especially emphasized for young children. By being present, parents would convey the message that the child was in a safe place and that the child could rely on its parents. Parents also tried to increase predictability by guiding their child through the procedure, for example by explaining what nurses were doing. Comfort was provided by soothing or rocking the child, or holding the child's hand. Parents offered distraction by watching a video or by playing with their child. Parents could also serve as their child's 'spokesperson' in relation to the health care professionals, as they 'knew their child best' in terms of their character and preferences, hereby adjusting the procedure to the child's needs. This father explained intervening on the nurses' strategies during the first procedure, based on the knowledge of his son's preferences: *'That you can also let them know what he likes. Imagine they'd thrown the cup of water over him every day, then we'd probably have said: he really doesn't like that, can't we just do that differently, because you know how your child reacts.'* [Father of a 2-year-old boy].

Parents who were absent during wound care could not address the child's needs at the moment of the procedure, but they emphasized being responsive afterwards. Parents described comforting and supporting the child and adjusting their behavior to the child's needs shortly after being reunited with the child.

6. Gaining overall control

In the course of hospitalization, being present during wound care resulted in an increased sense of control in parents. In contrast, some of the parents that had no opportunity to be present, described a need for control that could not be met by being absent. In case of parental presence, control was gained from the information provided during wound care, a better understanding of the situation and from the idea that the parent meaningfully contributed to the procedure.

Information provision and understanding the situation

Parents expressed the benefits of observing their child's wound healing and the need for an understanding of the situation. Parents got more habituated to the burn wounds over time and seeing the wound closure helped parents to be positive towards the future and increased their sense of control. Parental presence also provided the opportunity to track the progress by taking pictures, that could be used to discuss the progress with the other parent or could be integrated in a photo-book on the child's hospitalization. Parents felt that by seeing the process themselves, reassurance was higher than when health care providers had only told them about the healing progress. Interpreting the wound healing was done with the help of nurses and doctors. It was a source of frustration when health care professionals provided only minimal information on the wound healing. Overall, the healing process provided hope and a sense of control, as parents saw their child improve day-by-day.

By being present parents also thought they could help in interpreting their child's behavior (e.g., whether crying was a display of discomfort or pain) as well as the situation as a whole. The wish to 'know what the nurses were doing to the child' was expressed by parents. Observing the nurses' behavior and the child's reaction led to a feeling of reassurance. Parents' expected imagining worst-case scenarios when they wouldn't have had the opportunity to accompany their child during wound care. Moreover, parents expressed the wish to 'see what their child had seen', to be better able to later talk about this with their (older) child. Being present was therefore thought to be contributing to the processing of the event for the child as well as the parent.

Some parents not allowed to be present expressed they were glad not being confronted with the burn wounds, which helped them to stay positive during the distressing hospitalization period. Other parents expressed the need to understand and know what was happening during wound care procedures and were interested in the wound healing process. By not being admitted to wound care, the wounds of their child stayed 'a secret' until a short period prior to discharge. One of the mothers

described the discomfort of not having seen the burns of her son: *'Then I think: it's awful really that I wasn't able to see what the scar's like, where it starts, where it ends. And he did. He saw his legs in the morning. So he's got to tell me, if he feels like it, what his legs are like. And not once has he done that or wanted to'* [Mother of a 13-year-old boy]. Information provided by the nurses and child life specialist after wound care was, however, valued by all parents.

Perception of meaningful contribution

During hospitalization, most control was out of the parent's hands. Being present during wound care was regarded as one of the few things parents could do for their child: *'You can't take the pain away, you can't take away what happened. The only thing you can do is be with your child'* [Mother of a 2-year-old boy]. Some parents contributed to wound care by washing or bathing their child, which led to a sense of empowerment: *'While they were caring for the wound, I could just hold the shower head over his hair and then what I could do as a parent, was just wash him. That's a nice thing to do and that stays with you. Then it gives you the feeling that you're looking after him instead of just standing there looking on'* [Mother of an 8-year-old boy]. This suggests that a continuation of the parental role was valued by parents.

Most parents considered their role during wound care valuable and meaningful. Validation of the belief that their presence was valuable was found in their child's reactions: searching for physical contact with the parent, decreased distress over time, or the child's explicit wish for their parent's presence. However, a minority of parents questioned the added value of their presence. This was related to the (anticipated) behavior of their child with the parent present. One mother expected her child to show more resistance when she would be present, while another mother thought a complicating factor was her adolescent child being conscious of the mother's emotions. She reported her child trying to hide her suffering to some extent to prevent upsetting the parent.

7. Child- and parent- focused care

In all three burn centers, parents had a great trust in health care providers. A comparison was often made to the care provided at the Emergency Department of a local hospital, in which parents were not convinced by the capabilities of the staff and doubted whether the child received the best care. Upon arrival in the burn centers, parents felt relief when feeling 'their child was in good hands'. Parents felt that care in general as well as during wound care was adjusted to the child and parent.

During wound care, parents appreciated the staff's involvement with and focus on the child. Initiating contact with the child in a friendly, playful, and age-appropriate manner was regarded helpful for their child to be at ease. Also, staff paying attention to the child's reaction to specific procedures was appreciated. Explanation and predictability of the procedures, and adjusting the pace to the child's need was considered beneficial. Parents thought the distinction between the nurses and child life specialist (not involved in actual wound care) was relevant, as the child life specialist could be regarded a 'safe person'. The child life specialist also paid attention to the parent's emotions and needs. Parents identified the need for control in (older) children. Adolescents sometimes helped to remove the bandages or clean the wounds, and needed information about the length of the procedure. Providing children a choice also helped (e.g., with which body part to start the procedure). Additionally, rewarding the (younger) child after the procedure was considered beneficial.

Parents who were not present because of hospital policy also showed a very strong trust in the professional skills of nurses and the child life specialist. Over time, they observed their child to become more at ease with the staff. Hearing back how their child had been doing during wound care increased parents' trust and appeared to result in less stress feelings during subsequent wound care procedures.

Looking back at wound care after discharge

Three to six months after discharge, overall, parents thought that either their presence or absence had been in their own and their child's best interest. Parents that had been present described being glad having had the opportunity to support their child and provide safety. Also, they mentioned perceived benefits for themselves, such as increased control and a better understanding of what their child had been through that opened avenues to talk about the event: '*Now, she still mentions it sometimes, that cleaning and peeling the skin off. And then she asks me: 'do you remember there used to be a big hole there?'. And then I say: 'yes, I remember, you can still see the difference there', we know that. We were there. And otherwise you don't have that. So I do think that's an advantage.'* [Mother of a 16-year-old girl]. On the other hand, parents described vivid memories in terms of their child's pain, suffering and the view of the burn wounds, although these could not be classified as intrusive for most parents. Only two parents reported intrusive thoughts concerning the wound care procedures. Still, in their view, the perceived benefits for their child outweighed the disadvantages for the parent.

For parents that had not been allowed present during wound care, the strong trust in the health care professionals again emerged as the most important theme. Although

the majority of the parents ultimately thought their absence had more advantages than their presence, about half of the parents mentioned they would have preferred to decide themselves. One mother also expressed the burden of not having seen her adolescent son's wounds in the first weeks of hospitalization. Because her son did not share his experiences on his wounds and the wound care, both his parents felt unable to relate to his experience and to adequately support their son on this issue after discharge. Memories of the wound care primarily concerned the child's distress when the nurses and child specialist entered the room and parents had to leave the child prior to the procedure. For three out of four parents, seeing the wounds for the first time shortly before discharge was 'shocking', while one parent described a more neutral feeling.

Integrative model of parental presence during wound care

Based on the themes derived from the interviews, an integrative model was developed that represents important aspects when considering parental presence during wound care (Figure 1). The parents' own emotions and ability to control these, and their ability to be responsive to the child's needs are considered essential and interrelated facets. By controlling their own distress reactions, parents may increase their emotional availability, and thereby their responsiveness to their child. Responsiveness may also increase emotion control, by a focus on the child, instead of parents' own feelings. Both emotion control and responsiveness are assumed to be related to gaining a sense of control, which is a central element in this model. Parental feelings of control concern an ability (e.g., acquiring a meaningful role during wound care), as well as a need (e.g., wanting to be informed). The process depicted in the model has a dynamic nature. This entails that aspects central to wound care may change on a daily basis. For example, the belief that parental presence is in the best interest of the child may change depending on the parental experiences of wound care the previous day. The model also gives direction for burn care professionals in supporting families in the context of wound care procedures.

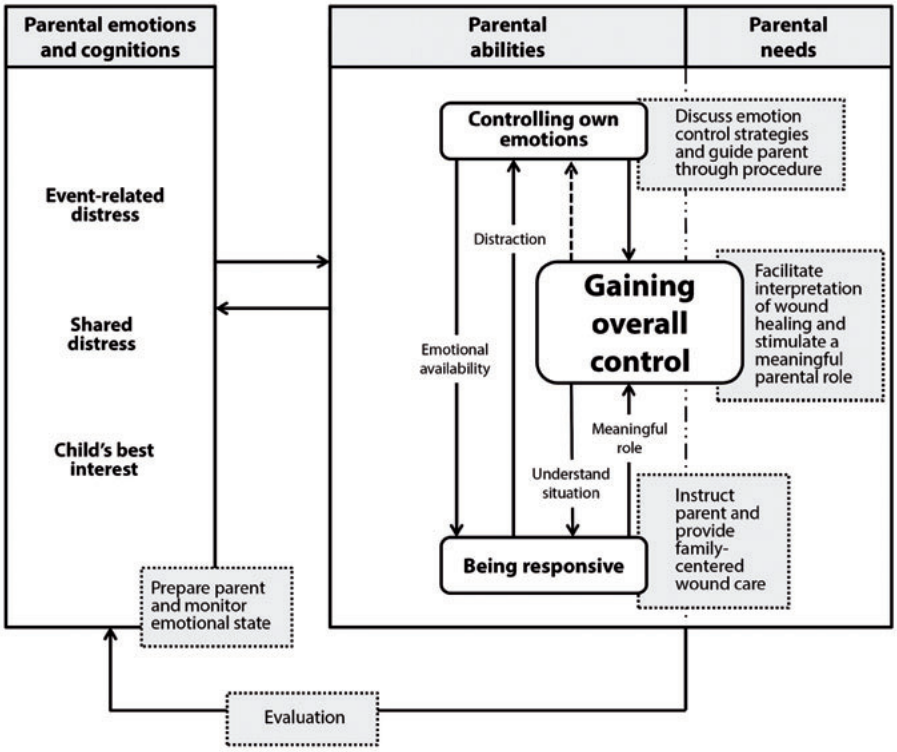

Figure 1. Integrative model of parental presence during their child's wound care procedures. Dotted-lined squares depict the role of burn care professionals.

Discussion

The purpose of this study was to describe and explain parents' experiences of presence or absence during their child's wound care procedures and to identify aspects that could be monitored by professionals. Based on qualitative interviews, an integrative model was developed, representing the aspects relevant to parental presence during wound care. This model gives directions for ways in which burn care professionals can enhance beneficial outcomes of parental presence (the blocks with a dashed border in Figure 1 summarize the professional's role).

Many parents reported that they wished to attend their child's wound care, but that its distressing nature and their emotions related to the burn event influenced their decision. The emotional state of the parent prior to the first wound care appears to be

a critical factor, as a small number of parents described overwhelming emotions that made them to decide not to be present initially. Also, observing the child's distress during the procedures and feeling hopeless in not being able to take away the pain from the child was reported to influence a parent's decision to be present at subsequent wound care procedures. Many parents felt that the benefit of their presence for their child outweighed the disadvantage of their own distress, except when parents' own emotions were that overwhelming that presence was not in the child's best interest. Preparation of the parent and monitoring and evaluation of the parent's state are considered important to support the parent.

In order to be present and to meet the needs of the child, parents in the current study considered control of their emotions desirable. Parental control of emotions will likely influence parental responsiveness during wound care (Brown, Kenardy, de Young, & Kimble, 2017). Vice versa, being responsive and focus on the child may serve as distraction resulting in reduction of emotions. Findings are in agreement with previous studies that described parents wanting to 'stay strong' and 'put on a brave face' during hospitalization (McGarry et al., 2015), and wound care in particular (Morley et al., 2017). According to social referencing theory (Feinman, 1982), by not expressing negative emotions such as fear or sadness as a parent during wound care, the child may interpret the situation more positively. This is especially salient to young children, who are more dependent on their parents when interpreting new and possibly frightening situations. However, control of emotions can be difficult in case of such a strong situation as seeing one's child suffer. Therefore, although parents indicated that the temporal suppression of their own emotions helped in supporting their child, they reported the need to express their emotions *after* wound care at a more appropriate time. Literature suggests that temporary suppression combined with later expression (i.e., emotion modulation) is associated with better psychological outcomes compared to emotional suppression without later expression (Compas et al., 2014).

Being present during wound care contributed to a sense of control in parents in two ways; by being informed and understanding the situation, and by experiencing a meaningfully contributing parental role. The parents' wish to be informed about their child's hospital care was also reported in previous studies (Engström, Dicksson, & Contreras, 2015; Power & Franck, 2008). In case of parental absence during wound care, it was not possible to observe the child's behavior and the wound healing, or to take up a meaningful role, thereby reducing opportunities to gain control. In these cases, adequate information provision and trust in burn care professionals were important factors, that also appeared to contribute to feelings of reassurance. Nevertheless, some

parents expressed their regret of not having seen the wounds and not knowing what their child had gone through, leaving them with feelings of having missed a principal part of the process, and preventing them to discuss this with their (older) child.

An essential aspect of the ability to be responsive, that in turn added to parents' overall sense of control, was whether parents perceived their behavior and role during wound care as meaningful and valuable. Parents' perception of a meaningfully contributing role entail self-efficacy beliefs, i.e., "parents' beliefs in their ability to influence their child and the environment in ways that would foster the child's development and success" (Jones & Prinz, 2005, p. 342). Research in another pediatric population confirmed higher parents' self-efficacy beliefs in their ability to keep their child calm during invasive procedures to be related to parents' experiencing lower negative affective reactions at the time of the procedure (Harper et al., 2013). This may be particularly salient in the burns population as a prior study reported that parents may feel deskilled (Horridge, Cohen, & Gaskell, 2010). In the current study, when parents did not perceive their role as valuable, i.e., when they felt like a passive bystander (in adolescent patients), this was reported to have a detrimental effect on their wellbeing. Stimulating self-efficacy beliefs may improve outcomes of parental presence.

The results quite unequivocally indicated that although wound care procedures were a stressful experience for parents, parents wished to be present. The stressful nature has also been reported in previous studies (McGarry et al., 2015; Morley et al., 2017; Smith et al., 2011), with one of these studies reporting the occurrence of parental intrusions related to wound care (McGarry et al., 2015). Parents in the current study reported emotional memories concerning wound care after discharge, but these memories were not judged as intrusive or troublesome by most parents. The non-intrusive nature of the wound care memories in the current study is perhaps due to the child-focused and calm atmosphere during wound care, the role of the nurses and particularly the role of child life specialist, who exclusively focused on the child's and parent's wellbeing during wound care procedures. An aspect that might explain why parents prefer to be present relates to their perception of increased predictability and control, seeing the wound healing progress and the continuation of their parental role. These aspects may predominate their own distress and might lead to more positive appraisals of the situation. Although from the present study no conclusions can be drawn in terms of the potential risk of parental presence during wound care of eliciting traumatic stress reactions, minimization of potentially traumatic aspects of wound care (e.g., loss of control) is warranted.

Of notice, the age of the child may be a factor of significance when considering parental presence during wound care procedures. Based on the young child's reactions and parental feelings associated with leaving the room prior to wound care, it seems that the balance tips in favor of parental presence. With school-aged children and adolescents, presence of the parent needs to be discussed not only with the parents but also with the child.

Clinical implications

The results of the current study indicate several recommendations for clinical practice. Strategies to support the child and parents may be carried out by any team member involved in wound care, depending on the burn team's composition. Burn care professionals could offer procedural preparation to decrease anticipatory anxiety and feelings of uncertainty. They can do this by addressing the procedures' process and by discussing the role of the parent during wound care. The parent's emotional state may also be assessed prior to wound care and it may be discussed which parent will be present. Ideally, procedural preparation and assessment should be provided before the first wound care procedure (shortly after admission), as research has shown parent's psychological state to be related to the parent's behavior during the first procedure (Brown et al., 2017).

Professionals could try to help in reducing the intensity of parental emotions by creating calmness and trust in a positive atmosphere and by providing detailed information and guiding the parents through the procedure. Prior to wound care, the role of parental emotions may specifically be discussed by addressing the influence of parental emotions on the child's distress, as well as possible emotion control strategies to be used during wound care (e.g., focus on positive outcomes, focus on the 'here and now'). Moreover, the professionals can use instruction or modeling to show parents how to guide the child through the procedure, and emphasize that when emotions appear, they will help the parent and child to overcome this situation. After wound care, parents should be offered the opportunity to express their emotions and concerns. Moreover, the procedure in terms of the parental role and influence on the child should be evaluated.

Reports of parents that were present during wound care indicate that burn care professionals may inform parents and enhance parental feelings of control by helping parents interpreting the wounds. When parents cannot observe the situation and the child's behavior directly because they are not present during wound care, burn care professionals have an essential role in informing parents about these issues after wound

care. Furthermore, burn care professionals may enhance parents' self-efficacy beliefs and skills by modeling responsive behavior, reinforcing parents' helpful behaviors, emphasizing the value of their presence, explicitly addressing the influence of parental behaviors on their child, and by offering parents concrete tasks, such as bathing the child.

Strengths and limitations

With the inclusion of burn centers with different policies on parental presence, the current study benefits from the perspectives of parents who were present and parents who were absent during wound care. Another strength of the study is the large and diverse sample, including fathers and parents of school-aged children and adolescents. Still, the relatively high proportion of native Dutch parents and parents with a high education in the current sample may not be representative of the entire population of families that are admitted to the Dutch burn centers. It is unknown whether findings are generalizable to parents who experience substantial language difficulties (such as recently immigrated families). Also, findings must be read keeping in mind the wound care contexts of the particular burn centers under study, which are often characterized by the presence of two nurses and one child life specialist. The composition of the team carrying out the wound care procedures, is a relevant topic for further study. In addition, the current findings elicit relevant questions that should be addressed in future quantitative studies, such as whether burn severity is related to parents' experiences and after how many procedures parents feel more comfortable with the process. Last, this study was carried out in children that did not require Intensive Care (IC) or after IC. Therefore, findings may not be generalized to wound care procedures carried out during the IC-phase.

Conclusion

Overall, findings suggest that parents should be offered the choice for presence or absence during wound care. Despite the undeniable distress evoked by being present during wound care procedures, the benefits of being present often exceed the disadvantages in terms of the ultimate gain of control. This study suggests that parental capabilities such as emotion control during the procedure in order to be there for the child and consequently, to act as a responsive parent, foster beneficial outcomes of their presence. Central aspects to consider for professionals therefore include preparing the parent, assessing the parent's emotional state, instructing and guiding the parent through the procedure, explaining the wound healing progress,

stimulating a meaningful parental role and evaluating the procedure. Parents failing to cope with the situation could be offered room to withdraw, be it temporarily or definite. In these cases, good communication and adequate information on the wounds' progress and child behavior during procedures offered by professionals are imperative.

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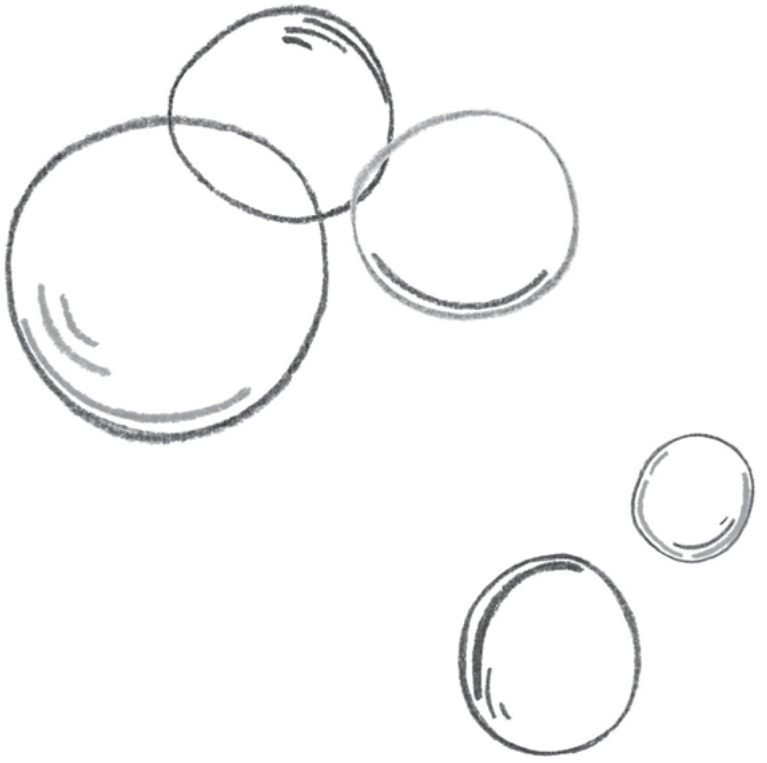

Chapter 7

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.

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, Kassam-Adams, Alderfer, Christofferson, & Kazak, 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, van de Schoot, Geenen, & Van Loey, 2018; Landolt, Buehlmann, Maag, & Schiestl, 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.

Adjusting to burns can be challenging (Jones, Buchanan, & Harcourt, 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 & Van Niekerk, 2011; Williams, Reeves, Cox, & Call, 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.

Method

Participants and procedure

The study is part of a larger qualitative research project in which child, parent (Egberts, de Jong, Hofland, Geenen, & Van Loey, 2018) and nurse (de Jong, Egberts, Hofland, & Van Loey, 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 contacts 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 (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% (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 seven months after discharge from the hospital (range four to 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 that 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, heath, 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 ambiance 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 hypervigilant 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 (for example 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 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, Kenardy, & Hendrikz, 2008; Ehlers, Mayou, & Bryant, 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, Kenardy, & Dow, 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, Holmes, & Brewin, 2001; Holmes, Grey, & Young, 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, Opmeer, Boer, Mannarino, & Lindauer, 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, O'Donnell, Evans, Kazantzis, & Creamer, 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, Boeije, Jongmans, & Kleber, 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, de Jong, et al., 2018). 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, Salmon, Sinclair, & Davidson, 2007). A decrease in these appraisals and safety-seeking behaviors have been shown mechanisms in lowering child posttraumatic stress in cognitive-behavioral therapy (Meiser-Stedman et al., 2017).

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

	Implications for care
Trauma	
Appraisals of accident and hospitalization	• 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	• 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	• Target appraisals in cognitive therapy to decrease posttraumatic stress
Hospitalization phase	
Parental presence during wound care	• 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	• 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	• 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	• Educate parents about coping assistance • Provide opportunity for parents to express worries about the child's recovery
Peer support	• Offer opportunities for peer support (e.g., support groups or burn camps)

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, van der Heijden, van Son, van de Schoot, & Van Loey, 2011; Lau & 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, Boeije, Jongmans, & Kleber, 2011; Lau & 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 & Roesch, 2007; Roth & Cohen, 1986). Specifically, avoidant coping has been associated with more posttraumatic stress (Marsac et al., 2017; Stallard, Velleman, Langsford, & Baldwin, 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 strengthen adaptive responses that are already present, positive psychosocial outcomes may be fostered.

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Chapter 8

Parents' memories and appraisals after pediatric burn injury: A qualitative study

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Abstract

Background: Being confronted with pediatric burn injury is an emotional experience for parents. **Objective:** The aim of this study was to qualitatively examine the content and nature of parents' memories and appraisals of their child's burn injury. **Method:** Approximately three to six months after the burn event, semi-structured interviews were conducted with parents of 18 children (0-16 years old) that had been hospitalized for a burn injury. Thematic analysis was carried out to obtain themes. **Results:** Parents' emotional memories reflected the threat of the injury and the child's suffering. Intrusive memories had a visual and sometimes auditory nature, and were predominantly related to the threat of the injury. Later appraisals of the burn injury and its consequences included negative appraisals of increased vulnerability, responsibility, prolonged suffering and (risk of) permanent change, as well as positive appraisals with a focus on recovery. Emotions commonly reported were fear, sadness, guilt, and relief. **Conclusions:** This study yielded a broad range of appraisals and emotions in parents' memories as well as in their adjustment process. Attention to these appraisals and emotions in the pediatric burn care setting and in interventions for parents may enhance positive outcomes for the family as a whole.

Introduction

"It might have scarred his skin, but it's scarred my brain." As illustrated by this quote of a mother reported in a study of Mason (1993), the emotional impact of pediatric burn injury on parents has long been recognized. A substantial number of parents experience symptoms of posttraumatic stress disorder (PTSD) after their child's burn injury: within the first month, 22 to 50% of the parents experience clinically relevant levels of posttraumatic stress. This decreases to 7 to 25% one year after the injury (Bakker, van der Heijden, van Son, & Van Loey, 2013; De Young, Hendrikz, Kenardy, Cobham, & Kimble, 2014; Egberts, van de Schoot, Geenen, & Van Loey, 2017).

Different experiences during a child's injury event and subsequent medical procedures may evoke posttraumatic stress reactions in parents, such as re-experiencing symptoms (Kazak et al., 2006; Price, Kassam-Adams, Alderfer, Christofferson, & Kazak, 2016). A preliminary study by De Young and colleagues (2014) indicated that parents most often reported the actual burn injury (47%) as most traumatic, followed by wound care procedures (18%), and a combination of the burn event and wound care (15%). The cognitive model of PTSD (Ehlers & Clark, 2000) suggests that the nature of traumatic memories and appraisals of the traumatic event and its aftermath play a key role in the way people process and adjust to trauma. Qualitative research may be used to get more in-depth insight into these two potential targets for therapeutic interventions.

Thus, first it is important to examine how different aspects of pediatric trauma are reflected in parents' (intrusive) memories. A way to examine parents' memories is to obtain thorough information about 'hotspots'. These are the worst moments in memories that cause the highest levels of emotional distress (e.g., Grey, Holmes, & Brewin, 2001; Holmes, Grey, & Young, 2005). Research in populations of adult patients with PTSD has shown that the majority of re-experienced moments could be matched to a hotspot, and that hotspots contained a wide range of emotions (e.g., fear, sadness, anger, and shame) (Grey & Holmes, 2008; Holmes et al., 2005). In response to their child's trauma, parents may also respond with a variety of emotional reactions (Holt, Cohen, Mannarino, & Jensen, 2014), not only shortly after the traumatic event, but also when they recall the event later or consider its long-term impact.

Besides disturbed memories, negative appraisals of the trauma and its sequelae are considered to be a risk factor for the development of a continuous posttraumatic sense of threat (Ehlers & Clark, 2000). These appraisals can be related to the event itself, for example when someone negatively appraises the fact that the traumatic event happened and expects that a similar event will take place again. Appraisals may also

be based on trauma sequelae. For example, other people may be unsure how to react and therefore rather avoid to discuss the traumatic event, which might be interpreted as a sign that nobody cares. The sense of current threat that arises can be external (e.g., the world is perceived as dangerous) as well as internal (e.g., a threat to seeing oneself as a worthy person). In addition, negative appraisals are proposed to be maintained by maladaptive behavioral strategies such as avoidance and cognitive strategies, such as rumination (Ehlers & Clark, 2000).

In order to inform the development of programs to prevent the development of long-term posttraumatic stress symptoms and to offer support that fits with the traumatic nature of pediatric burn injury, an in-depth qualitative examination of parents' memories after their child's injury, the associated emotions, and the way they appraise the injury and related events is needed. Therefore, the aim of this study was to qualitatively examine parents' memories, appraisals, and associated emotions, in relation to their child's burn injury.

Method

Participants and procedure

The current study is part of a larger project in which parents' experiences after pediatric burn injury were examined. The first part of the study was based on interviews conducted during the child's hospitalization, with a specific focus on parents' experiences of their presence or absence during child wound care procedures (Egberts, de Jong, Hofland, Geenen, & Van Loey, 2018). The current study analyzes interviews with parents three to six months after the burn event. Data were collected in the three Dutch burn centers, from December 2014 until June 2016.

Parents were eligible to participate if their child was younger than 19 years old, required hospitalization for a burn injury, and had undergone at least one wound care procedure. A local researcher approached parents while they were still in the hospital, explained the purpose of the study, and provided additional written information. Purposeful sampling was used to achieve a diverse sample (for example in child age, gender, burn severity, and burn type). All participating parents provided informed consent. Parents who participated in the first interview were contacted by the interviewer three to six months after the burn event and were asked whether they were willing to participate in a follow-up interview. Parents completed a questionnaire about their socio-demographic background. Child- and burn characteristics were obtained from the medical file.

Parents of 18 children participated in the interview three to six months after the burn event. The interviews were conducted at the family's home or in the burn center, in the case of check-up contacts. Six interviews were conducted with both parents, 11 interviews were conducted with just the mother and one interview was conducted with just the father. The child- and burn-characteristics of the sample are displayed in Table 1. The mean age of participating parents was 37 years (range: 25-54) for mothers and 41 years (range: 32-46) for fathers. Parents' highest obtained educational level was classified as low (elementary school, technical and vocational training until the age of 16: 21% of the parents), middle (technical and vocational training until the age of 18: 25% of the parents) or high (technical or vocational training for ages 18 and older or university: 54% of the parents). Most parents were currently employed (83%) and the majority of children lived in a two-parent household (83%).

The study was conducted according to the principles of the Declaration of Helsinki (revision, Fortaleza, Brasil, 2014). The Ethical Committee of the Faculty of Social and Behavioral Sciences of Utrecht University approved the study (FETC15-085).

Table 1. *Child- and burn characteristics (n = 18)*

	M	*SD*	Median	Range
Age (years)	6.9	5.8	3.6	0-16
TBSA (%)	9.7	7.6	7.5	3-34
Length of stay hospital (days)	18.3	13.8	11.0	4-50
	n	%		
Gender (boys, girls)	8, 10	44, 56		
≥ 1 surgery during initial hospitalization	10	56		
Burn type				
Scald	12	67		
Flame/fire	5	28		
Electrical	1	5		

Note. TBSA = estimated percentage total body surface area affected by partial- or full-thickness burns.

Interviews

Semi-structured, face-to-face interviews were carried out by a trained female researcher/psychologist (first author). Interviews were digitally recorded and lasted, on average, 57 minutes (range: 41-78 minutes). An interview guide was used to broadly structure the topics to be addressed (see Table 2 for example questions). Questions were open-ended and follow-up questions were used to further explore experiences brought

up by parents. The main topics in the interviews were parents' memories of the burn event and hospitalization. These memories were further explored by using probing questions to elicit the memories' content and associated emotions, cognitions, and behaviors. After the ninth interview, a specific question was added, which asked parents to identify the 'worst part' in their memory of the burn event and/or hospitalization period. Other topics in the interview guide were the impact of the child's burn injury on the parent's life, and the way parents coped with their child's injury. To determine the appropriateness and workability of the interview guide, two pilot interviews were carried out. The interview guide was continuously adapted based on information that was obtained from the interviews. The interviewer created field notes to record issues important in interpreting the interview information (such as non-verbal behavior and contextual factors). After the interview, all parents were reminded of the availability of psychosocial aftercare in case they had remaining concerns, regardless of the interviewer's perception of the need for support.

Data analysis

Data were analyzed using thematic analysis, including the constant comparison method (Boeije, 2010). The interviews were transcribed verbatim and names were replaced by pseudonyms. Transcripts were analyzed within the software program MAXQDA 12 (2016). In the first step of the coding process, the first and last author independently coded the first five interviews. Interviews were read line-by-line and meaningful fragments were selected and assigned a code that reflected the fragment's content. Differences in coding were discussed until consensus was reached. The remaining interviews were coded by the first author and discussed in detail with the last author. In the second step, relationships between codes were discussed and codes were combined into overarching themes.

Table 2. *Expert from interview guide with example questions relating to parents' memories, appraisals, impact and coping after pediatric burn injury*

Memories and appraisal of burn event and hospitalization
In which way do you look back on the accident that caused the burn injury/the hospitalization period/the wound care procedures?
What do you recall when you think about the burn injury/the hospitalization period/the wound care procedures? Which emotions do you experience when you recall these events?
Recalling the accident and the hospitalization, can you identify the worst part in your memory?
Have you experienced, or do you still experience intrusions? (e.g., vivid, involuntary memories of the events that happened, that suddenly arise. These are not the moments in which you voluntary or deliberately think about the events. Intrusions may come in various forms, for example visual, auditory or olfactory)
Impact of the injury
Can you describe the period after discharge and any special moments in this period?
Can you describe how the injury has impacted you?
Have you noticed changes in your child after the injury?
Have you noticed changes in the family after the injury?
To what extent do you avoid reminders of the injury?
To what extent do you talk about the injury?
Coping with the injury
What helped you cope with your child's injury?
How did you support your child in the aftermath of the injury?

Results

Parents' reflections of the burn injury and its aftermath were categorized into memories of the injury event and hospitalization (category 1) and later appraisals of the burn injury and its consequences (category 2). Within these categories, six themes were identified, that are described in detail below. Table 3 provides a summary of the appraisals in relation to the child's burn injury. For each theme, appraisals are presented in terms of emotions, their content and the situation that is appraised, and examples of appraisals are shown.

Emotional memories and intrusions

Within the category 'emotional memories and intrusions', two themes were present: threat of the injury and the child's suffering. These themes will be reported in detail below.

Threat of the injury. Parents reported vivid memories of the burn accident and first aid procedures, associated with strong emotions, such as feelings of shock, fear, and panic. They could often describe their memories in great detail. Parents remembered particularly well the moment they realized the severity of the injury: "*For me it's the moment I realize that that cup, that that's boiling water. That I stand there and I, sort of realize, he's now got boiling water over him.*" [mother of a 2-year-old boy]. Also, they remembered their uncertainty about the severity of the child's injury. Especially parents who were not present at the time of the accident, but were informed by others, said it was hard not knowing how serious the situation was and felt helpless as a result: "*You've lost your grip, you don't know exactly what happened, but something awful has happened, life-threatening, and you're not there. You're not where it's happened. You can't judge the situation. So you can't reassure or protect your child and that's the worst moment.*" [mother of a 13-year-old girl]. Several parents mentioned that, at some point, they were afraid their child would not survive the accident. Given the highly stressful uncertainty about the child's medical status and potential outcomes, parents looked for cues or information that their child would be alright. Several parents mentioned that the moment they entered the burn center was a turning point, because they knew that burn staff had the expertise to treat their child, which they thought had been lacking in local hospital staff.

Parents predominantly reported visual memories, including images related to the cause of the injury (i.e., water falling over their child, their child in flames, or their child being electrocuted), the face of their child during the accident (i.e., in panic, in pain, or crying), how the wounds looked shortly after the accident, and their child being intubated. Several parents also reported an auditory memory of their child's screams during the accident: *"I still think the worst moment was his screaming. Because of course I was upstairs and he was downstairs. I'll never forget it, that was a scream that went right through you. It was absolutely horrible."* [mother of an 8-year-old boy]. Some parents said that shortly after the injury, they could hardly think or talk about what happened without experiencing intense emotions, but this became easier over time.

Most parents reported they had re-experienced certain moments of the accident and first aid during the first weeks after the injury. Intrusive memories dissipated with time for most parents, but a few parents still experienced these at the time of the interview. Visual moving or static images were most common, but sounds were sometimes also re-experienced. Parents said these intrusions were accompanied by the same emotions they had experienced during the actual event (e.g., fear), and sometimes other emotions (e.g., sadness) as well. Specific triggers of intrusive memories included

the sight or sound of an ambulance, trauma helicopter, the place of the accident, a TV report of a similar event, and seeing the child's scars, although intrusive memories also occasionally seemed to come out of the blue.

The child's suffering. When recalling the hospitalization period, most parents thought of their child's suffering, in terms of pain, distress, sleeping problems, itch, and the inability to drink or eat. Parents expressed great sympathy and sadness. Not being able to relieve their child's suffering made them feel helpless. When parents recalled the wound care procedures, they also remembered the child's pain and distress. However, they also emphasized the good care they had received and positive feelings due to wound healing.

Again, emotional memories appeared to be mainly visual in nature, although some were primarily described in terms of thoughts. For the majority of parents, memories of wound care did not come to mind involuntary or spontaneously in their daily lives. Only one mother reported visual and auditory intrusions of wound care, and she re-experienced feelings of powerlessness. Of note, this mother also reported intrusive images and sounds related to the accident, and had had a previous traumatic experience.

Appraisals of the burn injury and its consequences

The category 'appraisals of the burn injury and its consequences' contains four themes. The appraisals that were identified in parents' reports were also linked to certain behavioral or cognitive strategies, that will be described in relation to these appraisals.

Increased vulnerability. Nearly all parents of young children reported an increased awareness of their child's vulnerability and were afraid an accident would happen again. One mother reported 'flash-forwards' in which she had intrusive images of something bad happening to her child, such as hot food falling on her child and causing injuries. Especially parents of young children had become more cautious. Safety behaviors included keeping hot drinks far away from their child, not allowing their child into the kitchen, or monitoring other people's behavior around hot substances: "*I'm really very cautious when it comes to the kettle, when it comes to hot tea and things like that. I can find it quite frightening. And also towards her, reacting more impatiently than necessary. I don't let her climb while I'm cooking and I also don't want her coming into the kitchen while I'm cooking.*" [mother of a 1-year-old girl]. Some parents reported hypervigilance, avoidance of potentially dangerous situations, or agitation in situations where they

feared an accident might happen again. However, a few parents reported awareness of the risk of overprotecting their child and therefore tried not to be too restricting.

Responsibility. Parents reported appraisals and emotions regarding the responsibility for, or possible prevention of, the child's injury. Several parents described a process of trying to differentiate rational thoughts concerning their own responsibility for the injury from emotions such as guilt (e.g., they reasoned that their child's injury resulted from an accident, but still felt guilty). *"Actually I couldn't really do anything about it. Yes, of course, you can always do something about it, I mean, if you'd been more careful then you could have avoided it, say. But you don't do it on purpose. It's more like it's just stupid. But if I see her scars now, then I already blame myself less, but in the beginning I blamed myself more."* [mother of a 1-year-old girl]. It was difficult for parents to deal with feelings of guilt or thoughts such as 'I let this happen'. In case someone else was present during the child's accident, most parents emphasized the accidental nature of the injury and did not assign blame. This was especially the case when it concerned the other parent or another family member. One parental couple expressed more ambiguous feelings towards the person present during the child's injury. Although they acknowledged that it had been an accident and no one was to blame, they still experienced anger, especially since the people involved showed little expression of regret or remorse. Parents noticed that other people were also concerned with perceived responsibility for the injury. Some parents perceived reactions of others regarding the parent's or someone else's responsibility as supportive (e.g., 'this could have happened to anyone') and others found it hurtful (e.g., 'this is a lesson learnt for you').

Prolonged suffering and (risk of) permanent change. Some parents reported that it was hard for them to be confronted with negative consequences of the injury in everyday life, for example, in terms of the child's permanent scarring, physical impairments, infections, negative mood, or anxiety. A few parents reported feelings of loss and grief due to the difference between the pre- and post-burn situation and found it difficult to accept these changes. The general realization of everything that had happened to their (young) child and family came to mind at certain times, which was often associated with sadness: "*It also casts a shadow over the whole year. For instance if someone asked or asks how it's going. Someone I haven't spoken to yet, the first thing I think of is, do you know what we've been through. And it dominates everything actually. If I think about last year, the only thing I can think about is this.*" [mother of a 1-year-old boy].

Parents said that the development of scars evoked feelings of helplessness, and that unpredictability and uncontrollability over scar development were difficult to deal with. Several parents reported uncertainty about future outcomes and worries about the future looks of the scar, reactions of other people, physical complications, or the child's behavioral and emotional response at a later age.

Focus on recovery. When reflecting on the accident and hospitalization, some parents particularly focused on the child's and family's current positive situation. Despite the stressful nature of the past experiences and associated negative emotions, some parents also described the presence of positive emotions, such as relief and gratitude, and they focused on positive outcomes and the child's recovery. They mentioned, for example, that their child had not developed any fears, was developing normally, or had only minor scarring: "*So it did turn out alright, so you can go through something that at that moment is totally awful. You feel like everything stops. But that's not the case, our child only has a scar on his arm or whatever, you know? Everything has just carried on.*" [mother of a 2-year-old boy]. Some parents mentioned that they 'had been lucky' or 'it could have been worse' as in hypothetical or actual cases. They said that seeing their child do well and focusing on positive experiences strengthened their own recovery. In addition, almost all parents expressed positive appraisals and feelings of gratitude when they reflected on the medical care and support from family, friends, and the hospital staff.

Table 3. *Appraisals, emotions, and situation that is appraised, categorized in six identified themes, including appraisal examples*

Appraisals of the burn accident and hospitalization	
Theme 1: (Life) Threat	
Emotions	Fear, shock, horror, helplessness
What is appraised	Witnessing the burn event and first aid Being informed about the burn event The child's chance of survival The (uncertainty of) injury severity The appearance of the wounds
Examples	"My child's life is in danger" "My child's physical health is threatened"
Theme 2: Suffering	
Emotions	Sadness, helplessness
What is appraised	Child reaction during accident Child pain and distress during hospitalization The parent's role in reducing child pain and distress
Examples	"My child suffers" "I cannot do anything to relieve my child's suffering"
Appraisals of the burn injury and its consequences	
Theme 3: Vulnerability	
Emotions	Fear
What is appraised	The fact that burn injury happened The likelihood of re-injury
Examples	"My child and my family are vulnerable" "The world is dangerous" "An accident can happen any time"
Theme 4: Responsibility	
Emotions	Guilt, anger
What is appraised	Parent's own responsibility Other people's reactions about perceived parent's responsibility Other person's responsibility
Examples	"I caused the injury" "I could have prevented the injury" "They think the injury was my fault" "(They think) I am a bad parent" "Someone else is to blame for my child's injury"
Theme 5: Prolonged suffering and (risk of) permanent change	
Emotions	Sadness, grief, fear
What is appraised	Child physical and psychological consequences (e.g., pain and itch) The fact that burn injury happened The difference from the preburn situation (Risk of) scars

Examples	"My child suffers" "My child did not deserve this to happen" "My child will never be the same again" "My child has been damaged by the injury" "My child will be scarred for life" "My child's physical health is threatened"
Theme 6: Focus on recovery	
Emotions	Relief, gratitude, hope
What is appraised	The child's recovery Absence of child physical and psychological problems Information from burn care professionals Hospital care Social support Alternative outcomes Expectations about the future
Examples	"My child will be alright" "Others care about us" "My child is in good hands" "My child is doing well" "It could have been worse" "We have been lucky" "My child will have a positive future"

Discussion

The current study examined the nature and content of parents' memories after pediatric burn injury and the way parents appraise this traumatic experience and its consequences. This offers insight into the traumatic aspects of the injury event, hospitalization, and aftermath, and provides avenues to improve support for parents after pediatric burn injury.

Parents reported vivid and emotional memories of the child's injury event and hospitalization (themes 1 and 2), and some of these had an involuntary, intrusive nature. High arousal during an event leads to enhanced encoding of the memory, which is suggested to increase accessibility of both voluntary and involuntary memory (Berntsen, 2010; Hall & Berntsen, 2008). The visual and auditory involuntary memories reported by parents were mostly memories of the accident and first aid, while memories about the hospitalization and procedures such as wound care were described more in terms of voluntary emotional memories. Parents' intrusive memories were often characterized by a sense of perceived (anticipated) threat of injury. This is consistent with the 'warning signal' hypothesis, which suggests that intrusions often represent stimuli that mark the onset of the trauma or of moments with the largest emotional impact (Ehlers et al., 2002). Fear, sadness, and helplessness seemed to be the most prominent emotions in parents' memories. In previous research, a variety of emotions has been identified in hotspots of PTSD patients, with fear, sadness, anger, and surprise most commonly reported (Grey & Holmes, 2008; Grey et al., 2001; Holmes et al., 2005), which was confirmed in the current study.

In the present study, parents reported no isolated intrusive memories of wound care. Holmes and colleagues (2005) found that cognitions associated with hotspots concerned a sense of threat to physical integrity (either classified as an uncertain threat or general threat of injury) or to one's sense of self. Compared to memories about the accident, memories of wound care may have a smaller likelihood of being re-experienced because parents may appraise medical treatment as contributing to the child's recovery, instead of causing physical harm. During hospitalization, these helpful appraisals might be facilitated by a supportive burn care team that provides parents a sense of control (Egberts et al., 2018).

Themes reflecting parents' negative appraisals in the aftermath of the burn injury included a sense of increased vulnerability, ruminations about responsibility for the injury, and appraisals about prolonged suffering and permanent change. In some parents, these appraisals appeared to be linked to cognitive and behavioral strategies

that may be unhelpful, such as safety and avoidance behaviors. According to the cognitive model of PTSD, excessively negative appraisals of the traumatic event and its sequelae, and engaging in strategies that prevent change in appraisals, maintain a sense of current threat that characterizes PTSD (Ehlers & Clark, 2000). In the child trauma literature, parental appraisals have only recently received increased attention (Schilpzand, Conroy, Anderson, & Alisic, 2018; Williamson et al., 2018). The themes within the current study resemble three domains identified in a measure of parental appraisals following child trauma, namely permanent change or damage, preoccupation with child's vulnerability, and self-blame (Williamson et al., 2018). Attention to parental appraisals and emotions could assist in identifying parents at risk for long-term problems and may provide starting points for interventions.

In the aftermath of the injury, parents reflected or ruminated on the perceived responsibility for the child's injury, which could be accompanied by feelings of guilt or anger (theme 4). For guilt specifically, some parents rationalized that they were not responsible for the child's injury, although the negative affective reaction of guilt was still present. Guilt is suggested to include both cognitive and affective components (Kubany & Watson, 2003; Tilghman-Osborne, Cole, & Felton, 2010), and the current findings suggest that parents may experience a discrepancy between these components, potentially contributing to the persistence of guilt. Both parental feelings of guilt and anger have been longitudinally related to parents' posttraumatic stress after pediatric burn injury, and guilt has received most empirical attention (Bakker et al., 2013; Bakker, Van Loey, Van Son, & Van der Heijden, 2010; De Young et al., 2014; Egberts et al., 2017). How guilt and PTSD are related is still a topic of investigation. Trauma-related guilt might contribute to higher posttraumatic stress, although an opposite direction of effects is also likely (Pugh, Taylor, & Berry, 2015). In terms of treatment of PTSD and feelings of guilt, research has shown that Cognitive-Processing Therapy (CPT) and Prolonged Exposure (PE) are comparably efficacious in treating PTSD, but CPT is superior to PE in reducing two specific types of guilt cognitions (i.e., hindsight bias and lack of justification) (Resick, Nishith, Weaver, Astin, & Feuer, 2002). Compared to feelings of fear, which are often targeted in PTSD treatment such as exposure therapy, the retrospective emotion of guilt may be less prone to change through exposure (Dalgleish, 2004). Together, the current findings and previous studies suggest parents' feelings of guilt and anger should be addressed in burn (after)care and can be a unique target in clinical interventions.

In line with the findings of Williamson and colleagues (2018), appraisals of (risk of) permanent change were identified (theme 5). In the current study, these appraisals were

characterized by a negative perception of the child's (future) physical and psychological adjustment, and a comparison to a better pre-burn situation. After burn injury, parents seem to hold these appraisals in relation to the child's scars, which might explain the finding that mothers of children with more extensive permanent scarring, combined with feelings of guilt, experienced more posttraumatic stress 10 years after the child's burn injury (Bakker et al., 2010). The use of cognitive- (i.e., challenging and changing unhelpful thoughts) or acceptance-based (i.e., accepting the parts of the situation that cannot be changed) strategies might help to change these negative appraisals.

Besides negative appraisals of the injury and its aftermath, positive appraisals about recovery were also reported; some parents mainly focused on positive elements in their child's recovery process (theme 6). For example, they used downward comparisons to (hypothetical) worse-case scenarios. This strategy (i.e., putting into perspective) has been shown adaptive in adjustment after stressful events (Garnefski, Kraaij, & Spinhoven, 2001). Trauma-exposed individuals may also report positive psychological changes (i.e, posttraumatic growth), but this does not seem to enhance long-term adjustment to traumatic events (Engelhard, Lommen, & Sijbrandij, 2015).

The current study suggests several directions for future research. It would be relevant to unravel the interplay between parents' memories and appraisals of the accident, early symptoms of traumatic stress, the hospital experience, and longer lasting intrusive memories. Methods such as ecological momentary assessments may be useful to examine intrusions and its precursors and consequences more in-depth, allowing experiences to be sampled in real time and within the participant's natural environment (Shiffman, Stone, & Hufford, 2008). In addition, the present study indicated the presence of perceptions of loss, which could lead to feelings of grief. Parents' loss and grief are constructs that have not systematically been studied following pediatric burn injury, but that may be relevant in understanding the adjustment process and ultimately, the wellbeing of the parent and the family.

Some limitations of the current study merit note. First, parents' reports reflect their experiences within Dutch burn care. Experiences within other burn care systems might differ, for example, depending on the involvement of parents in their child's care and the psychosocial orientation of the burn care team. Second, compared to the general family population admitted to the Dutch burn centers, the current sample had a relatively high proportion of native Dutch parents and parents with a high education.

The knowledge obtained in the current study can inform the provision of trauma-informed care in the pediatric burn care system. To minimize the risk of negative psychological outcomes in parents, parental appraisals and emotions may be addressed

by including them in assessment and monitoring throughout the hospitalization and in aftercare, providing psycho-education targeted at these appraisals, and intervening on problematic appraisals or intense emotions.

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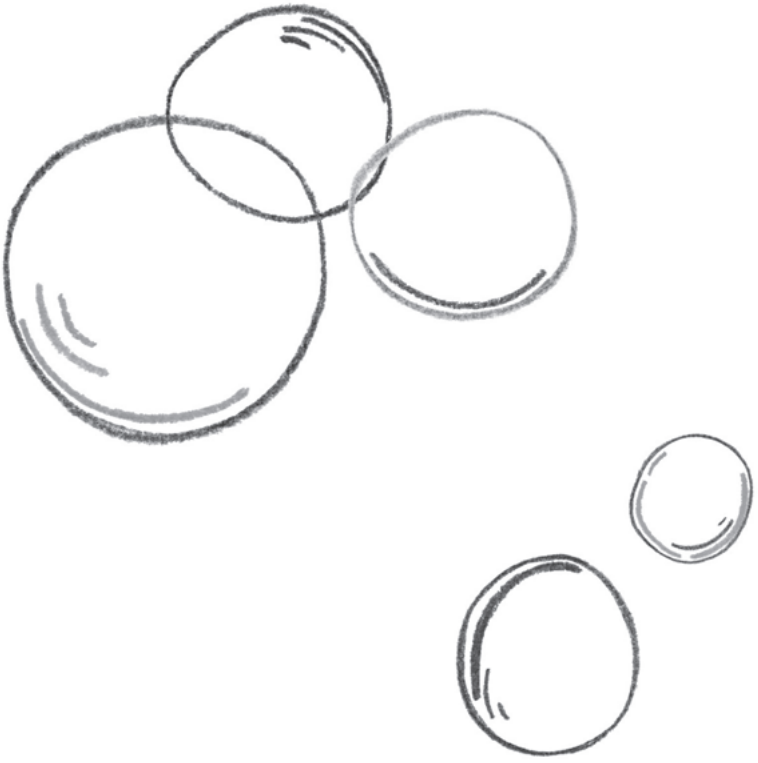

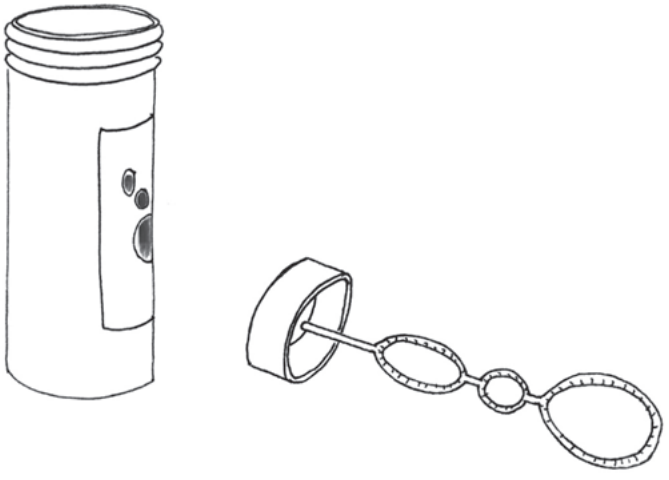

Chapter 9

Summary of main findings and general discussion

9

Summary of main findings and general discussion

This dissertation was aimed at better understanding the psychological impact of pediatric burns on the family. With the use of both quantitative and qualitative methods, and multiple informants, the perspectives of different family members across various time points postburn were described and analyzed. The first part of the dissertation covered a prospective, longitudinal study of children (8-18 years old) with burns and their parents, with assessments up to 18 months postburn. Within-family associations and predictors of children's, mothers' and fathers' psychological symptoms (such as those of posttraumatic stress) were examined. The second part comprised three qualitative studies that provided an in-depth picture of child and parent experiences after burn injury. Specific attention was paid to experiences surrounding child wound care procedures, as well as the content and nature of child and parent (intrusive) memories after discharge. The main findings of the dissertation are presented in Box 1 and are discussed in the current chapter. Besides a general discussion of the findings, this chapter also addresses the way findings inform the provision of burn (psychosocial) care for families, and directions for future research.

Box 1. Main findings of the studies
• Within the first three months after the burn event, more parents than children experienced posttraumatic stress symptoms in the clinical range. Child and parent symptoms showed within-family associations. Besides an actual co-occurrence of symptoms, higher traumatic stress in parents was also related to parents observing more traumatic stress in the child, regardless of the child's own report (Chapter 2).
• Child internalizing (e.g., anxiety or depressed mood) and externalizing (e.g., oppositional or aggressive behavior) problems were within normal limits one year postburn. The child's preburn functioning was related to postburn internalizing and externalizing problems, but only from the parent's perspective. In addition, parents reported more child internalizing problems when they experienced higher posttraumatic stress themselves (Chapter 3).
• Levels of parental posttraumatic stress generally decreased over time, although a substantial group of parents experienced serious levels of traumatic stress 18 months postburn. Higher initial levels of guilt and anger, as well as the perception of threat to the child's life, were risk factors for higher traumatic stress across time, particularly in mothers (Chapter 4).
• Mothers experienced various burn-related emotions, of which sadness and fear were most frequently reported. Emotions could be separated into primary (fear, sadness, horror, anger) and self-conscious (guilt and shame) emotions. A persistence in primary emotions was related to a persistence in posttraumatic stress- and depressive symptoms. Initial self-conscious emotions were longitudinally related to depressive symptoms, but not posttraumatic stress (Chapter 5).
• Most parents preferred to be present during the child's wound care procedures, despite the distressing nature of these procedures. It was considered beneficial if parents had the ability to control their own emotions and be responsive to the child's needs. Parents appeared to gain a sense of control from their presence (Chapter 6).
• In the aftermath of the burn injury, children had vivid memories about the accident, the appearance of the wounds in the acute phase, and pain. Intrusive memories were predominantly visual and accident-related. Lasting concerns were reported in relation to the reactions of other people and the risk of an accident happening again. Parents were seen as a great source of support (Chapter 7).
• Parents' involuntary, intrusive memories were mainly related to the threat of the injury, and parents reported no isolated intrusions of procedures such as wound care. In the injury's aftermath, parents appraised an increased vulnerability, and reported appraisals about responsibility, prolonged suffering and permanent change, and recovery (Chapter 8).

Pediatric burns: A family matter

Pediatric burn injury is not only traumatic for the child but it may be traumatic for the entire family. Besides attention to the physical consequences of burns and scar formation, this dissertation emphasizes that the family's psychological reaction is an equally important outcome. In the assessment of these psychological reactions and in the provision of psychosocial support, within-family dependency should be taken into account. Although in the long-term many family members are indicated to show resilient outcomes, the impact of a burn event does not go unnoticed.

A potentially traumatic experience for all family members

> "I think it's by far the worst thing that has happened to me in my whole life. It was the biggest shock you can imagine. And your thoughts often go back to that moment because you are confronted with it every day." [father of a 1-year-old-boy]

> "Well, you're just doing something, you stop for a moment and then suddenly an image of the moment pops into your mind. And then you feel that pain on your skin again, the pain you felt when the fire was coming towards you." [17-year-old boy]

Both the child and its parents may be profoundly affected by the threatening nature of the burn accident, invasive wound care procedures, and lifelong scars. The findings of this dissertation contribute to the trauma literature by demonstrating which factors contribute to the development of long-term psychological symptoms, which experiences are reflected in child and parent (intrusive) memories, and by showing that parents of older children are equally affected as parents of young children.

The results support the assumption that several elements of an injury and its aftermath may be experienced as traumatic (Kazak et al., 2006; Price, Kassam-Adams, Alderfer, Christofferson, & Kazak, 2016), but suggest that the burn event is the primary trauma for children and parents. Child and parent intrusive memories were predominantly related to the accident, and not to medical treatment. In accordance with literature (Brewin & Holmes, 2003; Ehlers & Clark, 2000; Holmes, Grey, & Young, 2005), appraisals of threat during the accident combined with high levels of distress, increase the likelihood of intrusive memories. In contrast, perceived threat is suggested to be lower during wound care, when procedures are appraised as contributing to recovery and when children and parents experience a sense of control (chapter 6 and 7). Although wound care procedures may have a lower likelihood of being the subject of intrusive memories, they are obviously distressing. A finding that should be further explored is that perceived lack of control during wound care combined with high levels

of early posttraumatic stress symptoms may magnify early traumatic stress reactions. In contrast to the accident experience, which cannot be modified, the distressing nature of wound care should be kept as low as possible.

In terms of posttraumatic stress, parents seemed to be more severely affected by the burn injury than children and a shared avoidance pattern may develop in parental couples after the burn event (chapter 4). Posttraumatic stress- and depressive symptom levels were high shortly after the injury, and a considerable amount of parents experienced long-term symptoms, which is consistent with previous studies (De Young et al., 2014; Landolt, Ystrom, Sennhauser, Gnehm, & Vollrath, 2012; Le Brocque et al., 2010). Burn-related emotions (e.g., sadness, fear, guilt, anger) were highly prevalent and persistent emotions were related to ongoing posttraumatic stress- and depressive symptoms (chapter 5 and 8). In therapeutic interventions for posttraumatic stress, such as imaginal exposure, emotions other than fear (e.g., anger and guilt) may be more resistant to change, despite a decrease in posttraumatic stress symptoms (Arntz, Tiesema, & Kindt, 2007; Grey, Young, & Holmes, 2002; Grunert, Weis, Smucker, & Christianson, 2007). Therefore, these emotions should also be targeted.

Noteworthy, child burn scars can be a permanent reminder of the trauma that trigger emotional and intrusive memories as well as grief and sadness in parents (chapter 8). A previous study reported that the combination of a child's permanent scarring and mothers' guilt feelings was related to higher posttraumatic stress ten years postburn (Bakker, Van Loey, van Son, & van der Heijden, 2010). Also, a subset of children may experience negative consequences (e.g., low body esteem, negative reactions of others) as a result of scarring (chapter 7; Lawrence, Rosenberg, & Fauerbach, 2007; Lawrence, Rosenberg, Mason, & Fauerbach, 2011). Thus, the child's visible scars may maintain parent and child long-term psychological symptoms through evoking vivid memories and by being subject of negative appraisals and emotions.

The interdependency of reactions within the family

> "I just won't allow myself to be confronted with such a devastating experience ever again. With things like that I have noticed I have become more protective" [mother of a 1-year-old girl]

The co-occurrence of posttraumatic stress symptoms in children, mothers and fathers suggests an interdependent nature of symptoms (chapter 2), which can be explained by several mechanisms. For example, parents that perceived their child to be vulnerable to future harm, also seemed more likely to engage in safety and avoidance behaviors (chapter 8), which in turn can increase the child's avoidance.

Parenting may be affected by child trauma and previous studies distinguished emotionally and functionally unavailable parents, overprotective parents, parents that are preoccupied with the trauma, and positive parents providing warmth and support (Bokszczanin, 2008; Scheeringa & Zeanah, 2001; Williamson et al., 2017). However, more research on trauma-specific parenting is needed and future studies should take into account the parent's own posttraumatic stress (Williamson et al., 2017). Also, future research should consider the impact of the child's appraisals on the parent's adjustment.

Overall, within-family dynamics may change after a pediatric burn event and negative appraisals and persistent emotions provide information about these dynamics and can be starting points for psychoeducation or family interventions.

Assessment of all family members

> "Initially we seemed to be sure her sleeping problems were due to her experiences and her burn injuries. But on the other hand, and that was also what a friend of ours said, it could also just be an age-related thing. That she was just trying to find out how far she could go." [father of a 1-year-old girl]

A family perspective should be applied to the assessment of psychological reactions after burn injury, including assessments of child- and parent posttraumatic stress symptoms. Similar to the findings reported in chapter 2, research in other trauma populations has shown parent-child discrepancies in reports of child posttraumatic stress (Kassam-Adams, García-España, Miller, & Winston, 2006; Meiser-Stedman, Smith, Glucksman, Yule, & Dalgleish, 2007; Shemesh et al., 2005), and we reported a similar discrepancy regarding child health-related quality of life in a previous study (Pan et al., 2015). It appears that parents' own posttraumatic symptoms may lead to overreporting of especially their child's symptoms on the internalizing spectrum, such as those of posttraumatic stress and anxiety (chapter 2 and 3; Kassam-Adams et al., 2006; Pan et al., 2015; Smith, Perrin, Yule, & Rabe-Hesketh, 2001).

The findings suggest a careful consideration of informants. The child's perspective should be incorporated when possible. For younger children, we have to rely on parents' reports of the child's symptoms, but the potential influence of their own symptoms should be taken into account.

Recognizing resilience

> "I thought it was really amazing how quickly you adapt. All of a sudden it's a fact, the burn event is over, and how fast you just accept that. So you suddenly find yourself in that hospital and that's your reality then. Just so quickly, the ability of your whole system to adapt, that everything seems to be settled in just a couple of hours." [mother of a 2-year-old boy]

Despite high initial levels of distress, the majority of children and parents appeared to adapt well in the long term (chapters 2 to 5). This is consistent with evidence that most people show a pattern of resilience after trauma, characterized by a brief period of disruption, though maintaining healthy levels of functioning (Bonanno, 2004). Findings in child trauma literature also emphasize the presence of resilience in children (Alisic, Boeije, Jongmans, & Kleber, 2011).

One of the proposed factors contributing to resilient outcomes is the ability to flexibly use different coping and emotional regulation strategies, depending on the demands of the situation (Bonanno, 2005; Bonanno, Papa, Lalande, Westphal, & Coifman, 2004). The presence of this ability was found in parents' reports of their attempts to control their emotions during wound care and to express them at a later time (chapter 6). Whether emotion regulation flexibility during wound care is also predictive of long-term parental psychological outcomes, is a relevant subject for further study.

Another factor that potentially contributes to positives outcomes in parents and children, is the ability of parents to be responsive to the child's needs during wound care and after discharge (chapter 6 and 7). Responsive parenting (i.e., being aware of the child's needs and acting on these needs) likely promotes the child's recovery (Alisic, Boeije, Jongmans, & Kleber, 2012).

Implications for psychosocial care for children and their families

Burn care is provided by a multidisciplinary burn team, including professionals such as medical doctors, nurses, psychologists, child life specialists, aftercare nurses, and social workers and *all* can have a role in providing psychosocial support. Parents reported that they felt relieved when the burn physician told them they provided the right first aid, or reassured them their child would be alright, and parents shared their experiences of receiving adequate care and support from the nurses and child life specialists. However, this dissertation indicates there is room to optimize psychosocial support for children and their parents.

Psychosocial support during wound care

To start with the daily recurrent painful dressing changes, our research led to the recommendation that parents should be offered the opportunity to be present during the child's wound care. Overall, the advantages of parental presence (e.g., the child's feeling of safety, parents' sense of control), appear to outweigh potential disadvantages (e.g., parent distress). The finding that the content of parents' intrusive memories after discharge was not related to wound care, also advocates for providing opportunities for parental presence. Careful monitoring of the abilities of the parents remains a point of attention and discussion. This may result in (temporarily) withdrawing the parent from the procedures and re-evaluating their presence on a daily basis. Most importantly, parental presence should be tailored to the family's wishes and needs, there will be no 'one-size-fits-all' approach.

Several interventions can be applied to minimize child and parent distress, and child pain (chapter 5 and 6; cf Brown, De Young, Kimble, & Kenardy, 2018; Martin-Herz, Thurber, & Patterson, 2000; Young, 2005). For both parents and children, predictability and control are important. Therefore, appropriate preparation and information provision during the procedure (for example about the interpretation of the wounds) is recommended. In addition, parents may be offered advice on how to regulate their emotions and how to best support their child. To promote their perceptions of a meaningful contribution, professionals may reinforce parents' beneficial behaviors, let the parent participate in concrete tasks, and express the value of their presence. For children, control might be increased by offering choices and by providing the opportunity to participate in wound care themselves (for example by cleaning the wounds). Cognitive restructuring techniques may aid in changing unhelpful cognitions (e.g., catastrophizing thoughts). Furthermore, the use of other nonpharmacological strategies (e.g., distraction, deep breathing, guided imagery) adjusted to the child's age may minimize child procedural pain and distress.

Early screening

To prevent chronic child and parent psychological symptoms and to target interventions at high risk groups, early risk screening is recommended. Although risk screening for posttraumatic stress has received most attention, screening for risk of depressive symptoms is also recommended (chapter 5). Early screening may be focused on concurrent symptoms, as well as risk factors, or a combination of the two. The first type of screening determines the likelihood of someone currently meeting PTSD criteria, based on a concise number of symptoms. The second type focuses on the presence

of risk factors, such as the perception of life-threat at the time of the injury. Only a few studies have evaluated screening instruments for accidently injured children. Both concurrent screeners and risk screeners have shown high sensitivity (e.g., the Pediatric Emotional Distress Scale Early Screener, the Child Trauma Screening Questionnaire, and the Screening Tool for Early Predictors of PTSD) (Kenardy, Spence, & Macleod, 2006; Kramer, Hertli, & Landolt, 2013; Winston, Kassam-Adams, Garcia-Espana, Ittenbach, & Cnaan, 2003). However, these screeners have shown relatively high rates of false positives. In addition, the same results may not be obtained when examining the screeners in other pediatric samples. For example, studies lowered the cut-off value for the Screening Tool for Early Predictors of PTSD (van Meijel et al., 2015) or modified the content of the original instrument (Nixon, Ellis, Nehmy, & Ball, 2010) to obtain a similar sensitivity. Overall, the use of screening appears promising, but refinement of existing instruments or the development of new instruments is necessary.

Furthermore, a topic of interest concerns the duration of screening or follow-up. Only screening in the acute phase does not seem sufficient to identify families at risk, which suggests prolonged screening and monitoring (chapter 5). Living with burn scars has a life-long impact (Jones, Buchanan, & Harcourt, 2017) and a recent study suggests that the use of mental health services is up to five times higher in people burned during childhood (Duke et al., in press). Currently, burn centers are dedicated medical expertise centers. Extending burn care centers with psychological expertise that allows persons to consult the burn center throughout the lifespan may assist in finding suitable help.

Prevention and intervention

Following a stepped-care approach, it is recommended that all families receive psychoeducation and a subgroup of families can receive more intensive support through preventive intervention programs. Based on the current dissertation's findings, psychoeducation and preventive intervention programs should include information about the way parents may influence children and vice versa (for example by avoiding to speak about the burns, or by overprotecting the child), child and parent negative emotions (such as guilt and anger) and appraisals, dealing with scars, and advice for responsive parenting. Information may also include the way distress reactions may emerge and develop, normalization of early distress, and coping advice. Whereas support for young children will be mainly focused on parents, programs for older children can include participation of the child itself.

Research suggests that preventive intervention should be delivered only to children and families that have an increased risk of long-term symptoms (Kramer &

Landolt, 2011, 2014). Elements recommended to be included comprise trauma exposure, coping skills, and attention to the parent-child relationship. The Coping with Accident Reactions (CARE) preventive intervention for young (1-6 years old) children and their parents, addresses these elements (De Young, Haag, Kenardy, Kimble, & Landolt, 2016). A preventive intervention for older children is the Child and Family Traumatic Stress Intervention (CFTSI) (Berkowitz, Stover, & Marans, 2011), which is focused on improving parental support by increasing parent-child communication and on improving coping skills in both the child and parent.

In case of child or parent chronic PTSD, more intensive forms of therapy, such as cognitive therapy, exposure therapy, or eye movement desensitization and reprocessing (EMDR) therapy may be indicated (American Psychological Association, 2017). For parents in particular, a decrease in trauma-related emotions such as guilt and anger, can be a complementary goal in treatment. Especially guilt can be a persistent and difficult-to-treat emotion.

Support for social challenges

Attention to the social impact of burns should be included in preparation for discharge and in aftercare. Reactions of others in response to scars and accepting a new appearance may be challenging, especially for school-aged children and adolescents (e.g., Kool, Geenen, Egberts, Wanders, & Van Loey, 2017). School reintegration is a central facet after discharge, and preparation should preferably start during hospitalization (cf. Pan et al., 2018). After discharge, a school visit with a burn team member aims to provide information to classmates about the physical and emotional consequences of burns. Peer support, such as through burn camps and support groups, may be of value in dealing with social and appearance-related concerns, and negative reactions of others (Bakker, van der Heijden, van Son, van de Schoot, & Van Loey, 2011; Lau & Van Niekerk, 2011; Williams, Reeves, Cox, & Call, 2004).

Future research directions

Throughout this chapter, suggestions for future research were indicated. Some additional topics to be examined in future studies are presented here.

The development and evaluation of risk screening measures and (preventive) intervention programs should be focus of future research. It should be examined whether screening instruments evaluated in other pediatric populations show a similar performance for children with burns and their parents, or whether burn-specific factors should be incorporated. The relatively high rates of false positives of current instruments

should be reduced. Our results indicate that it is relevant to screen for the presence of (early) posttraumatic stress- and depressive symptoms in combination with persistent trauma-related emotions in parents (chapter 5). To be able to provide evidence-based psychosocial care, preventive intervention programs should be further developed and it should be examined which families benefit most from programs, which intervention elements are most efficacious, and at which time point interventions can best be delivered. This may require international collaboration to obtain sufficient sample sizes.

Another topic for future research is the interplay between trauma-related emotions, appraisals, and posttraumatic stress symptoms. To capture the dynamic nature of these associations and to identify potential starting points for early intervention, the collection of time-intensive data would be helpful. Using ecological momentary assessments, repeated real-time experiences can be monitored in the participant's natural context (Shiffman, Stone, & Hufford, 2008) and analyzed with dynamic structural equation modelling (Asparouhov, Hamaker, & Muthén, 2018). For example, the time-intensive monitoring of parents' intrusive memories during hospitalization, and its interactions with experiences during wound care, would be relevant to study. Another suitable topic is the interplay between child pain and posttraumatic stress. However, during hospitalization studies with repeated assessments throughout the day may pose ethical as well as practical challenges.

Although the current dissertation emphasized a family perspective after pediatric burns, siblings were not specifically examined. Siblings of the burn-injured child may be profoundly affected by the injury, for example through witnessing the event, concerns about their sibling's health, a disruption of normal family life, and (emotional) unavailability of the parents. From research, very little is known about experiences of siblings (Bakker, Maertens, Van Son, & Van Loey, 2013). Future studies might identify potential support needs of siblings.

General conclusion

Burn injured children are left with outside scars and there is a risk for the whole family to be left with inside scars. Both outside and inside scars require clinical attention. This dissertation analyzed the psychological impact of pediatric burns on the child and its parents, from the early weeks after the injury up to 18 months postburn using quantitative and qualitative research methods allowing examination in breadth and depth.

Despite high levels of distress in the acute phase, most children and parents appeared to recover in the long term. Nevertheless, there was a considerable group of parents, particularly mothers, that experienced lasting posttraumatic stress reactions. Negative emotions and appraisals were identified as potential risk factors, that can be targeted through intervention. Furthermore, the results suggested that vivid and emotional memories of the accident and hospitalization remain, in both children and parents, and that memories of the burn event have a higher potential to be intrusive and involuntary than memories of the hospitalization.

The findings indicate that a family perspective on pediatric burn injury is essential, both in clinical practice and in research. Evidence for within-family interdependency of psychological reactions was found and the results call for assessment of both child and parent psychological symptoms. Assessment and support directed at parents may have indirect benefits for the child, since parents without psychological problems might be better able to support their child.

Efforts should be made to develop and evaluate screening- and preventive intervention and stepped-care integrative programs for children and parents, that can be incorporated in the pediatric burn care setting. Hereby, the intensity of psychosocial support can be tailored to the family's needs, which may contribute to the recovery of the entire family.

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Samenvatting

Summary in Dutch

Introductie

Als een kind brandwonden oploopt heeft dit gevolgen voor het hele gezin. Dit proefschrift richt zich op de psychische gevolgen van brandwondenongevallen voor kinderen en hun ouders. Door gebruik te maken van zowel kwantitatieve als kwalitatieve onderzoeksmethoden, hebben we de gevolgen voor het gezin zowel in de breedte als in de diepte onderzocht. In dit hoofdstuk wordt een samenvatting van de resultaten uit de verschillende hoofdstukken gegeven, gevolgd door een discussie van de bevindingen, de implicaties voor de praktijk, en een conclusie.

Samenvatting van de resultaten

Het eerste deel van het proefschrift omvat een prospectieve studie die is uitgevoerd in zeven brandwondencentra in Nederland en België. Dit onderzoek was gericht op kinderen tussen de 8 en 18 jaar en hun ouders. De psychische reacties van zowel kinderen als ouders werden bestudeerd aan de hand van vragenlijsten. Gezinnen werden tot 18 maanden na het ongeval gevolgd. Het onderzoek was onder andere gericht op emotionele- en gedragsproblemen bij kinderen, en posttraumatische stressreacties van kinderen en ouders. De klachten die binnen posttraumatische stressreacties centraal staan, zijn herbelevingen, vermijding, negatieve gedachten en stemming, en hyperactivatie.

In **hoofdstuk 2** richtten we ons op de samenhang van posttraumatische stressreacties binnen het gezin. Kinderen, moeders en vaders rapporteerden over hun eigen posttraumatische stress binnen de eerste maand en 3 maanden na het ongeval. Daarnaast vulden moeders en vaders ook vragenlijsten in over de posttraumatische stresssymptomen van hun kind. Meer ouders dan kinderen hadden hoge scores die kunnen wijzen op posttraumatische stress. Wel was er sprake van een samenhang van symptomen binnen het gezin; meer posttraumatische stress bij ouders ging gepaard met meer symptomen bij het kind. Binnen de eerste maand was dit alleen het geval bij moeders, maar na 3 maanden werd ook een samenhang tussen de symptomen van vaders en kinderen gevonden. Daarnaast leken ouderlijke posttraumatische stresssymptomen de observatie van het kind te kleuren; ouders die zelf meer klachten hadden, rapporteerden ook meer klachten bij het kind, onafhankelijk van wat het kind zelf rapporteerde.

Naast posttraumatische stresssymptomen kunnen kinderen ook meer algemene emotionele- en gedragsproblemen ervaren na een ongeval. Daarbij kan

een onderscheid worden gemaakt tussen internaliserende –naar binnen gerichte– problemen zoals angstig of teruggetrokken gedrag en externaliserende –naar buiten gerichte– problemen zoals opstandig of agressief gedrag. In **hoofdstuk 3** lag de focus op internaliserende en externaliserende problemen bij kinderen 12 maanden na het brandwondenongeval en onderzochten we de samenhang met het functioneren vóór het ongeval en met posttraumatische stresssymptomen van de ouder (binnen de eerste maand en na 12 maanden). Net als in hoofdstuk 2 rapporteerden zowel kinderen als ouders over de problemen van het kind. Twaalf maanden na het ongeval vertoonde de groep kinderen met brandwonden niet meer emotionele- en gedragsproblemen dan een normgroep van leeftijdsgenoten. De verbanden van deze lange-termijn internaliserende en externaliserende problemen met het functioneren vóór het ongeval en ouderlijke posttraumatische stress, waren afhankelijk van welk gezinslid over welk construct rapporteerde. Als ouders rapporteerden dat hun kind meer emotionele- en gedragsproblemen vóór het ongeval had, hing dit samen met meer externaliserende problemen 12 maanden na het ongeval. Daarnaast namen ouders meer internaliserende problemen bij hun kind waar als ze zelf meer posttraumatische stressklachten hadden. Dit leek voornamelijk het geval als acute stress (binnen de eerste maand) aanhield tot 12 maanden na het ongeluk. Als kinderen echter zelf over hun externaliserende en internaliserende problemen rapporteerden, vonden we geen samenhang met de inschatting van de ouders over het functioneren vóór het ongeval. Ook werd er geen verband met ouderlijke posttraumatische stress gevonden. Dit wijst erop dat de posttraumatische stress van ouders voornamelijk een effect had op de manier waarop zij de emotionele- en gedragsproblemen van het kind waarnamen, zonder dat hun kind zelf meer problemen rapporteerde.

In **hoofdstuk 4** verlegden we onze focus van het gezin als geheel naar het ouderkoppel in het bijzonder. We onderzochten het verloop van posttraumatische stressreacties bij moeders en vaders tot 18 maanden na het ongeluk. Er bleek sprake van een afname van symptomen over de tijd, al bleven klachten bij een substantieel deel van de ouders (vooral moeders) bestaan. Schuldgevoelens en boosheid in de eerste maand na het ongeval voorspelden meer posttraumatische stress over de tijd, vooral bij moeders. Ook als ouders op enig moment het idee hadden gehad dat het kind het niet zou overleven, hing dit samen met meer posttraumatische stress. Daarnaast onderzochten we de afhankelijkheid van symptomen binnen het ouderkoppel. De vermijdingssymptomen van moeders en vaders, zoals het uit de weg gaan van gesprekken of zaken die doen herinneren aan het brandwondenongeval, vertoonden

overlap tussen ouders uit hetzelfde koppel en wijzen op een gedeelde ervaring van vermijding.

In **hoofdstuk 5** richtten we ons alleen op de moeders. Waar we in de voorgaande hoofdstukken enkel ouders van kinderen tussen 8 en 18 jaar onderzochten, voegden we in dit hoofdstuk ook informatie over moeders van jonge kinderen (0 tot 4 jaar) toe. We onderzochten de emoties met betrekking tot het ongeval en het verband met posttraumatische stress- en depressieve symptomen 18 maanden na het ongeval. De emoties konden onderverdeeld worden in 'basisemoties' (angst, verdriet, boosheid, afschuw) en 'zelfbewuste emoties' (schuld en schaamte). Basisemoties die over een periode van een jaar bleven bestaan, hingen samen met meer posttraumatische stress- en depressieve symptomen 18 maanden na het ongeval. Daarnaast vonden we bij meer zelfbewuste emoties binnen de eerste maand na het ongeval meer depressieve klachten op de lange termijn. Deze resultaten geven een aanwijzing dat aanhoudende negatieve emoties een risicofactor vormen voor langdurige psychische klachten.

In het tweede deel van het proefschrift worden de resultaten van een serie kwalitatieve studies beschreven, waarvoor interviews met ouders (van zowel jonge als oudere kinderen) en jongeren zijn uitgevoerd. In dit onderzoek hebben we specifiek aandacht besteed aan de wenselijkheid van en ervaringen met aanwezigheid van ouders bij de wondverzorging van het kind. Daarnaast hebben we 3 tot 6 maanden na het ongeval onderzocht welke herinneringen ouders en jongeren aan het ongeval en de opnameperiode hadden en welke ervaringen deel uitmaakten van zogenaamde intrusieve herinneringen (opdringerige en ongewenste beelden, geluiden, geuren, lichamelijke sensaties of gedachten).

Of ouders de mogelijkheid krijgen aanwezig te zijn tijdens de wondverzorging van hun kind verschilt wereldwijd per brandwondencentrum. Er zijn veronderstelde voor- en nadelen van aanwezigheid, maar de ervaringen van ouders zijn niet eerder uitgebreid in kaart gebracht. In **hoofdstuk 6** rapporteerden we de resultaten van een onderzoek waarin we 22 ouders tijdens de opnameperiode interviewden. Ondanks de heftige emoties van ouders tijdens de wondverzorging (zoals verdriet en angst door het zien van het lijden van het kind), wilden de meeste ouders aanwezig zijn. Aanwezigheid gaf ouders een gevoel van controle, onder andere door het zien van de wondgenezing, een beter begrip van de situatie en doordat ze een waardevolle rol voor zichzelf konden vinden. Het tijdelijk onderdrukken van emoties om er voor het kind te kunnen zijn en responsiviteit (kijken wat het kind nodig heeft en hierop inspelen) hielpen ouders tijdens de wondverzorging. We concludeerden dat het wenselijk is dat ouders de optie wordt geboden aanwezig te zijn bij de wondverzorging.

Drie tot 6 maanden na het ongeval zijn ook jongeren zelf geïnterviewd. In het interview vertelden zij over hun beleving en herinnering van het ongeval zelf, de opnameperiode, de wondverzorging, en de nasleep. Op basis van 8 interviews bepaalden we de belangrijkste thema's, die in **hoofdstuk 7** beschreven staan. Jongeren hadden levendige en emotionele herinneringen aan het ongeval zelf, de aanblik van wonden en littekens, en pijn. Naast deze negatieve herinneringen hadden ze ook positieve herinneringen aan de periode in het brandwondencentrum. De steun van ouders gedurende de opname en na ontslag was belangrijk voor het kind. De jongeren benadrukten het veilige gevoel dat de aanwezigheid van ouders tijdens de wondverzorging gaf, maar gaven ook aan dat ouderlijke aanwezigheid niet dagelijks nodig was. Hoewel het merendeel van de jongeren aangaf zich goed te hebben aangepast na het ongeluk, hadden meerdere jongeren de zorg dat er opnieuw iets naars (zoals een ongeluk) zou gebeuren en maakte een deel van de jongeren zich zorgen om de reacties van anderen, bijvoorbeeld wat betreft hun littekens. Jongeren benoemden verschillende positieve manieren om met het ongeluk en de gevolgen daarvan om te gaan, zoals relativeren, zich richten op de positieve uitkomst, en het zich langzaamaan blootstellen aan zaken waar ze bang voor waren (zoals vuur).

Ook ouders werden 3 tot 6 maanden na het ongeval nogmaals geïnterviewd. Het doel van deze interviews was het onderzoeken van de emotionele en mogelijk intrusieve herinneringen die ouders aan het ongeval en de opnameperiode hadden. Daarnaast wilden we in beeld brengen welke interpretaties ouders aan het ongeval en de gevolgen ervan gaven. In **hoofdstuk 8** staan de thema's beschreven die in deze interviews naar voren kwamen. De herinneringen konden onderverdeeld worden in herinneringen over de dreiging van het ongeval (bijvoorbeeld het moment dat het hete water over het kind viel) en herinneringen over het lijden van het kind (bijvoorbeeld de pijn en het huilen in het ziekenhuis). Hoewel beide soorten herinneringen een emotionele lading hadden, hadden voornamelijk de herinneringen over de dreiging van het ongeval een intrusieve aard. Daarnaast gaf een deel van de ouders negatieve interpretaties aan het brandwondenongeval. Het idee dat het kind kwetsbaar was om nogmaals een nare gebeurtenis mee te maken, gedachten over de eigen (of andermans) verantwoordelijkheid voor het ongeval, en het idee dat het kind voor altijd veranderd was (bijvoorbeeld door het litteken), kwamen bij meerdere ouders terug. Dit ging gepaard met emoties zoals verdriet, angst, en schuld. Er was ook aandacht voor de positieve uitkomsten en daarmee het herstel van het kind.

Discussie

Een brandwondwondongeval bij een kind is niet alleen potentieel traumatisch voor het kind zelf, maar voor het hele gezin. De resultaten uit dit proefschrift onderstrepen dat aandacht voor de psychische reacties van het gezin evenzeer belangrijk is als aandacht voor de lichamelijke gevolgen van brandwonden.

Het brandwondenongeval zelf, de wondverzorgingen, eventuele operaties, en mogelijk levenslange littekens kunnen een grote impact op het kind en de ouders hebben. In de literatuur wordt verondersteld dat verschillende ervaringen rondom een ongeval en ziekenhuisopname traumatisch voor gezinnen kunnen zijn. Dit zou betekenen dat deze ervaringen ook kans hebben om herbeleefd te worden in de vorm intrusieve herinneringen. De resultaten uit ons onderzoek ondersteunen deze veronderstelling, maar wijzen met name op het ongeval als de bron hiervan. De intrusies (voornamelijk beelden) die ouders en kinderen tot een half jaar na het ongeval rapporteerden, hadden voornamelijk betrekking op het ongeval zelf. De herinneringen aan het ziekenhuis en aan de wondverzorging hadden niet deze opdringerige, ongewenste aard. Een gevoel van dreiging gecombineerd met emoties als angst en paniek, die tijdens het ongeluk vaak aanwezig zijn, vergroot de kans dat een gebeurtenis later herbeleefd wordt. Tijdens de wondverzorging is het gevoel van dreiging waarschijnlijk lager, omdat (oudere) kinderen en ouders ook beseffen dat deze procedures bijdragen aan het lichamelijk herstel. Daarnaast gaven ouders en kinderen aan dat ze een zekere mate van controle ervoeren tijdens de wondverzorging. Ondanks de bevinding dat wondverzorgingen een kleinere kans hebben herbeleefd te worden, zijn deze procedures uiteraard stressvol. De ervaring van het ongeval zelf kan in een brandwondencentrum niet meer veranderd worden, maar stress rondom de wondverzorgingen moet zoveel mogelijk beperkt worden.

In dit proefschrift was er veel aandacht voor de psychische gevolgen voor ouders. In de eerste maand na het ongeval hadden veel ouders posttraumatische stress- en depressieve klachten. Ondanks een algemene afname van deze klachten was er een aanzienlijke groep ouders, voornamelijk moeders, die over een periode van anderhalf jaar last bleef houden van posttraumatische stressklachten. Negatieve emoties (zoals angst, verdriet, boosheid, en schuldgevoel) lijken het risico op langdurige posttraumatische stress te vergroten, vooral als deze emoties over een lange periode aanhouden. Ook de manier waarop ouders tegen het brandwondenongeval en de gevolgen hiervan aankijken zijn van belang. Het idee dat het kind kwetsbaar is om nogmaals een ongeval mee te maken, het piekeren over de eigen verantwoordelijkheid

voor de het ongeval, en het idee dat het kind voor het leven getekend is, kunnen de verwerking in de weg staan. Hierbij lijkt ook de zichtbare impact van het ongeval in de vorm van littekens mee te spelen. Littekens kunnen (emotionele) herinneringen aan het ongeval oproepen. Ook benoemden ouders dat het zien van de littekens gevoelens van verdriet en rouw kon opwekken. Aanhoudende negatieve emoties en interpretaties rondom het brandwondenongeval lijken bij te dragen aan de instandhouding van psychische klachten bij ouders. Aandacht voor deze emoties en interpretaties in de klinische praktijk is dan ook gewenst.

In de nasleep van het ongeval zijn de psychische reacties van moeders, vaders, en kinderen afhankelijk van elkaar. Zo hingen hogere posttraumatische stressklachten bij de ouder samen met meer posttraumatische stress bij het kind. In de literatuur worden verschillende verklaringen voor deze samenhang van reacties genoemd. Eén van deze verklaringen is dat de psychische toestand van de ouder hun opvoedingsstijl kan beïnvloeden. Ouders kunnen bijvoorbeeld overmatig bezorgd of beschermend opvoedgedrag vertonen of zich juist (emotioneel) afsluiten voor het kind. Ons onderzoek laat ook zien dat er een gedeelde vermijding binnen het gezin kan ontstaan. Als één van de gezinsleden niet over de brandwonden wil praten of zaken die met het ongeval te maken hebben (zoals heet water en vuur) uit de weg gaat, is het mogelijk dat andere gezinsleden hierin meegaan. Hierdoor kunnen psychische klachten blijven bestaan. De manier waarop ouders en kinderen elkaar beïnvloeden nadat een kind een traumatische gebeurtenis heeft meegemaakt is een complex dynamisch proces. Omdat het gezin één van de belangrijkste omgevingen is waarin het kind leert met het ongeval en de gevolgen om te gaan, is verder onderzoek naar deze gezinsinteracties aan te bevelen.

Naast een daadwerkelijke afhankelijkheid van psychische reacties lijken posttraumatische stresssymptomen van ouders ook hun observatie van het kind te kleuren. Ouders met meer eigen klachten, rapporteerden ook meer problemen bij het kind, onafhankelijk van hoe het kind zijn of haar eigen klachten beoordeelde. De afhankelijkheid van reacties binnen het gezin, de hoge prevalentie van posttraumatische stressklachten bij ouders, en de invloed die deze ouderlijke klachten hebben op de manier waarop zij de klachten bij hun kind inschatten, geven aan dat in de klinische praktijk de psychische reacties van zowel kinderen als ouders ingeschat zouden moeten worden. Als de leeftijd en de lichamelijke toestand van het kind het toelaten, is het aan te raden dat het kind zelf over zijn of haar eigen reacties rapporteert. Bij jonge kinderen moet er vertrouwd worden op de beoordeling van ouders, maar hierbij moet

wel rekening gehouden worden met de potentiële invloed van de symptomen die ouders zelf ervaren.

Op de lange termijn lijken de meeste kinderen en ouders zich goed aan te passen. Dit is in overeenstemming met ander onderzoek waarin de meeste mensen na een traumatische gebeurtenis mentale veerkracht laten zien en geen langdurige klachten ontwikkelen. Eén van de factoren die mogelijk bijdraagt aan deze veerkracht is de vaardigheid om, afhankelijk van wat de situatie van je vraagt, flexibel gebruik te maken van bepaalde *coping*- en emotiereguleringsstrategieën. In ons onderzoek zagen we dat ouders tijdens de wondverzorging van deze vaardigheid gebruik maakten: ze probeerden hun emoties tijdens de wondverzorging te onderdrukken om er voor het kind te kunnen zijn, maar deelden deze emoties na de wondverzorging wel met anderen. Mogelijk draagt deze vaardigheid ook bij aan positieve uitkomsten voor de ouder en het kind op de lange termijn, maar dat zou verder onderzocht moeten worden. Een andere factor die een rol zou kunnen spelen in de aanpassing na het ongeval is het vermogen van ouders om responsief te zijn tijdens de wondverzorging en na ontslag. Dit houdt in dat ouders in kunnen schatten waar het kind behoefte aan heeft en hierop in kunnen spelen. Eerder onderzoek geeft aanwijzingen dat responsief ouderschap het herstel van het kind na een traumatische gebeurtenis bevordert.

Implicaties voor de praktijk

Brandwondenzorg wordt verleend door een multidisciplinair team. Dit team bestaat uit onder andere artsen, (nazorg)verpleegkundigen, psychologen, pedagogisch hulpverleners, fysiotherapeuten, ergotherapeuten en maatschappelijk werkers. Al deze professionals kunnen een rol hebben in het verlenen van psychosociale ondersteuning. Dit kwam ook naar voren in de verhalen van ouders. Zo voelden ouders zich bijvoorbeeld opgelucht als de brandwondenarts hen vertelde dat ze de juiste eerste hulp aan hun kind hadden geboden of als hen verteld werd dat het goed zou komen met hun kind, en gaven ouders aan dat zij tijdens de opnameperiode goede zorg en steun van verpleegkundigen en pedagogisch hulpverleners hadden ontvangen. Desondanks bieden de resultaten van dit proefschrift aanknopingspunten om de ondersteuning van gezinnen tijdens de opnameperiode en na ontslag te optimaliseren. Hieronder bespreken we de implicaties voor de psychosociale zorg rondom de wondverzorging, vroege screening, preventie- en interventiemogelijkheden, en ondersteuning bij de sociale gevolgen van brandwonden.

Op basis van de resultaten in dit proefschrift, is het aan te bevelen dat ouders de mogelijkheid krijgen aanwezig te zijn bij de wondverzorging van het kind. De voordelen van aanwezigheid, zoals het veilige gevoel bij het kind en een gevoel van controle bij de ouder, wegen zwaarder dan de nadelen, aldus ouders. De bevinding dat latere intrusieve herinneringen van ouders geen betrekking hadden op de aanwezigheid tijdens de wondverzorging, pleit ook voor het bieden van deze mogelijkheid. Het is echter wel van belang dat de manier waarop ouders met deze wondverzorgingen omgaan goed in de gaten gehouden wordt. Mogelijk is het voor sommige ouders beter om tijdelijk niet aanwezig te zijn, omdat het bijvoorbeeld op dat moment te stressvol voor hen is. In alle gevallen is het belangrijk dat er zorg op maat wordt geleverd, aangepast aan de behoeftes van het gezin; er is geen 'one-size-fits-all' aanpak.

Om de stress bij ouder en kind tijdens de wondverzorging zoveel mogelijk te beperken, zijn er verschillende interventies mogelijk. Voor zowel ouders als kinderen is voorspelbaarheid en controle belangrijk. Dit kan bevorderd worden door voorbereiding en het geven van informatie tijdens de procedure (bijvoorbeeld over de wondgenezing). Ook kan ouders geleerd worden hoe ze het beste kunnen omgaan met hun emoties en hoe ze hun kind kunnen ondersteunen tijdens te procedure, wat het gevoel bij ouders versterkt dat zij een waardevolle en nuttige rol hebben tijdens de wondverzorging. Om dit te bereiken kunnen professionals positief gedrag van ouders bekrachtigen, hen concrete taken geven (bijvoorbeeld het wassen van de haren van het kind), en de toegevoegde waarde van hun aanwezigheid benadrukken. Het gevoel van controle bij kinderen kan vergroot worden door hen keuzes te bieden en door hen mee te laten helpen in de verzorging. Daarnaast kunnen verschillende niet-farmacologische strategieën (zoals afleiding, ontspanningsoefeningen, geleide fantasie, en cognitieve herstructuring in het geval van niet-helpende gedachten), aangepast aan de leeftijd van het kind, helpen bij het verminderen van pijn en stress.

Daarnaast zouden we in de klinische praktijk idealiter in een vroeg stadium willen bepalen welke gezinnen risico lopen op langdurige psychische klachten. Hierin biedt vroege screening een mogelijkheid. Screening kan zich richten op de psychische klachten die het kind of de ouder ten tijde van de screening ervaart, maar kan ook gericht zijn op risicofactoren voor langdurige psychische klachten (bijvoorbeeld grote angst of paniek tijdens het ongeval of het idee dat het kind het niet zou overleven). Eerder onderzoek bij kinderen die een ongeval hadden meegemaakt heeft laten zien dat het grootste deel van de ouders en kinderen dat risico loopt op langdurige klachten door middel van screeningsinstrumenten vastgesteld kan worden; de instrumenten hebben een hoge sensitiviteit. Dit is veelbelovend, maar soortgelijke screening is in

de brandwondenpopulatie nog niet onderzocht. Daarnaast laten de onderzochte instrumenten een matige specificiteit zien, wat betekent dat een deel van de ouders en kinderen onterecht wordt aangemerkt als risico lopend op langdurige klachten. Daarom is het aan te bevelen dat bestaande screeningsinstrumenten verder worden ontwikkeld en geëvalueerd, of dat nieuwe instrumenten worden ontwikkeld.

Hoewel sommige vormen van psychosociale ondersteuning (zoals psycho-educatie) aangeboden kunnen worden aan alle gezinnen, wordt aanbevolen dat specifieke preventie- en interventieprogramma's zich enkel richten op de gezinnen die een hoog risico lopen op langdurige psychische klachten. Het doel van dit soort programma's is om een chronisch verloop van symptomen te voorkomen. Eerder onderzoek gaf al aan dat blootstelling aan het trauma, aandacht voor de ouder-kind relatie en het aanleren van *coping* vaardigheden essentiële onderdelen van zulke programma's zijn. Hoewel deze programma's na ongevallen bij jonge kinderen voornamelijk op de ouders gericht zullen zijn, is de deelname van het kind zelf wenselijk als het oudere kinderen betreft. Wereldwijd staat het onderzoek naar preventie- en interventieprogramma's na ongevallen of ernstige ziektes bij kinderen nog in de kinderschoenen. Onderzoek is daarom nodig om vast te stellen of een chronisch verloop van klachten hiermee te voorkomen is.

In het huidige onderzoek werden gezinnen tot 18 maanden na het ongeval gevolgd, maar de gevolgen van een brandwondenongeval kunnen zich uitstrekken tot ver na deze periode. Littekens blijven levenslang bestaan en kinderen kunnen in de loop van hun leven met nieuwe uitdagingen te maken krijgen. Om inzicht te krijgen in deze gevolgen op de lange termijn, zijn systemen nodig om gezinnen over een langere tijd te volgen.

Ook aandacht voor de sociale gevolgen van brandwonden bij kinderen is wenselijk in de voorbereiding op het ontslag en in het nazorgtraject. Voor kinderen en jongeren kan het een uitdaging zijn om hun nieuwe uiterlijk te accepteren en om te gaan met de reacties van anderen. Een belangrijk punt is de terugkeer naar school. Een schoolbezoek met een hulpverlener uit het brandwondencentrum kan ervoor zorgen dat klasgenoten leren over de fysieke en emotionele gevolgen van een brandwondenongeval en kan de terugkeer naar school vergemakkelijken. Daarnaast kan lotgenotencontact, bijvoorbeeld tijdens vakantieweken voor kinderen met brandwonden, van waarde zijn.

Conclusie

Brandwonden tekenen niet alleen de buitenkant van het kind; ze laten ook innerlijke littekens in het gezin achter. Beide soorten littekens behoeven aandacht. Dit proefschrift richtte zich op de psychische impact van brandwonden bij het kind op het gezin.

Ondanks de grote acute impact van een brandwondenongeval, lijken de meeste kinderen en ouders zich op de lange termijn goed te herstellen. Een aanzienlijke groep ouders, voornamelijk moeders, lijkt echter risico te lopen op langdurige posttraumatische stressklachten. Klinische aandacht voor aanhoudende negatieve emoties (zoals angst, verdriet, boosheid, en schuldgevoel) en negatieve interpretaties rondom het brandwondenongeval zijn van belang.

Levendige en emotionele herinneringen aan het brandwondenongeval en de ziekenhuisopname bleven bij zowel kinderen als ouders bestaan. Herinneringen aan het ongeval zelf leken de grootste kans te hebben om herbeleefd te worden. Aangezien de ervaringen rondom de wondverzorging niet terug lijken te komen in latere herbelevingen en ouders verschillende voordelen beschrijven van het aanwezig zijn tijdens deze procedures, concluderen we dat ouders de optie moeten krijgen aanwezig te zijn.

De resultaten in dit proefschrift onderstrepen het belang van een gezinsfocus, zowel in onderzoek als in de klinische praktijk. De psychische reacties van kinderen, moeders en vaders zijn afhankelijk van elkaar en de bevindingen benadrukken dat de reacties van zowel kinderen als ouders aandacht behoeven in de opnameperiode en het nazorgtraject. Een focus op ouders kan indirect ook voordelen voor het kind hebben, doordat ouders daardoor beter in staat zijn hun kind te ondersteunen.

Vervolgonderzoek gericht op het ontwikkelen, evalueren en implementeren van screeningsmethoden om het risico op langdurige psychische klachten bij ouders en kinderen vast te stellen is aan te raden, evenals een focus op preventieve interventies om klachten op de lange termijn te voorkomen. Onze hoop is dat deze vormen van ondersteuning bijdragen aan het herstel van littekens in het hele gezin.

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About the author

On a warm summer's day in 1989 (the 14th of August), Marthe was born in Emmen. She grew up in Ede and Doetinchem, where she lived with her parents and her brother Thom. After graduating from high school, Marthe moved to Utrecht. She completed her bachelor in Pedagogical Sciences at Utrecht University, after which she graduated cum laude from the research Master's programme 'Development and Socialisation in Childhood and Adolescence', for which she was awarded the Best Student Prize. Still not tired of studying, she obtained her clinical Master's degree in 'Orthopedagogiek' and thereafter worked as a psychologist at Altrecht Jeugd for a year. In August 2014, she found a PhD project that perfectly fit her interest in children and (medical) trauma at the Association of Dutch Burn Centres and Utrecht University, under supervision of Dr. Nancy van Loey, prof. Rinie Geenen, prof. Peter van der Heijden and prof. Rens van de Schoot. In the fall of 2017, she moved to Brisbane, Australia, for three months, to visit and collaborate with the Burns and Trauma Research Group, under supervision of prof. Justin Kenardy and Dr. Alexandra De Young. Besides her research, Marthe joined the annual burn camps for children as a staff member. In addition, she found a way to combine her passion for research and music, by singing in a band called Minor Revisions. In the next year, she will continue her research at the Association of Dutch Burn Centres, combined with a part-time position as a post-doctoral researcher at the department of Methodology and Statistics of Utrecht University.

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Egberts, M. R., de Jong, A. E., Hofland, H. W., Geenen, R., & Van Loey, N. E. (2018). Parental presence or absence during paediatric burn wound care procedures. *Burns, 44,* 850-860.

Egberts, M. R., Geenen, R., de Jong, A. E., Hofland, H. W., & Van Loey, N. E. (Epub ahead of print). The aftermath of burn injury from the child's perspective: A qualitative study. *Journal of Health Psychology.*

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Vanbrabant, L., Van Aelst, S., **Egberts, M. R.**, van de Schoot, R., & Rosseel, Y. Comparing inequality-constrained robust and non-robust regression estimation methods for one-sided hypotheses.

Manuscripts in preparation

Egberts, M. R., Engelhard I. M., van de Schoot, R., Bakker, A., Geenen, R. van der Heijden, P. G., & Van Loey, N. E. Mothers' emotions after pediatric burn injury: Longitudinal associations with posttraumatic stress- and depressive symptoms 18 months postburn.

Brown, E. A., **Egberts, M. R.**, Wardhani, R., Kimble, R. M., Griffin, B., Storey, K., & Kenardy, J. A. A qualitative study on communication between parents and healthcare professionals during the first pediatric outpatient burn dressing change.

De Young, A. C., **Egberts, M. R.**, Kimble, R. M., & Kenardy, J. A. Screening for parental posttraumatic stress after accidental injury in a young child: An evaluation of three measures.

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Veen, D., & **Egberts, M. R.** (submitted). Change analysis as predictor for factor scores: Modeling choices and strategies. *Small Sample Size Solutions – Part I.*

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Prizes & Awards

Professions Allied to Medicine (PAM) prize for the best presentation during the *17th European Burns Association Congress* in Barcelona, Spain

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