

Beyond pediatric burns

A family perspective on the psychological
consequences of burns in children

Anne Bakker

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Beyond pediatric burns

A family perspective on the psychological
consequences of burns in children

Na een brandwondenongeval bij een kind

Een gezinsperspectief op de psychische gevolgen
van brandwondenongevallen bij kinderen
(met een samenvatting in het Nederlands)

Proefschrift

ter verkrijging van de graad van doctor aan de Universiteit Utrecht op gezag van de
rector magnificus, prof.dr. G.J. van der Zwaan, ingevolge het besluit van het college
voor promoties in het openbaar te verdedigen op dinsdag 3 september 2013 des
middags te 2.30 uur

door

Anne Bakker

geboren op 10 mei 1981
te Muiden

Promotoren: Prof.dr. M.J.M. van Son
Prof.dr. P.G.M. van der Heijden
Co-promotor: Dr. N.E.E. Van Loey

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General introduction



“You see, one stupid accident and not even very large burn injuries. But the consequences and discomfort are still enormous. He does not have difficulties at the moment, he is far too young. Hopefully, it stays that way. We will see. Day by day. Step by step. Like we have always done.”

(Mother of a toddler with burns in:
Mijn zachtste huid. Over leven met brandwonden,
[My softest skin. About living with burn scars], p. 22)

This short quote from a mother whose child sustained accidental burn injuries -beautifully photographed by Lieve Blancquaert- aptly displays some of the characteristic features of pediatric burn injuries. Many can relate to the devastating effects of burn injuries in children, parental concerns about potential future psychosocial problems, and the impact on the entire family. European research on this topic is scarce. With financial support from the Dutch Burn Foundation and the Foundation Child & Burn, the Association of Dutch Burn Centres initiated a research project within the Psychosocial and Behavioural Research Program on the psychological impact of pediatric burns. Results of this study are described in this dissertation. In this introductory chapter, we describe the epidemiology, physical aspects, and treatment of pediatric burns, we provide a background on the psychological and social impact of pediatric burns, and we present the aims of our research and the outline of this dissertation.

PEDIATRIC BURNS

Epidemiology in the Netherlands

In the Netherlands, each year approximately 260 children (0-19 years) are admitted to a specialized burn center, located in Groningen, Beverwijk, and Rotterdam (Van Baar, 2013). These children only represent the most severe cases of burn injuries, with approximately 3000 children presenting to the emergency department with burns (Van Baar, 2013). Young children account for approximately two-thirds of the pediatric burn population and one fourth of the total burn population in the Dutch burn centers (Van Baar, 2013). The vast majority of burns in young children result from accidents with hot fluids in the home setting. Young children's natural curiosity, rapid motor and cognitive development, and inability to recognize dangerous situations contribute to an increased risk in these young children. In older children (5-19 years), burn injuries are more often caused by flames. In both age categories, boys are approximately twice as often admitted to a burn center than girls (Vloemans et al., 2011). The international literature suggests a considerable proportion

of pediatric burns to be the result of abuse or serious neglect, but an estimation of the prevalence of this problem is not available for the Netherlands.

Physical Aspects

Burn injuries may cause severe damage to the skin. The skin is the largest human organ and protects us against external factors such as cold, heat, bacteria, and protects our body from excessive fluid loss. Moreover, the skin helps to regulate our bodily temperature, plays a key role in sensation, and it shapes our esthetical appearance. Burn injuries not only locally damage the skin, but severe burns may as well cause a systemic response in the body.

The severity of a burn injury is dependent on the depth and extent of the injury, and the location on the body. The depth of a burn, regularly expressed as first, second, or third degree burn injury, refers to the damaged layers of the skin. A first degree burn touches only the outer layer of the skin, the epidermis, and does not damage the underlying skin structures. Second degree burn injuries do affect the lower dermis and are further subdivided in superficial- and deep second degree burns. Superficial second degree burn injuries have the ability to heal spontaneously without or only with minor scars. The healing process of deep second degree burn injuries, however, is more difficult and operative procedures may be necessary to close the wounds. Third degree burn injuries are the most devastating burns and damage the skin as deep as the subcutaneous fat layer. Deep second and third degree burn injuries will by definition cause permanent scarring. Another aspect of injury severity is the extent of a burn, mostly expressed as an estimation of the Total Body Surface Area (TBSA) with second or third degree burn injuries. To visualize, the surface of the hand palm (fingers closed) equals approximately 1% of the total body. The location of the burn, finally, may also partly determine the severity of the injury. Burns on for instance hands may limit functionality and burns on the chest area are associated with bad quality scars (Middelkoop, Monstrey, Téot, & Vranckx, 2011).

Treatment

As a general rule, only children with more severe burn injuries are admitted to a specialized burn center. Dutch referral criteria for children include burns greater than 5% TBSA, and burns in particular areas of the body, such as the face, hands, feet, perineum, genitalia, and major joints (for all referral criteria of the Emergency Management of Severe Burns course, see Vloemans et al., 2011).

Burn wound treatment may vary according to the severity of the injury, but an admission to a burn center often includes the following aspects. The primary survey of pediatric burn patients equals other trauma patients and vital functions (e.g., airway, breathing, circulation) are checked. Burn injuries cause severe pain, so pain medication is

started as soon as possible (Baartmans, Stas, Dokter, & Boxma, 2008). Further individual treatment is dependent on the estimation of the extent and depth of the wounds. Second degree burn injuries are mostly treated with ointments and dressings. Daily wound care procedures include removal of dressings, cleaning of the wounds, disinfection, debridement of dead tissue, and application of new dressings. As wound dressing changes may cause severe (procedural) pain, additional pharmacological and nonpharmacological interventions are used during these procedures (De Jong et al., 2010). In case of deep second or third degree burn injuries, surgical procedures to transplant skin from healthy parts of the body on the wounded area are by definition necessary in order to obtain wound closure. After a week, it is clear whether the skin transplant is successfully attached to the skin. Between 2000 and 2007, 27% of 0-4 year old children and 48% of 5-17 year old children admitted to a Dutch burn center required such a surgery during initial hospitalization (Vloemans et al., 2011).

Burn treatment may take several days, weeks, or even months depending on the severity of the injury and potential complications. The median length of stay in the burn center is 7 days for preschool-aged children and 10 days for school-aged children. Of notice, 30% of preschool- and 46% of school-aged children are hospitalized for 14 days or longer (Vloemans et al., 2011). During admission, treatment is provided by multidisciplinary teams including, but not restricted to, doctors, nurses, surgeons, physiotherapists, social workers, psychologists, and child life specialists. After discharge from the burn center, the evolution of the wounds and scar maturation is followed-up in outpatient clinics. It may take 1-2 years, before scars have completely matured and reached their final appearance (Middelkoop et al., 2011). In case of severe burn injuries or contractures, multiple reconstructive surgeries for functional or esthetical purposes may be necessary throughout the life span. The specific provision of psychosocial aftercare may differ somewhat across burn centers, but aftercare nurses and psychologists are part of the multidisciplinary outpatient teams that monitor the child's wound healing and scar formation. Initiatives to support children with burns and their families include return-to school projects, camps for 8-17 year old burn survivors, and a nationwide annual information meeting for parents.

PSYCHOLOGICAL AND SOCIAL IMPACT

Burns as a Traumatic Event

Burn injuries are considered one of the most traumatic injuries children may be faced with (Bakker & Walstra, 2013; Landolt, Buehlmann, Maag, & Schiestl, 2009). The sudden occurrence of the injury, threat to the bodily integrity, the invasive character and pain associated with medical procedures, and the additional burden of permanent scarring, an altered ap-

pearance and potential functional limitations are highly stressful. Although particular aspects of burn injuries such as daily recurrent wound dressings and scarring may distinguish burns from other pediatric populations (Liber, Faber, Treffers, & Van Loey, 2008), there are as well commonalities such as perceived life threat, feelings of helplessness, and uncertainty regarding the future.

Psychological Impact on Children

To date, a large body of literature has documented the considerable psychological impact of pediatric medical traumatic events on preschool- and school-aged children and their parents (Kazak et al., 2006). For instance, researchers have described symptoms of acute and posttraumatic stress and anxiety among injured and acutely ill children (Bronner, Knoester, Bos, Last, & Grootenhuis, 2008; Kassam-Adams et al., 2012; Meiser-Stedman, Smith, Glucksman, Yule, & Dalgleish, 2007). Moreover, research has shown that young children's responses to trauma are not by definition transient and symptoms may in fact become chronic if left untreated (De Young, Kenardy, & Cobham, 2011; Kazak et al., 2006).

The psychological impact of medical events may extend beyond the period of the acute medical trauma and hospitalization, resulting in long-term posttraumatic stress responses (Kazak et al., 2006). Children with burns may be continuously challenged as a result of their injuries and treatment, such as dressing changes and wearing pressure garment after discharge from the hospital, and in the longer run permanent scarring, potential loss of functionality, and a need for (multiple) reconstructive surgeries. Apart from the burden of repeated hospitalizations and invasive medical procedures, which may be considered ongoing potentially traumatic experiences, children with burns are confronted with lifelong alterations to their appearance. Children with (congenital or acquired) disfigurements, or less negatively framed as 'visible differences', may have a negative self-perception and experience difficulties in social interaction (Rumsey & Harcourt, 2007).

So far, few prospective studies have been conducted in the (sub)acute phase of the burn event and previous longitudinal studies focused only on the first 6 months after the injury. Consequently, there is a need for prospective studies that extend beyond the first 6 months after the burn event and that focus on early indicators to detect children at risk.

Psychological Impact on Parents

An important finding in the field of unintentional pediatric injury is that parents are as much, or sometimes even more, affected than the child (Kazak et al., 2006; Langeland & Olff, 2008). Witnessing the actual burn event of their child, fearing the child's life, being con-

fronted with the child's pain and serious skin damages, and experiencing feelings of uncertainty and uncontrollability regarding the future can be overwhelming for parents. Being confronted with an event that involves serious injury in a child specifies as a traumatic event for parents (APA, 2000). Consequently, parents may develop symptoms of traumatic stress, or even posttraumatic stress disorder (PTSD).

Apart from the *personal* impact of such a traumatic experience for the parent, previous research in the field of child (medical) trauma has consistently shown that parents' reactions to trauma are related to adverse child adjustment to the trauma (Alisic, Jongmans, van Wesel, & Kleber, 2011; De Young et al., 2011; Landolt, Ystrom, Sennhauser, Gnehm, & Vollrath, 2012; Langeland & Olff, 2008). Also after a pediatric burn trauma, it has been reported that parental and child posttrauma response were related to each other (e.g., Graf, Schiestl, & Landolt, 2011; Hall et al., 2006; Stoddard et al., 2006). Different mechanisms are hypothesized to contribute to this interrelatedness on posttrauma outcome within families, including parenting models referring to a decreased parental capacity to provide the child with an emotionally safe posttrauma environment, bidirectional models, in which symptomatology of different family members are thought to directly influence each other's symptomatology, and shared genetic vulnerability models hypothesizing that a shared genetic vulnerability in parents and children underlies the co-occurrence of posttrauma symptoms (De Young et al., 2011; Langeland & Olff, 2008).

To date, the knowledge on parents' responses to their child's medical condition is dominated by literature on mothers (Phares, Lopez, Fields, Kamboukos, & Duhig, 2005). Also in the literature on psychological consequences of pediatric burns, the perspective of fathers is missing. This hampers our understanding of both the impact of a medical traumatic event on couples and on potential posttrauma interactions between children and their fathers. A more detailed understanding of the family and its different subsystems may contribute to more knowledge about family posttrauma functioning.

A Bioecological Perspective on Postburn Adjustment

Bronfenbrenner's bioecological perspective on child development may be helpful to frame and understand child postburn adjustment from a broader perspective than the individual child. The bioecological model hypothesizes that the child develops through reciprocal interactions with persons, objects, and symbols within its different immediate environments (Bronfenbrenner & Morris, 2006). Both the child, with its biological, genetic, and personal characteristics, and the environment, consisting of different concentric structures surrounding the child, are acknowledged in this view on child development. Most closely to the child, the microsystem consists of the immediate settings the child participates in, such as the family (further composed of different, overlapping, subsystems like the mother-

father or parents-child subsystem), the classroom, and peers. Adaptation to an adverse event or resilience may in this perspective be framed as the result of interactions between the individual and its environments, rather than a characteristic of the individual child (Ungar, Ghazinour, & Richter, 2013). This ecological perspective on adjustment stresses the need to look beyond the individual and investigate the child within its significant environments.

Research Aims

Based on the scarcity of prospective studies and limited knowledge about fathers and couples and informed by the bioecological model, this thesis aimed to examine the psychological consequences of pediatric burns from a family perspective. Our primary focus and subject of most chapters was the family, which is the most direct and important environment for preschool-aged children (0-4 years). In prospective studies, we investigated the impact of a pediatric burn event on parents, and the interrelatedness between mothers and fathers and between parents and their child. We aimed to study short-term as well as longer-term effects on the family. We further examined the importance of another context for children, that is a peer group of children with burns, in a study about potential benefits from burn camp participation.

Specific aims of this thesis were to:

- Inform clinical practice about potential problems and related variables in young burn survivors and their families by means of a literature review
- Investigate postburn adjustment in preschool children with acute burns and the relationship with parental stress symptoms
- Investigate short- and long-term symptoms of traumatic stress in parents and couples
- Examine potential benefits of participating in a camp for young burn survivors.

Outline of this Dissertation

In Chapter 2, we review the empirical literature published in the past two decades on psychological, behavioral, and social outcomes in young burn survivors (0-28 years) and their families. The aim of this review is to provide an overview of postburn outcomes and associated variables that may assist clinical pediatric burn practice and to reveal methodological shortcomings that may assist scholars designing future studies in the field of pediatric burns.

Chapters 3, 4, and 5 contain results from a large prospective study on postburn adjustment in preschool children with burns and their parents. This study was conducted between 2007 and 2011 in seven burn centers in the Netherlands (Groningen, Beverwijk, and Rotterdam) and Belgium (Antwerp, Leuven, Neder-over-Heembeek, and Gent). Preschool children (0-4 years) were focus of this study, as they constitute an important risk group and burn injuries in this age group share many characteristics in terms of etiology and place of the burn accident. Mothers and fathers were both invited to participate and report on their child's behavioral problems and concerns about the child (at 3 and 12 months postburn) and their own symptoms of traumatic stress (within the first month, and at 3, 12, and 18 months postburn). In Chapter 3, we investigate acute stress symptoms in mothers and fathers and variables associated with parental acute stress symptoms. In Chapter 4, the relationship between parental acute stress symptoms and child behavioral problems is examined. Further, the relationship between parental acute stress symptoms and subsequent burn-related worries about the child is subject of study. Chapter 5 describes the course and predictors of parental traumatic stress symptoms in couples from hospitalization until 18 months postburn.

In Chapter 6, we focus on the long-term psychological impact of pediatric burns on mothers. In this study, maternal stress symptoms were assessed at 1 year and at 11 years after the burn event, providing a unique perspective on long-term consequences for mothers.

In Chapter 7, we turn to another potential important environment in the context of child postburn adjustment: burn camps, a week-long program for children with burns (8-17 years). We will examine possible benefits of burn camp participation on children's feelings of self-esteem, appearance-related satisfaction, and we report on participants' and their parents' perspectives on gains derived from the child's burn camp participation.

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Psychological Consequences of Pediatric Burns from a Child and Family Perspective: A Review of the Empirical Literature



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ABSTRACT

In order to inform clinical practice, we reviewed the empirical literature on emotional, behavioral and social outcomes in children with burns and their families published between 1989 and 2011. A systematic search of the literature yielded 75 articles. Qualitative synthesis of the results showed that child anxiety, traumatic stress reactions, and behavioral problems were considerably prevalent in the first months after the burn event. Among parents, high rates of posttraumatic stress, depressive symptoms, and guilt feelings were found. Cross-sectional studies, often performed many years after the injury, suggest that some children experience long-term psychological problems, such as anxiety, depression, and difficulties with social functioning. However, there was little evidence that behavior in general, self-esteem, or body image were impaired in the total population of children with a history of burns. Long-term family outcome studies suggest that psychological problems persist in a substantial subgroup of parents. Child peritraumatic factors anxiety and pain, parental posttrauma psychological reactions, and family functioning were the most consistently reported factors associated with child outcome. More recent studies have demonstrated that burn severity may have an indirect effect on child postburn psychosocial outcome. Clinical implications, methodological strengths and limitations of the reviewed studies, and directions for future research are discussed.

Keywords: children, burns, parents, family, adjustment, predictors

PSYCHOLOGICAL CONSEQUENCES OF PEDIATRIC BURNS FROM A CHILD AND FAMILY PERSPECTIVE: A REVIEW OF THE EMPIRICAL LITERATURE

The confrontation with serious pediatric burns irrevocably evokes questions about the child's and the family's adjustment and emotional wellbeing after the burn. Pediatric burn injuries suddenly disrupt normal life, threaten the child's health and bodily integrity, and may require intensive and long-lasting physical treatment. Children are possibly faced with permanent scarring and in some cases with limited functionality. How will these children be doing after hospitalization and later on in their lives? And how can they and their families be most effectively supported to cope with potential difficulties along their way? The purpose of this review is to contribute aggregated evidence on postburn adjustment in order to enhance clinical aftercare and future research on children with burns and their families.

In 1991, Tarnowski et al. substantively summarized the research literature on child and family outcome after pediatric burns (Tarnowski, Rasnake, Gavaghan-Jones, & Smith, 1991). The authors found mixed results regarding psychopathology in children, but cautiously concluded that a minority, 15-20%, of children seemed to develop negative psychosocial outcome. Parents, in particular mothers, presented with high rates of emotional disturbance. The authors documented the relatively modest importance of demographic and injury factors on postburn outcome, opposed to a stronger relation with maternal adjustment and family functioning. Small sample sizes, poor participation rates, questionable representativeness, lack or difficulty in assessment of premorbid functioning, and the predominant use of unstandardized measures were commonly reported methodological shortcomings. The authors proposed areas in need of further examination, such as predictors of psychosocial outcome, family and sibling wellbeing, and specific areas of child outcome such as social functioning and posttraumatic stress disorder (PTSD).

In the past 20 years, multiple aspects of burn care have changed, which might have had implications for psychological adjustment. Advances in pediatric burn care including critical care, such as control of shock and sepsis, and surgical improvements have resulted in substantially higher survival rates of even the most severely injured children (Sheridan, 2002). To illustrate, children with massive burns $\geq 70\%$ TBSA (i.e., Total Body Surface Area burned, the estimated proportion of the body with second or third degree burns) now have a realistic chance to survive their injuries (Sheridan, 2002). The multidisciplinary team, including surgeons and nurses, social workers, psychologists, occupational and physiotherapists, child life specialists etc. has become increasingly acknowledged for optimal pediatric burn treatment (Arceneaux & Meyer, 2009). Pain registration, pharmacological, and nonpharmacological pain interventions are on the clinical and research agenda (De Jong et al., 2010). Today, parents can opt for rooming-in in most hospitals, or can stay nearby a

hospital in facilitated homes. Notwithstanding these significant changes, other important aspects of a burn trauma have remained the same. Burns are still associated with a significant amount of pain (Martin-Herz, Thurber, & Patterson, 2000). Hospitalization inevitably leads to separation from home and to family life disruption. Invasive medical procedures such as frequent wound dressing changes and skin grafting procedures are imperative. Deep dermal burns still cause permanent scarring, which may require medical attention throughout the life span. So in spite of many positive recent developments, burns may still have a tremendous psychological impact on the child and its family. The current review presents an updated overview of empirical evidence published in the past two decades concerning psychological outcome following pediatric burns in children and their families and factors associated with this outcome.

METHOD

Selection of Studies

Electronic databases PubMed/ MEDLINE and PsycINFO were searched for English-language empirical studies, published between January 1989 and December 2011. Search terms included combinations between keywords: 'children', 'parent'; 'burns', 'thermal* AND injur*'; 'psycholog*', 'behavio*', etc. Reference sections of the selected articles were hand searched to find additional eligible articles.

Inclusion and Exclusion criteria

Articles were included if they described: (a) empirical data on the presence and/or predictors of child and/or family postburn behavioral, psychological, or psychiatric outcome; (b) children, adolescents, and/or young adults, up to 28 years, with childhood burns (0-18 years); and (c) burns resulting from flame, hot fluid, chemicals, contact, electricity, or lightning that required hospitalization. Excluded were: (a) articles with quality of life or functional outcome data only; (b) articles with mixed populations, that is children and adults, without separate child data; (c) case studies or specific subgroups that would limit generalizability of this review's results; (d) papers not published in peer-reviewed journals, for example, book chapters; and (e) studies with a primary focus on prevention programs, epidemiology, or factors related to pediatric burns, instrument validation, management of or interventions for burn patients.

Coding of Studies

The literature search resulted in 3069 records of which 105 duplicates were removed. One reviewer (AB) subsequently screened titles, and if necessary abstracts, to determine

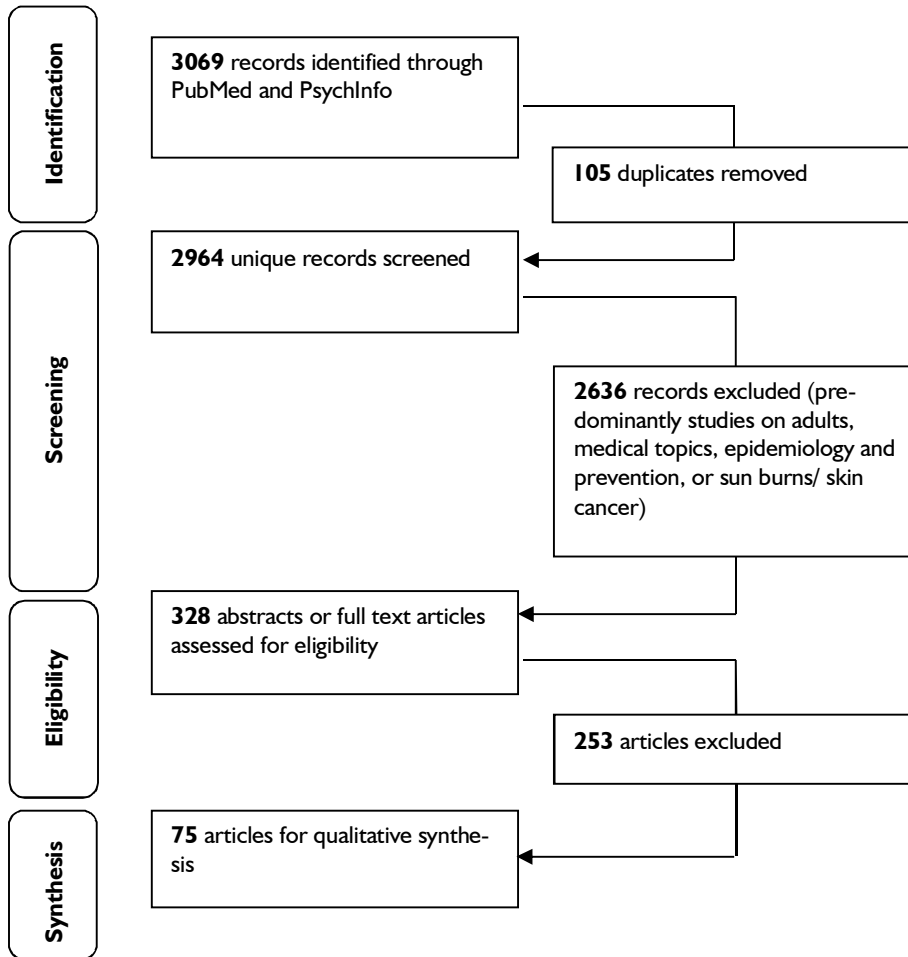


Figure 2.1 Flow diagram of study selection process

eligibility. Studies excluded in the first step of this process predominantly concerned adults, medical topics, epidemiology and prevention, or sun burns/skin cancer ($n = 2636$). Then, two reviewers (AB, KM) independently screened all 328 remaining abstracts, and if necessary full text articles. In case of disagreement, consensus was reached through discussion with a third reviewer (NVL). In sum, 75 articles met the inclusion criteria for this review (see Figure 2.1 for an overview of the study selection process).

A quality checklist (Latal, Helfricht, Fischer, Bauersfeld, & Landolt, 2009) concerning recruitment (avoidance of selection- and nonresponse bias), design (course of measurement, informants, type of controls), outcome assessment, confounding and effect modi-

fication was completed for each study. Interrater reliability on a random subsample of 20 articles in this study was acceptable (intraclass correlation coefficient = .78**). We primarily used the checklist to generate an overview of quality aspects of included studies. Further, synthesis of prevalence rates of psychological problems was guided by ratings for recruitment procedures. That is, we did not extract prevalence rates from 9 studies that neither reported their selection method, nor reported the response rate or had a response rate < 65%, nor described information on nonresponders (see also Tables 2.1 and 2.2).

RESULTS

Characteristics of the Studies

Tables 2.1 and 2.2 show study characteristics of child and family studies, main outcomes, and associated factors. Sample sizes ranged from 9 to 250. Three quarters of the studies had a cross-sectional design, and 74% used standardized validated measures. Notably, in 63% of the studies, the response rate was either not reported, or below 65%. Moreover, 70% of the studies did not report information on nonresponders.

Results from Child Studies

Anxiety and traumatic Stress

In preschool children, acute stress was reported in 25-29% of the children (De Young, Kenardy, & Cobham, 2011; De Young, Kenardy, Cobham, & Kimble, 2012; Stoddard, Saxe, et al., 2006). Separate symptom clusters were highly prevalent: 80% for reexperiencing, 62% for avoidance, and 39% for arousal (Stoddard, Saxe, et al., 2006). At 1 month postburn, 16% of a sample 0-4 year olds were newly diagnosed with separation anxiety disorder, which decreased to 8% at 6 months postburn (De Young et al., 2012). De Young and colleagues (2012) reported a high comorbidity between PTSD and other disorders at 1 month postburn, such as separation anxiety disorder and oppositional defiant disorder. Longitudinal analyses from 1 to 6 months postburn showed that most children had resilient or recovery patterns, but 8% had chronic PTSD and 2% were diagnosed with delayed onset PTSD (De Young et al., 2012). At an average of 1 year postburn, 13% of a sample of preschool children were diagnosed with PTSD (Graf, Schiestl, & Landolt, 2011).

In school-aged children, acute stress disorder (ASD) was diagnosed in 31% of the children within the first 2 weeks postburn (Saxe, Stoddard, Chawla, et al., 2005). Intrusion (79%), hyper arousal (72%), and dissociation and avoidance (44%) were highly prevalent. High self- or mother-reported state anxiety scores also pointed at (temporary) increased anxiety during hospitalization (Delgado Pardo, Garcia, Marrero Fdel, & Cia, 2008), but the

scores were lower in comparison with children awaiting minor surgery (Delgado Pardo, Garcia, & Gomez-Cia, 2010).

At an average of 4 years postburn, two cross-sectional studies found PTSD in 0 and 19% of school-aged children respectively (Fukunishi, 1998; Landolt, Buehlmann, Maag, & Schiestl, 2009). The first study (Fukunishi, 1998) had a small sample size ($n = 16$), used the adult PTSD algorithm, and the author suggested that the absence of long-term physical damage might have contributed to the favorable outcome. At an average of 14 years postburn, a diagnostic interview study documented PTSD in 9% of young adults with large burns (TBSA $\geq 30\%$) and 21% had experienced PTSD at some moment postburn (Meyer et al., 2007). Overall, anxiety disorders, 31% at the time of assessment, and 38% lifetime, were highly prevalent among these survivors of large burns. Qualitative studies documented the content of survivors' long-term concerns or worries. Examples are preoccupation with health, denial about what happened, awareness of changing relationships (Robert et al., 1997), and specific anxieties, such as being teased, or feeling anxious about minimal dressing for bathing (Rivlin & Faragher, 2007b).

In sum, several studies point at significant traumatic stress reactions in preschool children in the first year after the burn event, ranging between 25 and 30% in the acute phase to approximately 10% at 1 year postburn. Among school-aged children, acute stress was prevalent in one third of children and qualitatively strong cross-sectional studies found current PTSD in 10-20% of the children and young adults at many years postburn. Anxiety disorders were in the long run considerably prevalent among survivors of large burns.

Associated variables with anxiety and traumatic stress

In preschool children, demographic factors such as age (De Young et al., 2012; Graf et al., 2011), and gender (De Young et al., 2012) did not significantly influence stress and anxiety reactions. The size of the burn and length of stay in the hospital were linked to short-term traumatic stress (Drake et al., 2006), but only tentatively to PTSD approximately 1 year postburn (Graf et al., 2011). Incidental reports document a relationship between traumatic stress and an elevated heart rate, in-hospital pain (Stoddard, Saxe, et al., 2006), and aspects of burn treatment (De Young et al., 2012; Graf et al., 2011) in preschool children. Maternal PTSD symptoms and family relations were associated with stress reactions in young children in the first year postburn (Graf et al., 2011; Stoddard, Saxe, et al., 2006). Finally, some evidence exists for a relationship between acute stress during hospitalization and less vocalizations and smiles at 1 month after discharge in infants and toddlers. This may point at developmental risks associated with traumatic stress in young children (Stoddard, Ronfeldt, et al., 2006).

In school-aged children, pre-trauma factors younger age (Saxe, Stoddard, Hall, et al., 2005), body image (inversely related), and more previous life stressors (Saxe, Stoddard,

Chawla, et al., 2005) were related to acute stress. Burn extent indirectly affected child traumatic stress shortly after the burn event (Saxe, Stoddard, Chawla, et al., 2005; Saxe, Stoddard, Hall, et al., 2005), but not showed long-term effects (Landolt et al., 2009; Meyer et al., 2007). Separation anxiety, pain, and dissociation were related to PTSD at 3 months postburn (Saxe, Stoddard, Hall, et al., 2005). The relationship between pain and PTSD symptoms is of particular interest in burn practice, but not well understood. One study showed that a higher dose of morphine was related to a larger decrease in PTSD symptoms after 6 months (Saxe et al., 2001), emphasizing the potential role of pain in relation to psychological problems. At averages of 4 and 9 years postburn, PTSD symptoms were related to several subdomains of health-related quality of life (Landolt et al., 2009), and depression (Stoddard, Stroud, & Murphy, 1992). Long-term anxiety disorders were, like in the general population, more frequently diagnosed in female than in male survivors (Meyer et al., 2007; Rivlin & Faragher, 2007a).

In sum, the current level of evidence indicates that child-related factors, such as pain and separation anxiety, and parent-related factors, such as parental traumatic stress reactions, are linked to short-term child traumatic stress reactions. Importantly, the available evidence suggests a role of the injury and pain related to trauma symptoms in children of all ages. In the long run, anxiety was more prevalent in female than in male survivors and a co-occurrence with depression and impaired quality of life was found. Little is further known about risk factors for persistent anxiety.

Depression and mood disturbances

One study involving 16 children with minor burns reported no child depression at several weeks or at 4 years postburn (Fukunishi, 1998). However, two cross-sectional studies found major depression in 3% of 7-19 year olds at 9 years (Stoddard et al., 1992), and in 9% of young adults at 14 years postburn (Meyer et al., 2007). Both studies included survivors of extensive burns. Life time rates for depression were 27% (Stoddard et al., 1992), and 34% respectively (Meyer et al., 2007), which seems high in comparison to the general population (Bromet et al., 2011). Of notice, children often indicated a precursor other than the burns as the cause of their depression (Stoddard et al., 1992). Prevalence rates for any affective disorder were 18% at an average of 14 years postburn and 44% lifetime in survivors of large burns (Meyer et al., 2007).

Long-term cross-sectional studies on depression-related concepts, such as mood and psychological adjustment, have reported mixed results. Overall depression ratings in adolescents 3-14 years postburn were higher compared to both healthy controls and controls with fractures (Rivlin & Faragher, 2007b). Young adults with large burns, 14 years postburn, displayed more feelings of hopelessness and a considerable concern for suicide

probability compared to the norm (Rosenberg et al., 2006). Contrarily, at approximately 10 years postburn, adolescents with mild to moderate burns had similar or even lower depression scores than a normative group (Liber, Faber, Treffers, & Van Loey, 2008), or a control school sample (Pope, Solomons, Done, Cohn, & Possamai, 2007). Differences in burn severity across the samples, with the more positive studies comprising less severely injured adolescents (Liber et al., 2008; Pope et al., 2007), may have contributed to the divergent results. Further, sample bias might be under discussion, for example, 72% was lost to follow-up in one study (Liber et al., 2008), and 75% of another study sample was recruited through burn camps (Pope et al., 2007).

In sum, diagnostic studies have shown that depression might be a long-term problem for a small subgroup of survivors. Significant rates of depression were particularly found among survivors of large burns. Point prevalence rates seem comparable, but life-time rates were higher than the norm. Self-report studies found mixed results.

Associated variables with depression and mood disturbances

In line with the general population, female gender (Meyer et al., 2007; Orr, Reznikoff, & Smith, 1989; Pope et al., 2007), and the adolescent stage (Stoddard et al., 1992) were linked to depression in burn survivors. Cross-sectional studies did not find evidence for a relation between depression and time elapsed since the burn (Blakeney, Portman, & Rutan, 1990; Rosenberg et al., 2006), or burn extent (Pope et al., 2007; Rivlin & Faragher, 2007b; Rosenberg et al., 2006). Adolescents and young adults from more positively functioning families (Blakeney et al., 1990; Rosenberg et al., 2006), and with more social support from friends (Orr et al., 1989) were less depressed than others. Some personality characteristics were linked to postburn adjustment, that is, emotionally stable, and agreeable/ extravert persons reported less depression (Liber et al., 2008; Moore et al., 1993; Rosenberg et al., 2006). Finally, depression was linked to anxiety (Stoddard et al., 1992), worse quality of life, negative body esteem, and dissatisfaction with appearance (Pope et al., 2007).

Summarizing, female burn survivors of childhood burns seem at greater risk for experiencing depression. Other associations are less clear due to cross-sectional study designs, but family functioning, social support, and personality characteristics may play an important role.

Internalizing and externalizing problems

In preschool children, mothers observed disturbed externalizing behaviors, such as temper tantrums, and aggression in 28% of a sample shortly after discharge which increased to 53% at 2 months postburn and decreased to 33% at 6 months (Mason & Hillier, 1993a). A study on psychological morbidity in preschool children, assessed through diagnostic parent interviews, reported new onset oppositional defiant disorder in 14% of mildly injured pre-

school children at 1 month postburn which persisted in the majority of them at the 6-month measurement (De Young et al., 2012). A third study detected significantly more externalizing problems in 1-17 year olds, compared to hospitalized children awaiting a minor surgery (Delgado Pardo et al., 2010). At 6-12 months postburn, overall problem behavior of young children with moderate burns did not differ from norm data (Graf et al., 2011; Kent, King, & Cochrane, 2000).

Internalizing problems, such as anxious, depressed, or withdrawn behavior, were often investigated simultaneously with externalizing problems by means of the Child Behavior Checklist (CBCL). Several studies point at the presence of internalizing problems shortly after the burn: 22-25% of a sample of 2-14 years old children presented with clinical internalizing problems (Liber et al., 2006), a sample of toddlers with severe burns had significantly higher rates of sleeping, somatic, anxious/depressed, and withdrawal problems compared to the norm (Meyer, Robert, Murphy, & Blakeney, 2000), and high rates of anxious/ depressed problems were noted in a sample of school-aged children (Delgado Pardo et al., 2008). A qualitative interview study with mothers, finally, showed that 81% of a sample of 0-4 year olds displayed internalizing behaviors shortly after discharge, such as withdrawal and clinginess. The rates decreased to 61% and 44% at 2 and 6 months postburn respectively (Mason & Hillier, 1993a). Importantly, although longitudinal studies documented an overall decrease in internalizing symptoms, a minority of children continued to show problems at six months postburn (De Young et al., 2012; Mason & Hillier, 1993a).

In the long run, cross-sectional studies have reported clinical behavior problems ranging between 17% (Liber et al., 2008) and 37% (Meyer et al., 1994) according to parent reports. For youngsters' self-reports, the rates varied between 5% (Rosenberg et al., 2007) and 24% (Blakeney et al., 1998). Finally, teachers reported behavior problems in 42% of a sample of school-aged children (Andersson, Sandberg, Rydell, & Gerdin, 2003).

When comparing average behavior problem scores with normative data, many studies did not find significant differences between the group of children with burns and norm groups (Blakeney, Meyer, Moore, Murphy, et al., 1993; Landolt, Grubenmann, & Meuli, 2002; Liber et al., 2008; Rosenberg et al., 2007). Others reported elevated problem behavior scores, but noted that the scores were still within normal limits (Blakeney et al., 1998; Blakeney, Meyer, Moore, Broemeling, et al., 1993; Meyer et al., 2004; Russell et al., 2008). However, contrasting findings are also available. One study actually found significantly less internalizing and externalizing symptoms in a small sample of adolescents with burns, compared to same-age, same-gender friends (Barnum, Snyder, Rapoff, Manie, & Thompson, 1998), while other studies documented more internalizing and externalizing problems in school-aged children on average 7 years postburn compared to age- and gender-matched norm controls (Andersson et al., 2003), or less adaptive behaviors in 9-19

year olds at 1-5 years postburn (Meyer, Blakeney, LeDoux, & Herndon, 1995). One explanation may relate to the measure used, as nearly all studies used the CBCL or related instruments, whereas the latter studies used different instruments.

Notably, some studies encountered differences between cross-informants, with usually parents or teachers reporting more behavior problems than adolescents or young adults themselves (Blakeney, Meyer, Moore, Broemeling, et al., 1993; Meyer, Blakeney, Holzer, et al., 1995; Russell et al., 2008). Further, parents' and teachers' reports strongly correlated for social competence and externalizing problems, but not for internalizing problems (Andersson et al., 2003). Observations of informants may differ because of the setting in which they observe the child, for example, children may behave differently in the classroom in company of their peers, than at home. Otherwise, it has been suggested that children suppress or deny some difficulties, and parents may 'have developed habits of expecting their children to be distressed' (p. 567, Meyer, Blakeney, Holzer, et al., 1995). The observed inconsistency underlines the importance of consulting multiple informants (Meyer, Blakeney, Holzer, et al., 1995).

In conclusion, results suggest that the general level of long-term postburn internalizing and externalizing symptoms in young people with burns not greatly deviates from normative groups. Only a minority of young survivors is at risk for developing clinical behavior problems.

Associated variables with internalizing and externalizing problems

In preschool children, gender and age were not linked to short-term internalizing and externalizing symptoms (De Young et al., 2012; Graf et al., 2011). In school-aged children, short-term externalizing problem behavior was more often reported in boys and in older children (Delgado Pardo et al., 2010; Delgado Pardo et al., 2008). Postburn rated internalizing and externalizing symptoms did not differ from retrospectively determined pre-injury behavior in toddlers with large burns (Meyer et al., 2000). None of the preschool child studies found a relation between short-term postburn problem behavior and the extent of the burn (De Young et al., 2012; Graf et al., 2011; Kent et al., 2000; Mason & Hillier, 1993b; Meyer et al., 2000), or visibility of the burn (Kent et al., 2000; Mason & Hillier, 1993b). Family functioning (Graf et al., 2011), and maternal postburn psychological reactions were associated with total behavior problems in preschool children (Graf et al., 2011; Mason & Hillier, 1993b) and internalizing symptoms in a sample of 2-14 year olds (Liber et al., 2006). Finally, preschool children that met criteria for PTSD showed more internalizing and externalizing problems than children that did not meet criteria for PTSD (De Young et al., 2011).

Summarizing factors associated with in- and externalizing problems in the first months postburn, parental psychological reactions seem the most robust predictors for

(parent-reported) symptoms in the preschool child. Burn extent was not significantly associated with child symptoms.

Regarding long-term symptoms, only cross-sectional studies, with assessments ranging between 1 and 18 years postburn, are available. Information on the child's pre-trauma functioning was often missing. Socioeconomic status was not related to total behavioral problems in one study (Landolt et al., 2002), but another study found an influence of paternal education on the child's internalizing and externalizing symptoms (Willebrand et al., 2011). The majority of studies reported that burn size was not related to postburn total behavioral problems (Andersson et al., 2003; Blakeney, Meyer, Moore, Broemeling, et al., 1993; Landolt et al., 2002; Liber et al., 2008; Meyer et al., 2004; Rivlin & Faragher, 2007a; Willebrand et al., 2011). However, other studies noted a tentative relation between visible scarring and 'total psychological difficulties', hyperactivity, and inattention (Willebrand et al., 2011), and between poor hand functioning and an increase in internalizing symptoms (Baker, Russell, Meyer, & Blakeney, 2007). Time elapsed since the burn was not related to problem behavior in children with massive burns (TBSA \geq 80%) evaluated 0-13 years postburn (Blakeney et al., 1998). Parental stress, more conflict, less cohesion, and less expressed emotion within families were consistently linked to higher parent ratings of children's internalizing and externalizing problem behavior (Landolt et al., 2002; LeDoux, Meyer III, Blakeney, & Herndon, 1998; Meyer et al., 1994; Rosenberg et al., 2007; Willebrand et al., 2011), and parental psychological symptoms were related to less prosocial behavior in one study (Willebrand et al., 2011). Of notice, mostly the parent assessed both family functioning and child adjustment, which may have led to similarities among these reports. Anecdotic evidence was found for the role of social support (Barnum et al., 1998), and personal factors, such as hope (Barnum et al., 1998), coping style, and the personality dimension emotional stability (Liber et al., 2008).

In sum, findings from cross-sectional studies suggest that burn severity did not influence the level of long-term total behavioral problems in school-aged children. Family characteristics, such as more conflict and less cohesion, and parental stress were a much stronger predictor of the child's behavior. However, heterogeneity between the studies in terms of time frame and burn severity hampers the interpretation of several risk factors.

Social functioning

Studies on social functioning were performed at 0-14 years after the burn event and all were cross-sectional. Specific short-term information is not available. A considerable proportion of children experienced problems in domains of social functioning; 24-37% had troubled social competence scores at 0-13 years postburn (Blakeney et al., 1998) and 19% had problems with peers at 0.3-9 years postburn, compared to 10% in the norm popula-

tion (Willebrand et al., 2011). More than half of the studies that statistically compared competence scores with reference data or a control group reported significantly lower social competence in burn survivors (Andersson et al., 2003; Blakeney et al., 1998; Blakeney, Meyer, Moore, Broemeling, et al., 1993; Rivlin & Faragher, 2007b), but two studies added that the scores were still within normal limits (Blakeney et al., 1998; Blakeney, Meyer, Moore, Broemeling, et al., 1993). One study found competency scores comparable to published reference data (Meyers-Paal et al., 2000). Perhaps, scales used in studies that reported impaired social functioning, such as the Social Competence Inventory, and 'Peer problems' of the Strengths and Difficulties Questionnaire (Andersson et al., 2003; Rivlin & Faragher, 2007b; Willebrand et al., 2011) tap into other constructs than the social competence scale of the Achenbach measures used by others.

Children's experiences with bullying were investigated among 250 children attending pediatric burn camps (Rimmer et al., 2007). Between 39 and 61% reported they were bullied because of their burns and only half of them told an adult. This high rate may be specific to the research setting and needs replication. Nonetheless, the findings are considerable and address a potentially important understudied area of problems for young burn survivors. Finally, parents tended to underestimate feelings of stigmatization in children (8-18 years) that reported high levels of stigmatization their selves. In the low stigmatization group, however, there was no discrepancy between child self-report and parent report (Lawrence, Rosenberg, Mason, & Fauerbach, 2011).

In sum, social functioning in young people with burns might be more affected than their general behavior. Nevertheless, in most survivors, social functioning appeared not deviant from norm populations. Experiences with bullying and feelings of stigmatization warrant further investigation.

Associated variables with social functioning

Girls showed more prosocial behavior than boys (Andersson et al., 2003; Rivlin & Faragher, 2007a), which was in line with a reference population (Andersson et al., 2003). However, in a study investigating young survivors with large burns (mean TBSA 49%), girls were found to be less socially competent (Blakeney, Meyer, Moore, Broemeling, et al., 1993). Further, older children were more socially competent (Blakeney, Meyer, Moore, Broemeling, et al., 1993), but time elapsed since the injury, related with child age, was also positively associated with more problems with peers (Willebrand et al., 2011). Willebrand et al. (2011) suggested that older children get increasingly involved in social contacts outside the family and could therefore also experience more problems with peers. Of notice, time postburn was in survivors with massive burns not related to social competency (Blakeney et al., 1998). In some studies, burn-related factors were linked to social problems. For example, children with mobility problems were less competent in activities

(Moore et al., 1996), and children with visible scars more often reported bullying as a problem (Rimmer et al., 2007). Finally, parental depression and anxiety were related to more parent-reported peer problems and less prosocial behavior in the child (Willebrand et al., 2011).

In summary, the extent, visibility, or location of the burn may affect specific domains of social functioning, such as social activity competence or experiences with being bullied. More prospective information is needed on particular social difficulties and determinants.

Self-esteem

At 1 month postburn, self-esteem was comparable to reference data (Delgado Pardo et al., 2008). Four cross-sectional studies at 1-17 years postburn found that self-esteem in young burn survivors did not differ from norm data (Blakeney, Meyer, Moore, Murphy, et al., 1993; LeDoux, Meyer, Blakeney, & Herndon, 1996; Robert et al., 1999) or a comparison group of friends without burns (Barnum et al., 1998). Some of them reported that self-esteem was higher in particular subgroups (e.g., boys, Blakeney, Meyer, Moore, Murphy, et al., 1993), or on particular subscales, (e.g., social competence, Robert et al., 1999). Contrarily, the athletic competence and physical appearance domains of self-esteem in 14 adolescents with large burns were significantly lower than the norm (Robert et al., 1999).

Associated variables with self-esteem

Girls reported lower self-esteem than boys in one study (Orr et al., 1989). Most studies did not address the relationship between burn severity and self-esteem, but one found a negative relationship between scarring severity and self-esteem in boys (Abdullah et al., 1994). Social support from friends (Barnum et al., 1998; Orr et al., 1989), hope (Barnum et al., 1998), and a positive mood (Robert et al., 1999) were all positively associated with self-esteem in adolescents on average 5-10 years after a burn event. One study described that children "are satisfied with themselves in those areas they perceive as important" (LeDoux et al., 1996, p. 474). That is, children seem to value areas of functioning that cannot be changed, for instance physical handicaps, as less important than areas that they can actively influence. This positive use of denial was suggested a functional coping mechanism (LeDoux et al., 1996). Notably, this coping mechanism did not apply to the physical appearance domain (Robert et al., 1999).

In sum, self-esteem of young people with childhood burns in general does not seem to be impaired. A suggested coping mechanism, that is, being more satisfied in domains that young survivors designated important, may partly explain these positive findings and may be valuable information to assist children who experience more difficulties in this domain.

Body image

All three cross-sectional studies on body image or body esteem, performed at approximately 5, 8, and 12 years postburn respectively, reported comparable scores between young burn survivors and their peers (Jessee, Strickland, Leeper, & Wales, 1992), or even slightly higher scores when using standardized questionnaires and norm data (Lawrence, Rosenberg, & Fauerbach, 2007; Pope et al., 2007). This positive finding applied in one study to girls (Lawrence et al., 2007) and in another to satisfaction with weight and survivors' evaluations of how other people see their body or appearance (Pope et al., 2007). In both studies, half or more of the participants were recruited at burn camps. Of notice, Lawrence et al. (2007) documented that body esteem did not significantly differ between study participants recruited at burn camps and study participants recruited at burn reconstruction clinics.

Associated variables with body image

Both among 5-15 year old burn survivors and their age- and gender matched control subjects, older children reported a less positive body image (Jessee et al., 1992). This was not the case in two other studies that assessed 11-19 year old adolescents (Lawrence et al., 2007; Pope et al., 2007). Body esteem scores of female adolescents were higher than the norm (Lawrence et al., 2007), but comparisons between male and female survivors showed that females were at increased risk for very low body esteem scores (Lawrence et al., 2007), lower body image scores (Orr et al., 1989), and more negative evaluations of how others see their appearance (Pope et al., 2007). Adolescents with more severe burns had a more negative body image (Lawrence et al., 2007; Pope et al., 2007) and adolescents were less satisfied about body parts with scars than about body parts without scars (Pope et al., 2007). Subjective scar evaluations, parent-rated at approximately 8 years postburn, were modestly linked to body image (Lawrence et al., 2007). Finally, cross-sectional studies showed bivariate relationships between body image, quality of life, and mood (Pope et al., 2007), and between body image, feelings of stigmatizations, and social comfort (Lawrence et al., 2007).

In sum, although body image of young burn survivors in general did not differ from the norm, some findings are to be considered. Female gender and more severe scarring were associated with more negative self-evaluations in young people with burns. Furthermore, a negative body image tended to co-occur with a negative mood, impaired quality of life, feelings of stigmatization, and uncomfortable feelings in social situations.

Sexuality

The lack of a control group without burn injuries or an up-to-date or matched reference group made the results concerning sexuality somewhat difficult to interpret. However, a

cross-sectional study with young adults on average 10 years postburn did not find evidence for negative or impaired sexual beliefs and behaviors (Meyer, Russell, Thomas, Robert, & Blakeney, 2011). A minority (9%) of the young adults sexually active before the burn was not sexually active anymore after the burn.

Associated variables with sexuality

Sexual activity did not differ between male and female survivors during adolescence (Robert, Blakeney, & Meyer, 1998), but Meyer and colleagues (2011) reported that young male adults, as in the reference population, were lagging behind female burn survivors in terms of sexual experience. Burn severity was not related to sexual behaviors in adolescents or young adults with extensive burns (mean TBSA 39-54%, Meyer et al., 2011; Robert et al., 1998).

In sum, there is insufficient research on sexuality in young people with childhood burns to draw meaningful conclusions. Moreover, only the experiences of severely burned young people are documented. Replication of the findings in young people with less extensive burns and comparative studies with matched control groups are warranted.

Development

Only two studies addressed development in young children with burns (Gorga et al., 1999; Nayeb-Hashemi et al., 2009). Some concerns about developmental delays were noted, but methodological shortcomings, such as a large attrition rate (Gorga et al., 1999), small sample size, and a retrospective study design (Nayeb-Hashemi et al., 2009) limit any conclusions.

Sleep problems

Sleep problems after a burn event were rarely studied. A prospective clinical study reported fragmented sleep and the lack of normal sleep in a group of 1-16 year olds with acute burns, which improved in function of the number of days postburn (Gottschlich et al., 1994). Information on self-reported nightmares and enuresis on average 7 years postburn in another study (Kravitz et al., 1993) was not sufficiently reliable to draw conclusions.

Return to school

Missing school may be an important indicator for the impact of a burn event on school-aged children. A chart review study found that children with moderate burns (mean TBSA 14%) missed on average 38 days and returned to school approximately 10 days after discharge from the hospital. Apart from a longer hospital stay, male gender and an older age were independently associated with a longer time to return to school (Christiansen et al.,

2007). Engagement from school towards the family during hospitalization may foster a quick and successful return to school (Horridge, Cohen, & Gaskell, 2010).

Cognitive functioning

Too little evidence is available to draw conclusions on cognitive functioning in young burn survivors. The three available studies had very limited sample sizes, may be hampered by selection or nonresponse bias, and differed too much in outcomes studied (Barnum et al., 1998; Nayeb-Hashemi et al., 2009; Stokes, Dritschel, & Bekerian, 2004).

Results from Family Studies

Parental anxiety and traumatic stress

In the first months after a burn event, PTSD was reported in 9-19% of parents (Fukunishi, 1998; Hall et al., 2006), and one study showed clinically significant posttraumatic stress symptoms (PTSS) in 47% of parents (Hall et al., 2006). Symptoms of general anxiety were reported by 43-69% of parents in the acute phase (Kent et al., 2000; Phillips & Rumsey, 2008). A qualitative study conducted in the first days of hospitalization described that many parents expressed significant worries about their child, for instance about their child's health, pain, and its future (Thompson, Boyle, Teel, Wambach, & Cramer, 1999).

In the long run, diagnostic interview studies described PTSD in 0 of 16 mothers of children without sequelae at 4 years postburn (Fukunishi, 1998), in 16% on average 7 years postburn, and a life time prevalence rate of 52% in parents of severely injured children (Rizzone, Stoddard, Murphy, & Kruger, 1994). A longitudinal study showed self-reported PTSS in 42% of mothers at 1-2 years after the burn event and in 19% of mothers 10 years later (Bakker, Van Loey, Van Son, & Van der Heijden, 2010). A cross-sectional study found PTSS in 14-29% of parents at 1-5 years after the burn event (LeDoux et al., 1998). As only 29% of an original sample could be analyzed in one study (Bakker et al., 2010), and information on the response rate was absent in another study (LeDoux et al., 1998), generalizability is limited.

Associated variables with parental anxiety and traumatic stress

As nearly all study participants were mothers, there is no separate information on post-traumatic stress in fathers. Extended conflict with the family prior to the burn event, as indicated by the parent during hospitalization, influenced parents' dissociation reactions which in turn affected parents' PTSS at 3 months postburn (Hall et al., 2006). Burn extent was in most studies (indirectly) positively linked to short-term and long-term parental PTSS (Bakker et al., 2010; Hall et al., 2006; Rizzone et al., 1994). Finally, child dissociative reac-

tions during hospitalization affected parent PTSS at 3 months postburn through child PTSD symptoms (Hall et al., 2006).

A posttrauma risk factor for psychopathology of particular interest in parents of children with burns is feelings of guilt. Empirical studies, conducted at different time points postburn, showed guilt feelings in 27-81% of mothers (Bakker et al., 2010; El Hamaoui, Yaalaoui, Chihabeddine, Boukind, & Moussaoui, 2006; Mason, 1993; Rivlin & Faragher, 2007c). Guilt feelings appeared related to (specific) PTSS (Bakker et al., 2010; Fukunishi, 1998). For example, the level of maternal PTSS at 10 years postburn was particularly high in mothers who both expressed feelings of guilt at 1-2 years postburn and whose children had more extensive permanent scarring (Bakker et al., 2010).

In summary, a considerable proportion of parents seem to develop traumatic stress and anxiety reactions following their child's injury, which in some parents maintain for many years. Parents of more severely injured children might be affected more, although this association between burn severity and PTSS was not always a direct relation. Parental dissociation, anxiety, and guilt feelings may be important risk factors for parent PTSD.

Parental depression

Feelings of depression, measured with self-report questionnaires, were present in 19% and 44% of parents in the acute phase of a burn event (Fukunishi, 1998; Phillips & Rumsey, 2008). A longitudinal study demonstrated that in-hospital high depression rates decreased to a significantly lower level 6 months later (Kent et al., 2000). In another study, psychiatric morbidity was examined in mothers of preschool children from hospitalization until 6 months postburn. At baseline, mothers also rated their pre-injury feelings. Results showed a sharp increase of psychiatric morbidity after the burn event, from 7% to 81%. At 1 week, 2 and 6 months, the figures dropped to 37%, 32%, and 14% respectively (Mason, 1993).

At 0-5 years postburn, diagnostic studies detected major depression in 0 and 35.7% of mothers (El Hamaoui et al., 2006; Fukunishi, 1998), and studies with self-report questionnaires demonstrated symptoms of depression in 31-54% of mothers (El Hamaoui et al., 2006; Fukunishi, 1998; LeDoux et al., 1998; Phillips & Rumsey, 2008). Further, mothers experienced significantly more psychopathology at 3-14 years after their child's burn event than mothers of children with fractures or healthy children (Rivlin & Faragher, 2007c). Common symptoms included tiredness, guilt, worries, tension, and a depressed mood.

Associated variables with parental depression

A younger maternal age (Phillips & Rumsey, 2008), lower parental extraversion (Phillips & Rumsey, 2008), and previous mental health problems or family stressors, such as financial

problems (Mason & Hillier, 1993b), were associated with higher levels of depression. Two studies did not find a relation between burn size and depression in the first year postburn (Kent et al., 2000; Phillips & Rumsey, 2008), and two others found only tentative relationships (El Hamaoui et al., 2006; Mason & Hillier, 1993b). Associations were found between parental depression, parental worries about the child's pain, and poorer family functioning (Phillips & Rumsey, 2008), parental anxiety (El Hamaoui et al., 2006; Phillips & Rumsey, 2008), and decreased maternal global functioning (El Hamaoui et al., 2006).

In sum, approximately one third of mothers experienced depression in the aftermath of their child's burn event depending on the instrument and timeframe of the study. Preburn personal and socioeconomic characteristics contributed to postburn maternal depression.

Family functioning/ parenting stress

Three prospective short-term studies described that parenting stress and family characteristics, such as cohesion, control, and conflict were not deviant from reference data (Delgado Pardo et al., 2008; Liber et al., 2006; Phillips & Rumsey, 2008). Nonetheless, two child studies mentioned that a considerable number of families had suspect home environments (Gorga et al., 1999), or were considered high risk for child abuse (Meyer et al., 2000), pointing at serious premorbid family problems in some cases.

Long-term parents' and young adults' self-reported family functioning was comparable to reference groups (Phillips & Rumsey, 2008; Rivlin & Faragher, 2007c; Rosenberg et al., 2007). In some studies, cohesion and control (LeDoux et al., 1998), or emphasis on moral religion (LeDoux et al., 1998; Rosenberg et al., 2007) were elevated. This may be considered a response to the burn event and therefore indicative of family coping (LeDoux et al., 1998). On the other hand, some families experienced long-term problems. Studies reported for instance an increased divorce rate after a burn event (Blakeney, Meyer, Moore, Murphy, et al., 1993; Rivlin & Faragher, 2007c) and high levels of parenting stress in parents of children with severe burns (Blakeney et al., 1998; Meyer et al., 1994). Parents tended to attribute their stress to specific child characteristics, such as demandingness and mood (Blakeney, Meyer, Moore, Murphy, et al., 1993; Blakeney, Moore, et al., 1993).

Associated variables with family functioning/ parenting stress

Both family functioning and parenting stress were in many studies evidently related to child adjustment (e.g., Landolt et al., 2002; Liber et al., 2006; Meyer et al., 1994; Rosenberg et al., 2007), but not to burn severity (Blakeney, Moore, et al., 1993; Meyer et al., 1994).

To summarize, general family functioning seems not deviant from reference data and adaptive family outcomes in response to the child's burn event, such as more cohesion or more emphasis on religion, have been suggested. However, parents may experience

increased levels of parenting stress related to particular characteristics of the child. Family functioning was consistently found to have an important impact on child outcome.

Sibling functioning

A cross-sectional study found that siblings, at least 5 months after the injury, had similar or less behavior problems than a normative group. However, social competency seemed impaired, in particular in siblings of a brother/sister with moderate or severe burns (Mancuso, Bishop, Blakeney, Robert, & Gaa, 2003). Brothers and sisters, on average 2.6 years after the burn event, retrospectively indicated that they would have wanted to be more involved in the care for their injured sibling (Phillips, Fussell, & Rumsey, 2007). Further, siblings reported they felt upset the first time they saw the burn wound, pointing at the importance of sensitive preparation before visiting the burn center (Phillips et al., 2007). The response rate of 24% hampers the reliability of the findings.

In the longer run, parents indicated in qualitative parts of cross-sectional studies that siblings had become more mature, protective, and closer to the injured sibling (Mancuso et al., 2003). Siblings themselves reported warmth and closeness in their relationships with the injured sibling and a gradual normalization process covering family relations, equal parental treatment to the injured child and the noninjured sibling, and the resumption of normal activities (Lehna, 2010).

In sum, incidental reports documented no deviations concerning sibling problem behavior, but the finding on impaired social functioning may call for further investigation. Apart from difficulties in the period of hospitalization, siblings also reported positive aspects such as more closeness and warmth.

DISCUSSION

Clinical Implications of Synthesized Results

A substantial proportion of children was consistently found to display at least some distressed behavior during hospitalization and within the first months after the burn. Acute and posttraumatic stress was prevalent in one fourth to one third of the different study samples. Recent studies highlighted that even children below the age of five, who constitute an important risk group for pediatric burns, experienced PTSS. In children, increased rates of internalizing problems, such as anxiety and withdrawal, and externalizing behaviors, such as aggression and oppositional defiant behavior were found shortly after the burn. Parents may experience profound guilt and depressive feelings, anxiety, traumatic stress, and many worries about their child's health and future appearance. These short-term results concur with other pediatric medical trauma literature and may be interpreted as transient, normal

reactions to stressful events, which may help children to adapt to their situation (Kazak et al., 2006).

Despite a gradual decrease in symptoms reported in some longitudinal studies, the first phase after a burn event should be considered a critical and highly demanding phase for children and their families which requires efforts from all involved in clinical pediatric burn practice. In this phase, child and family support from a trauma-informed health care system is indispensable, such as information provision about normative emotional reactions in children and their families, or consultation from psychologists to the health care team about the potential impact of particular experiences in the hospital (Kazak et al., 2006). Consideration of the child's developmental stage is important in burn care and "effective use of psychological interventions can dramatically reduce pain and suffering for children and adolescents who have burn injuries" (Dise-Lewis, 2001, p. 255). This review indicates that reactions of the family are important to consider as well, because they affect both the parents' and child's well-being. In older children, attention should be paid to prior life stressors and the child's body image, as they may affect their postburn traumatic stress responses. Importantly, results suggest a significant role of pain during hospitalization on subsequent short-term traumatic stress symptomatology which warrants clinical attention and adequate pain interventions (Martin-Herz et al., 2000). Although the mechanism behind the relationship between pain and traumatic stress is not yet clear, some studies suggest that pharmacological interventions to reduce pain may also reduce acute- and post-traumatic stress symptomatology (Ratcliff et al., 2006; Saxe et al., 2001). These results underline the need for further research on this topic in order to be better able to anticipate on this aversive effect of burn injuries.

In the context of child postburn adaptation, the child's and family's background are important to consider as well. Epidemiological studies have suggested that child preburn behavior problems, (e.g., Piazza-Waggoner et al., 2005; Rowe, Maughan, & Goodman, 2004), a poor socioeconomic family background (e.g., Joseph, Adams, Goldfarb, & Slater, 2002), or (suspected) cases of child abuse or serious neglect (Peck & Priolo-Kapel, 2002; Thombs, 2008) are well present in the pediatric burn population. Regarding this latter factor, estimated prevalence rates of pediatric burns related to child abuse range between 1-25% (Thombs, 2008). Most studies in this review did not report whether or not (suspected) cases of abuse were present in their samples and its specific impact may not be entirely clear. Nonetheless, the considerable prevalence rates warrant clinical attention in order to detect whether or not the burn event is part of a pattern of child abuse or neglect, for obvious reasons, but also in terms of recognition and consequences for the child's postburn psychological functioning.

In the longer run, cross-sectional studies on psychological functioning showed some overall trends that may be relevant for clinical practice. First, diagnostic outcome studies found considerable rates of anxiety and affective disorders in adolescents and young adults with burns.¹ Contrarily, the vast majority of self- or parent-report studies did not show evidence of worse psychological or behavioral postburn outcomes on a group level compared to the norm. Furthermore, despite great challenges that children may face as a result of their changed functional abilities and appearance, young burn survivors as a group did not have substantial different thoughts and feelings about their self-worth, competencies, bodies, or sexual relationships. Some evidence exists for a modest decrease in social functioning and for concerns about children's experiences with being bullied or feelings of social stigmatization. Regarding family outcome, general family and sibling functioning did not seem to be negatively affected by the burn event. However, maternal depression and anxiety were highly prevalent long-term after the burn event and therefore essential to monitor. Furthermore, parenting stress and siblings' feelings about postburn support may be important to address as well. In order to prevent distortion of beneficial family processes and subsequent problems in survivors and siblings, medical care may be vigilant for disruption of family processes and may provide family support where necessary.

These longer-term results suggest that after hospitalization, the persistence of depression, anxiety, and traumatic stress symptoms should be subject of systematic observation among young burn survivors in clinical practice. Moreover, burn survivors may encounter particular problems at certain vulnerable developmental stages which are worth monitoring as part of psychosocial aftercare, such as social problems during school years or body image issues during adolescence. These results suggest the relevance of an open offer for (psychological) professional help in the aftermath of the hospitalization for young burn survivors and their families. To systematically incorporate patient reported outcome measures in clinical practice, pediatric burn care may benefit from recently developed innovative web-based tools in other patient groups (Haverman, Engelen, van Rossum, Heymans, Grootenhuis, 2011). However, an important message to young burn survivors and their families may be that the majority of young people with burns showed to adapt well, although we should recognize that it is currently difficult to determine which children, at what stage in their lives, under which conditions are at increased risk for persistent problems and/or problems in the long run. The field of burn research is in need of larger studies that allow the identification of subgroups at risk shortly after the burn event as well as over time. Future studies may shed more light upon important risk factors and vulnerable developmental stages, which may contribute to more sensitive screening.

¹ Of notice, a recent study has found personality disorders to be frequently prevalent among young adult survivors of large pediatric burns (Thomas et al., 2012).

As the vast majority of studies featured a cross-sectional design, it is premature to determine causal relationships and predominant risk factors for child postburn problems in the longer run. However, our aggregated results provide insight in factors associated with postburn adjustment, some of which seem in line with broader child (accidental) trauma literature (e.g., Alisic, Jongmans, van Wesel, & Kleber, 2011; Cox, Kenardy, & Hendrikz, 2008; Kazak et al., 2006; Trickey, Siddaway, Meiser-Stedman, Serpell, & Field, 2012). As such, they may provide starting directions for clinical practice and future research. Examples of associated factors with acceptable evidence for long-term outcome that may for instance be integrated in monitoring protocols are earlier preburn life stressors, female gender (linked to anxiety, depression, and a more negative body image), parental adjustment, and family functioning. Children with larger burns were overall not more affected than children with minor burns in terms of problem behavior, self-esteem, and sexuality. However, it should be mentioned that in particular prevalence rates for affective and anxiety disorders in studies focusing on survivors of large burns were significant. Further, in line with short-term findings, an indirect relationship between burn size and psychological reactions might be possible. And, in line with a meta-analysis on factors associated with postburn adjustment (Noronha & Faust, 2007), burn severity was actually directly related to postburn body image and social functioning in several studies. Of notice, the long-term impact of for instance the child's acute stress responses, pain, and peritraumatic responses is not yet known.

Directions for Future Research

Some overall methodological strengths and limitations of studies published in the past two decades clearly emerged from this review. In comparison with the previous comprehensive review on this topic (Tarnowski et al., 1991), the use of standardized measures has progressed from approximately 40% to approximately 75% among the currently reviewed studies. Recently developed and validated measures for psychopathology in preschool children have enabled clinicians and researchers to assess psychological symptoms in infants and toddlers who had not been systematically investigated before. Furthermore, although approximately half of the studies in this review reported on samples with 50 children or less, it is no longer needed to predominantly rely on case descriptions. These improvements have resulted in more reliable findings on generic child functioning and posttraumatic stress responses.

Future studies might consider investigating constructs that may be more specific for young burn survivors. Examples derived from reviewed studies are: coping with burn related matters, body image, and particular aspects of social life, such as bullying and social comfort. Paying interest to these phenomena (with to be developed measures for some

constructs) and their longitudinal trajectories may better tap into challenges, difficulties, resiliency, and recovery of young survivors that may be overlooked when solely using generic instruments. Finally, this review showed that topics as cognitive functioning and development, sleep problems, sexuality, and bullying were scarcely investigated and findings were limited by small sample sizes, lack of norm populations or control groups. In particular sleep problems, sexuality, and bullying require more adequate future investigation.

A serious shortcoming among the reviewed studies is the often absent description on enrollment procedures, participation rates, informants (mothers, fathers, other caregivers), and comparisons with nonresponders. More systematic reporting on these issues in future studies is essential in order to appropriately interpret generalizability of the findings.

Further challenges for future research concern the introduction of larger longitudinal designs and the inherent ability to examine causal relationships between proposed risk factors and outcome in children and their families. Several recent short-term studies used a prospective design to study adjustment in the first months postburn. However, nearly all studies beyond the first 6-12 months postburn had a cross-sectional design from which only bivariate associations between hypothesized predictors and outcomes may be induced. Future prospective studies including early risk factors and longer follow-ups and/or measurements at transition moments in a child's life should give more insight into questions concerning risk and protective factors for long-term postburn adjustment. Examples of potential problems at sensitive moments could be social vulnerabilities upon transition from elementary school to high school, or potential problems with depression or self-esteem when young adults leave the home environment. Advanced statistical techniques, such as latent growth modeling, may contribute importantly to the field, as they may enable to identify the small but significant subgroups at risk.

Finally, while the body of research on maternal adjustment has increased over the past two decades, still very little is known about family dynamics and experiences of fathers and siblings. Importantly, one of the most consistent findings on factors related to child postburn outcome is the great impact of the family. Longitudinal investigations with assessments of multiple family members are warranted to study prospective reciprocal dynamics within the family system. Interestingly, in broader child trauma literature, research has begun to focus on interactions within the family system (e.g., Landolt, Ystrom, Sennhauser, Gnehm, & Vollrath, 2012). In pediatric burn practice, initiatives to longitudinally follow-up children and their families with a multidisciplinary team and assess different aspects of physical and psychological functioning are promising (Maertens, Lafaie, & Ponjaert-Kristoffersen, 2007).

Final Remarks

Recent studies with predominantly standardized and validated measures demonstrated that Tarnowski's (1991) conclusion, i.e. the majority of children with burns do well, still holds today. However, a subgroup of children develops significant problems and particular domains of child functioning, such as social functioning and anxiety, and parental adjustment seem vulnerable. Future research should ideally address the *nature* of currently established associations between risk factors, protective factors, and postburn outcome. Longitudinal studies, with sufficient sample sizes, advanced statistical techniques, sensitive standardized measures, and multiple family members participating will increase our knowledge about true risk factors, relevant postburn family dynamics, and potentially vulnerable periods in a child's life after experiencing a burn event.

The ultimate goal of all research efforts should be to translate this knowledge into interventions for children and their families. Currently, documented psychosocial support for young burn survivors consists of burn camps (Maslow & Lobato, 2010) and a social skills intervention for adolescents (Blakeney et al., 2005). Additionally, anecdotic reports of support groups for adolescents with burns (Chedekel & Tolia, 2001) and parents (e.g., Cahners, 1979) have been published. The profound impact of pediatric burns on an important minority of young survivors and their families calls for more initiatives to develop and implement evidence-based, sensitive, targeted (early) interventions for this group.

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Table 2.1 Characteristics and Main Findings of Child Studies (65 Studies in 70 Articles)

| Author | N (% boys) | Age at test | % TBSA | Design ^c and Timeframe ^d | Outcome measures | Main outcomes | Associated Factors with Negative Outcome ^e (statistics ^f) | Remarks |
|---------------------------|---|-------------------|----------------|---|---|--|--|--|
| Abdullah et al., 1994 | 59 (57%) | 5-18 yrs | 15-99 | Cross-sectional 1-7 yrs | PH | Factors for self-esteem were investigated. | Visible scarring severity x male gender, reconstruc- tive needs x male gender, total body scarring, age, female gender (<i>r</i>). | Unknown selection and non-response. |
| Andersson et al., 2003 | 44 (64%) and 158 matched normative controls | 7-12 yrs | 0.5-29, M 9 | Cross-sectional M 7.7 (2.6) yrs | SCI, items from CBQ and CHS (PR, TR) | Lower competence and increased level of internaliz- ing and externalizing behav- ior problems. | TBSA, visible scarring, gender (<i>F</i> , <i>T</i>). | Measure: a selection of items of an existent in- strument was used. |
| Baker et al., 2007 | 83 (63%) | 18- 28 yrs | 30-99, M 52 | Cross-sectional M 14 (5) yrs | YASR | Factors for behavioral prob- lems in young adult survivors were investigated. | Poor hand functioning (<i>r</i>). | |
| Barnum et al., 1998 | 14 (71%) and 14 matched controls (friends) | 13- 19 yrs | M 15 | Cross-sectional M 9.9 yrs | SPP, POMS, SSRS, Hope Scale, FDI, CBCL | Comparable mood, global self-worth and school per- formance, and slightly less problem behavior than con- trols. | Hope (-), social support (-), social status, gender, func- tional disability (<i>F</i>). | Low response rate and small sample. |
| Blakeney et al., 1990 | 44 (66%) | 12+ yrs | M 66 | Cross-sectional ≥ 1 yr | SPS, FESI | Factors for psychological adjustment were investigat- ed. | Time PB (+, trend), family characteristics: more co- hesion, conflict, independ- ence, expression in family, IQ (<i>R</i> ²). | Unknown selection and non-response. |

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|---|----------------------|--|-----------------------------------|---|--|---------------------------------|
| Blakeney, Meyer, Moore, Murphy et al., 1993 | 1-19 yrs 25 (72%) | Cross-sectional 0.5-10 yrs, M 5 and partly longitudinal (yearly assessment) | CBCL/ TRF/ YSR, PH, PSI | Problem behavior comparable with reference data. Girls' self-concept scores were comparable to the norm; boys scored higher on behavior, intellectual abilities, and physical appearance domains. | Time PB (-, R²). | Unknown non-response. |
| Blakeney, Meyer, Moore, Broemeling et al., 1993 | 4-18 yrs 60 (58%) | Cross-sectional M 4 yrs | CBCL/ TRF/ YSR | Parents reported more problem behavior and diminished competence. Teacher-, and self-reports revealed few differences from reference data. | Gender (female), age (younger), TBSA (T with norm). | Unknown non-response. |
| Blakeney et al., 1998 | M 11 yrs 47 (68%) | Cross-sectional 0-13 yrs | CBCL/ TRF/ YSR | Problem behavior higher than the norm, but still within normal limits. Troubled social competence in 24-37% of the sample, but mean social competence within normal limits. | Time PB (r). | |
| Christiansen et al., 2007 | 6-18 yrs 64 (81%) | Chart review | Dates discharge, return to school | Mean time to school reentry after discharge was 10 days (range 0-40 days). | Gender (male), age (older), LOS, TBSA, head and neck burns, hand burn, pressure garments (R²). | Unknown non-response. |
| Delgado Pardo et al., 2008 | 1-17 yrs 83 (63%) | Longitudinal In hospital & 1 mnth | STAIC, SABDH, CBCL, SCFA | More problem behavior and state anxiety compared to reference data. Self-esteem at 1 month PB was comparable to reference data. | Gender (male), age (older), flame burns (F). | Follow-up rate at 1 month: 25%. |

Table 2.1 Continued

| Author | N (% boys) | Age at test | % TBSA | Design ^c and Timeframe ^d | Outcome measures | Main outcomes | Associated Factors with Negative Outcome ^e (statistics) | Remarks |
|---|--|-------------------|-----------------|---|---|---|---|---|
| Delgado Pardo et al., 2010 | 103 (66%), and 36 controls (gen. surgery) | 1- 17 yrs | 1-70, M 13 | Cross-sectional In hospital | STAI-C, CBCL, SABDH | Children with burns experi- enced more externalizing problem behavior than chil- dren awaiting a minor sur- gery, but a lower level of state anxiety. | <i>In this extended study sample, the same risk factors as the 2008 Delgado Pardo study were found.</i> | Unknown non- response. |
| De Young et al., 2011 & 2012 ^a | 130 (52%) | 1-6 yrs | M 3.2 | Longitudinal 1 & 6 mnths | DIPA, CBCL | 25% met criteria for PTSD. Other emotional and behav- ioral difficulties co-occurred, e.g., SAD (16%) and ODD (16%). Children with PTSD had higher CBCL scores than children without PTSD. Trajectories of many children were resilient (72%) | Gender, age, TBSA, child trauma history (F), total problems CBCL (T). | |
| Drake et al., 2006 | 70 (61%) | 1-4 yrs | 0.5-84, M 15 | Cross-sectional M 10 dys | DICA-P, PTSDSSI, CSDC-B | Children experienced acute stress and physiological reac- tions, such as an elevated heart rate and pain. | TBSA, LOS, and # dress- ing changes (r, F). | Small sample. |
| Fukunishi, 1998 | 16 (gen- der ND) | M 8 yrs | ND | Longitudinal 1-2 wks & 4 yrs | SCID-DSM- III-R | 6% had PTSD and 0% had depression at 1-2 wks PB. At 4 yrs PB, none of the children had PTSD or depression. | None specifically investigated. | |
| Gorga et al., 1999 | 51 (61%) | 0.5- 6 yrs | 1-20, M 6 | Longitudinal 1 & 6 & 12 mnths | HSQ, Den- ver II, PDMS, Gross and Fine Motor tests | Over time, more children got suspected for developmental delay in language domain. Fine and gross motor skills improved over time. | Time PB (Cochran's Q). | Unknown non- response. Complete data available for 21% of origi- nal sample. |

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|-----------------------|---|----------|-------------|---------------------------------------|---------------------------|--|--|---|
| Gottlich et al., 1994 | 11 (73%) | 1-16 yrs | 17-90, M 55 | Cross-sectional Acute phase | Polysomnographic measures | Mean total sleep time was adequate, but sleep was fragmented and there was a lack of normal sleep. | Time PB (GLM). | Unknown non-response and small sample. |
| Graf et al., 2011 | 76 (58%) | 1-4 yrs | 1-50, M 8 | Cross-sectional 0.3-4 yrs, M 1 | PTSDSSI, CBCL, PDS, FRI | 13% had PTSD; problem behavior was comparable to reference data. | Age at burn, age at test, injury occurred at home, injury severity (trend), time PB, SES, preceding life events, number of maternal PTSD symptoms, family relationships , number of paternal PTSD symptoms (R ²). | |
| Horridge et al., 2009 | 9 (67%) | 8-15 yrs | 1-13, M 5 | Cross-sectional 0.9-2.4 yrs, M 1.9 | SSI | Parents described many factors to be related to their child's return to school process. | Parental confidence, role adaptation, and school receptivity (no statistics). | Unknown non-response, retrospective design, non-standardized measure, low response rate and small sample. |
| Jessee et al., 1992 | 32 (53%) and 32 matched controls (school) | 5-15 yrs | 3-95, M 48 | Cross-sectional M 5 yrs | HFD | Tendency for lower body image scores in children with burns. | Gender, age (older) , racial group, urban or rural residence, location of burns, TBSA (T.). | Unknown non-response, non-standardized measure. |
| Kent et al., 2000 | 40 (55%), and 3 x 40 controls: 0-4 yrs non ill/injured, ill, fx | 0-4 yrs | 1-25, M 8.5 | Longitudinal 3 days & 6 mths | CBCL | No significant behavioral sequelae at 6 months PB. | Visible scarring, TBSA (statistics ND). | Small sample (CBCL was completed for 18 2-3 year olds). |

Table 2.1 Continued

| Author | N (% boys) | Age at test | % TBSA | Design ^c and Timeframe ^d | Outcome measures | Main outcomes | Associated Factors with Negative Outcome ^e (statistics) | |
|-------------------------|---------------|-------------------|----------------|---|--|--|---|--|
| Kravitz et al., 1993 | 82 (50%) | 2- 20 yrs | 2-91, M 44 | Cross-sectional 1-19 yrs, M 7.3 | Sleep history (PR/SR), and in-hospital nurse observation | Nightmares (37%) and enuresis (24%) were commonly reported. | Age at burn, time PB, cause of burn (χ^2). Predominantly based on retrospective information. Unknown non-response, non-validated measure. | |
| Landolt et al., 2000 | 104 (65%) | 5- 17 yrs | 10-64, M 18 | Cross-sectional 1-13 yrs, M 6.6 | CBCL | Mean behavior scores were within normal limits. Aggressive behavior (8-19%) and somatic complaints (16-23%) were most frequently reported. | Head burns (χ^2 , T). | |
| Landolt et al., 2002 | 105 (65%) | 5- 17 yrs | 10-64, M 18 | Cross-sectional 1-13 yrs, M 6.6 | CBCL, TACQOL- PF, FRI | Mean behavior scores were within normal limits. | Gender, age at burn, SES, TBSA, visible scarring, complicated family relationships (R^2) | |
| Landolt et al., 2009 | 43 (65%) | 7- 16 yrs | 1-70, M 13 | Cross-sectional 1-7 yrs, M 4.4 | CAPS-CA, TACQOL (SR) | 18.6% of the sample had full PTSD. | Gender, age at burn, age at test, SES, TBSA, facial scarring, LOS, number of surgeries, fire injury, time PB, mother present at site accident, HRQOL (r) | |

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|-----------------------|-----------|-----------|----------------------------------|--------------------------------|---|--|---|-----------------------|
| Lawrence et al., 2007 | 195 (63%) | 12-18 yrs | M 5.5 scarred body parts (of 14) | Cross-sectional M 8 yrs | BES, PSQ, SCQ, subjective scar severity/visibility (PR) | Body esteem scores ($n = 148$) were comparable (males) or higher than the norm (females). | Gender, age at burn, age at test, parent education, household income, number of surgeries , facial scarring, number of scarred body parts , time PB, subjective rating of facial scarring , scar visibility and overall scar rating (PR) , parent worry about appearance , perceived stigmatization (SR) , social comfort (PR, r) | Unknown non-response. |
| Lawrence et al., 2011 | 85 (62%) | 8-18 yrs | M 2 surgeries | Cross-sectional M 5.8(4.5) yrs | PSQ (SR and PR) | In children that experienced high stigmatization, parents tended to underestimate perceived stigmatization. This was not the case for children that reported low stigmatization. | Gender, age (older) , ethnicity (discrepancy in African American dyads > European education, household income, number of adults active in the child's life, age at burn, time PB, number of scarred body parts, facial scarring, number of surgeries, degree to which scarring had changed the child's appearance (PR), parental worries about the child's appearance, child academic success, quality of the school, child trouble at school, degree of school overcrowdedness, neighborhood quality and safety (r). | Unknown non-response. |

Table 2.1 Continued

| Author | N (% boys) | Age at test | % TBSA | Design ^c and Timeframe ^d | Outcome measures | Main outcomes | Associated Factors with Negative Outcome ^e (statistics ^f) | Remarks |
|------------------------|---------------|-------------------|--|---|---------------------------------|---|--|---|
| LeDoux et al., 1996 | 32 (84%) | 10- 17 yrs | 10-67, M 37 | Cross- sectional 1-5 yrs | PH, SPP | Self-esteem was comparable or higher than the norm. | Assigned importance of respective domains (no statistics provided). | Unknown non- response. |
| LeDoux et al., 1996 | 32 (84%) | 10- 17 yrs | 10-67, M 37 | Cross- sectional 1-5 yrs | PH, SPP | Self-esteem was comparable or higher than the norm. | Assigned importance of re- spective domains (no statistics provided). | Unknown non- response. |
| LeDoux et al., 1998 | 35 (83%) | 9- 18 yrs | 3-92, M 37 | Cross-sectional 1-5 yrs | CBCL, FES | 26% had behavior problems in the clinical range. | Gender, age at burn, age at test, TBSA, time PB, family characteristics: cohesion (-), organization (-), achievement orientation (-), and conflict (+) in the family , parental traumatic stress, and depression (T). | Unknown non- response. |
| Liber et al., 2006 | 29 (69%) | 2- 14 yrs | 1-42, M 11 | Cross-sectional In hospital | CBCL, FES | 22-25% had internalizing problem behavior. | Gender, age, TBSA, visible scarring, control (-), conflict, cohesion in the family, family income (r). | Unknown non- response. |
| Liber et al., 2008 | 62 (56%) | 11- 18 yrs | M 2.7 scarred body parts (of 20), 42% > 1 sur- gery | Cross-sectional 10-11 yrs | CBCL/ YSR, QBF, CDI, CERQ | 17% had behavior problems in the clinical range. Depres- sion, advantageous coping styles, and personality factors were higher than the norm. | Age, number of scarred body zones, active coping styles, passive coping styles (with behavior), personality dimen- sions: extraversion, agreea- bleness (-, with behavior and depression), conscientious- ness, emotional stability (-, with behavior and depres- sion), flexibility (R ²). | Unknown non- response. Com- plete data availa- ble for 32% of the original sample. |

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|--------------------------------------|----------|----------|------------|---|-------------------------------------|--|---|--|
| Mason & Hillier, 1993 ^b | 57 (65%) | 0-4 yrs | 1-41 | Longitudinal In hospital & 2 wks & 2 mnths & 6 mnths | SSI with mother BQ-U-2/BSQ (age) | Disturbed behavior (per interview and questionnaire) in acute phase was common (56.4%), but diminished over a 6-month period (to 19.3%). | SES, TBSA, LOS, scar severity, itching, maternal self-blame for the accident, history of depression, additional financial or marital worries, maternal adjustment (χ^2). | Unknown non-response and results partly based on non-standardized measure. |
| Meyer et al., 1994 | 38 (61%) | M 10 yrs | M 44 | Cross-sectional M age at burn 7 yrs | CBCL, PSI, 85Q | 37% had behavior problems in the clinical range. | Parenting stress (child domain, parent domain, and situational/ demographic life stress issues), parent anxiety, parent depression and guilt , parental stress, regression, fatigue, extraversion, and arousal (T). | Unknown non-response. |
| Meyer, Blakeney, Holzer et al., 1995 | 72 (60%) | 4-18 yrs | 15+, M 50 | Cross-sectional 1-5 yrs | CBCL (n=35), YSR (n=17), TRF (n=31) | Children themselves and their teachers reported children to be doing well. Parents reported more behavior problems and lower social competency. 24% had behavior problems in the clinical range. Adaptive behavior scores (VABS) were significantly lower than a reference group. | None specifically investigated. | Unknown non-response. |
| Meyer, Blakeney, LeDoux et al., 1995 | 34 (82%) | 9-19 yrs | M 36 | Cross-sectional 1-5 yrs | CBCL VABS | More internalizing problem behavior than the norm. Ratings were comparable to retrospectively determined pre-injury behavior. | Gender, age at burn, age at test, TBSA, time PB (T). | Unknown non-response. |
| Meyer et al., 2000 | 33 (58%) | 2-3 yrs | 2-95, M 50 | Cross-sectional M 1 yr | CBCL | | TBSA, retrospective parent-reported pre-injury behavior (r, T) | Unknown non-response. |

Table 2.1 Continued

| Author | N (% boys) | Age at test | % TBSA | Design ^c and Timeframe ^d | Outcome measures | Main outcomes | Associated Factors with Negative Outcome ^e (statistics ^f) | Remarks |
|-----------------------------|---------------|-------------------|---------------|---|---------------------|---|--|---|
| Meyer et al., 2004 | 101 (57%) | 18- 28 yrs | > 30, M 54 | Cross-sectional 3-28 yrs, M 14 | YASR | Overall, behavior problems were within normal limits. Young men indicated more somatic complaints, and young women indicated more somatic complaints, withdrawn behavior, thought problems, aggressive and delinquent behavior. | TBSA (<i>r</i>). | |
| Meyer et al., 2007 | 101 (57%) | 18- 28 yrs | > 30, M 54 | Cross-sectional 3-28 yrs, M 14 | SCID - DSM IV | Affective disorders in 18% (current) and 44% (lifetime) of survivors; major depression in 9 and 34%. Depression was particularly severe during adolescence. Anxiety disorders: 31 and 38%; PTSD: 9 and 21%, specific phobias: 10 and 13%. | Gender (female) , age at burn, age at test, ethnicity, TBSA, time PB, education (OR). | Measure: a selection of items of an existent instrument was used. |
| Meyer et al., 2011 | 92 (54%) | 18- 28 yrs | > 30, M 55 | Cross-sectional M 14 yrs | Items of WYPBD-R | Sexual beliefs and activities comparable with reference data. | Gender, age at burn, age at test, TBSA, face/neck scarring, limb amputations (<i>r</i>). | |
| Meyers-Paal et al., 2000 | 41 (68%) | M 7 yrs | M 88 | Cross-sectional M 5 yrs | CBCL, TRF, YSR | Behavior and competence scores were within normal limits. | Dependency in activities of daily living (<i>T</i>). | |

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|----------------------------|---|-----------|--------------|-------------------------------------|-------------------------------|--|---|--|
| Moore et al., 1993 | 32 (66%) | 12+ yrs | ≥ 25, M 62 | Cross-sectional M 6 yrs | 16 PF, SPS | Factors for psychological adjustment were investigated. | Gender, age at burn, age at test, time PB, 3/16 personality factors were related: extra-version, social boldness , emotional stability (trend) (MWU). | Unknown selection and non-response. |
| Moore et al., 1996 | 19 (68%) | 4-19 yrs | M 90 | Cross-sectional M age at burn 7 yrs | YSR, CBCL | Factors for competence and behavior were investigated. | Range of motion impairments was associated with activity competence (r). | Unknown selection and non-response. |
| Nayeb-Hashemi et al., 2009 | 14 (86%) with; 14 matched controls without FT scalp burns | 0-16 yrs | M 40 | Chart review | Miscellaneous | Young children displayed developmental problems in the acute phase and tended to have cognitive difficulties in the long run. For older children, no differences were found. | Full thickness scalp burns (no statistics). | Retrospective design, small sample, results partly based on non-standardized measures. |
| Orr et al., 1989 | 121 (gender ND) | 14-27 yrs | I-90, M 27 | Cross-sectional 0-10 yrs, M 5 | SD, RSES, BDI, PSS-Fa, PSS-Fr | Body image, self-esteem, and depression were related. | Gender (female) , age at burn, TBSA, location of scarring, time PB, social support from family, and in particular from friends (-, r, R ²). | |
| Pope et al., 2007 | 36 (36%) and 41 age-matched controls (school) | 11-19 yrs | I-63, M 22.5 | Cross-sectional M 12 yrs | BES, SWAP, BDI-II, YQOL | Body esteem and QoL were higher and mood was comparable to the control group. Body image, mood and QoL were strongly related. | Gender (female) , age at burn, age at test, TBSA . Adolescents were less satisfied about scarred body parts compared to non-scarred body parts (r, T). | Low response rate. |
| Rimmer et al., 2007 | 250 (58%) | M 12 yrs | ND | Cross-sectional Timeframe ND | PRQY, items on bullying | 39-61% of children indicated being teased about their burn and this being a problem (63%). Bullying often occurred at school. Only half of bullied children told an adult. | Visible scarring (X ²). | Unknown non-response. |

Table 2.1 Continued

| Author | N (% boys) | Age at test | % TBSA | Design ^c and Timeframe ^d | Outcome measures | Main outcomes | Associated Factors with Negative Outcome ^e (statistics) | Remarks |
|----------------------------------|---|-------------------|----------------|---|---|---|--|--|
| Rivlin et al., 2007 ^b | 44 (50%), and 2x24 controls: healthy and fx | 11- 16 yrs | 4-50 | Cross-sectional 3-14 yrs | GRPAL, EPQ, MAS, AECOM- DP, DAQ, MSSA-SDS | More psychological problems than controls, in particular regarding social and recreational functioning, feelings of depression, general and situation-specific anxiety, anti-social and neurotic disorders. | Gender, age at burn (<5 or >5 yrs), stage of adolescence, TBSA, location of scarring, intelligence were reported significant (T, χ^2), but too many uncorrected comparisons were made to draw meaningful conclusions about significant associations. | Statistics: not controlled for multiple comparisons. |
| Robert et al., 1997 | 60 (gender ND) | 6-19 yrs | 15-99, M 61 | Cross-sectional 0-10 yrs, M 3 | ISC | Five major themes of post-burn worries: preoccupation with health, struggle for internal acceptance, reconstruction of personal goals, changing relationships, and redefining the world. | None specifically investigated. | Unknown non-response, results based on non-standardized measure. |
| Robert et al., 1998 | 19 (53%) | 13-20 yrs | 7-85, M 39 | Cross-sectional 1-17 yrs, M 12 | Items of WYPBD-R | Adolescents with burns had sexual ideas and behaviors comparable to other adolescents (norm group 1972). | Gender, score for scarring on body parts most likely to be associated with sexual attractiveness (head, neck, hands, chest, and genitals, r, F). | Unknown selection and non-response, small sample size. Measure: a selection of items of an existent instrument was used. |

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|------------------------|----------|-----------|------------|-------------------------------------|--|---|---|--|
| Robert et al., 1999 | 14 (43%) | 13-20 yrs | 7-85, M 39 | Cross-sectional 2-17 yrs, M 8 | SPP-A, CBCL anxious/depressed subscale | Self-competence and mood were in the normal range. Some self-competence subscales were lower (e.g., physical appearance), others were higher (e.g., social competence) than the norm. | Assigned importance of respective domains (except for subscale physical appearance, r). | Unknown non-response, small sample size. |
| Rosenberg et al., 2006 | 85 (54%) | 18-26 yrs | > 30, M 53 | Cross-sectional M 14 yrs | SPS, FES, I6PF | 32% displayed at least moderate concern for suicide probability. | Age, TBSA, time PB, history of substance abuse, 6/16 personality factors: (emotional stability [-], vigilance, abstractedness, apprehension, self-reliance, tension), 2/5 personality traits: (extroversion [-], anxiety), 1/10 family characteristics (conflicts in the family, r). | |
| Rosenberg et al., 2007 | 93 (54%) | 18-26 yrs | > 30, M 54 | Cross-sectional M 14 yrs | YASR, FES | 95% of behavior scores were within normal limits. | Gender, family of origin vs. relationships with significant others, family characteristics: cohesion, expressiveness, conflict , independence, achievement, intellectual-cultural, active-recreational (-), moral-religious, organization (-), control (r). | |

Table 2.1 Continued

| Author | N (% boys) | Age at test | % TBSA | Design ^c and Timeframe ^d | Outcome measures | Main outcomes | Associated Factors with Negative Outcome ^e (statistics) | Remarks |
|--|---------------|-------------------|---------------|---|---|---|--|---------------------------|
| Russel et al., 2008 | 72 (51%) | 18- 28 yrs | > 30, M 55 | Cross- sectionalM 14 yrs | YABCL, YASR | Parents/partners/siblings reported more problem behavior compared to refer- ence data, but still within normal limits. In general, cross-informants reported more problems than partici- pants themselves. | Gender, age at burn, age at test, who the subject is living with, ethnicity (discrepancy in Black and Hispanic families > Caucasian families), educa- tion, TBSA, time PB (partial r). | |
| Saxe et al., 2001 | 24 (54%) | 6- 16 yrs | 1-41, M 12 | Longitudinal M 10 dys & 6 mnths | CPTSD-RI | PTSS decreased over a 6- month period (reliability of change 0.78). | Higher dose of morphine (independently from TBSA, LOS, pain, and benzodiaze- pines) was associated with decrease in PTSS, partial r). | Unknown non- response. |
| Saxe, Stoddard, Hall et al., 2005 | 72 (67%) | 7- 17 yrs | 1-85, M 18 | Longitudinal M 10 dys & 3 mnths | CPTSD-RI, CSDC, MASC | A multifactorial model to predict child PTSD was investigated. | 2 pathways: 1) Age, TBSA, pain > separation anxiety > PTSD, 2) TBSA > disso- ciation > PTSD (path mod- eling, R ²). 3 pathways: 1) TBSA > parent's ASD symptoms > ASD, 2) TBSA > Pulse rate > ASD, 3) Life stress > body image > ASD (path modeling, R ²). | |
| Saxe, Stoddard, Chawla et al., 2005 | 72 (67%) | 7- 17 yrs | 1-85, M 18 | Cross-sectional M 10 dys | DICA-C (+ ASD items), CSDC, PH, LES, SASRQ | 31% had ASD, 44% met the criterion for dissociation, 79% reexperiencing, 55% avoidance, 72% hyperarous- al. | | |

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|----------------------------------|--|-----------|--------------|--------------------------------------|--|---|--|
| Stoddard et al., 1992 | 30 (47%) | 7-19 yrs | 5-95, M 39 | Cross-sectional M 9 yrs | DICA-C, DICA-P | Lifetime: 73% depression, 27% major depression, 43% suicidal feelings. Comorbidity between depression, anxiety, PTSD, abuse, and behavioral disorder. | Gender, age at burn, age at test, having caused burn themselves, TBSA, cosmetic disfigurement, precipitant : burn, hospitalization/ surgery, but equally reported: breakup of relationship, death of loved one, family problems, social problems (no statistics). |
| Stoddard, Saxe, et al., 2006 | 52 (58%) | 1-4 yrs | 0.5-84, M 14 | Cross-sectional Acute phase | CPTSDSSI, SASRQ | 29% had ASS, 80% met the criterion for reexperiencing, 62% avoidance, 39% arousal. | 2 pathways: 1) TBSA > pulse > ASS , 2) pain > parent acute stress > ASS (path modeling, R ²). |
| Stoddard, Ronfeldt, et al., 2006 | 72 (63%) | 1-4 yrs | 0.5-84, M 15 | Longitudinal Acute phase & 1 mnth PD | DICA-P, videotaped laboratory assessment | Factors for less vocalizations and smiles at 1 month PD were investigated. | In-hospital PTSS, heart rate and pain (r). Follow-up rate at 1 month was 44%. |
| Stokes et al., 2004 | 12 (0%) and 12 controls (orthodontics) | 11-16 yrs | ND | Cross-sectional Age at burn 0-14 yrs | Cueing task, CAMI, IES | Factors for autobiographical memory recall were investigated. | Unknown selection and non-response, small sample size, results partly based on non-standardized measures. |

Table 2.1 Continued

| Author | N (% boys) | Age at test | % TBSA | Design ^c and Timeframe ^d | Outcome measures | Main outcomes | Associated Factors with Negative Outcome ^e (statistics) | Remarks |
|----------------------------|---------------|-------------------|----------------|---|---------------------|--|--|---------|
| Willebrand et al., 2011 | 94 (63%) | 3- 18 yrs | 0.1-70, M 9 | Cross-sectional 0.3-9 yrs, M 4.5 | SDQ | SDQ scores were adequate for emotions, hyperactivity/inattention and prosocial behavior, but impaired for conduct problems, peer relationships and total difficulties. | For total difficulties: gender, age (older) , preburn health problems, maternal education, paternal education , living with both parents, living arrangement changed after burn , TBSA (FT), LOS, time PB, scars, visible scarring , parent factors: anxiety, depression . Additionally for hyperactivity/inattention: gender (male) , living with both parents ; additionally for peer problems: time PB (trend, +, R ²). | |

Note. Eight State Questionnaire (8SQ); 16 Personality Factor Questionnaire (16 PF); Activities of Daily Living (ADL); AECOM-DP measure for Depression (AECOM-DP); Acute Stress Disorder (ASD); Beck Depression Inventory (BDI); Beck Depression Inventory-II (BDI-II); Body Esteem Scale for Adolescents and Adults (BES); Behaviour Questionnaire (BQ-U-2); Behaviour Screening Questionnaire (BSQ); Children's Autobiographical Memory Inventory (CAMI); Clinician-Administered PTSD Scale for Children and Adolescents (CAPS-CA); Child Behavior Checklist (CBCL); Children's Behaviour Questionnaire (CBQ); Children's Depression Inventory (CDI); Cognitive Emotion Regulation Questionnaire (CERQ); Conner's Hyperactivity Scale (CHS); Child PTSD Reaction Index (CPTSD-R); Child PTSD Semi-structured Interview (CPTSDSSI); Child Stress Disorders Checklist (CSDC); Child Stress Disorders Checklist Burn Version (CSDC-B); Death Anxiety Questionnaire (DAQ); Denver Developmental Screening Test – Revised (DDST-R); Denver Developmental Screening Test – Second Edition (DDST-II); Denver Developmental Screening Test Denver-II (Denver-II); Diagnostic Interview for Children and Adolescents – Child Interview (DICA-C); Diagnostic Interview for Children and Adolescents – Parent Interview (DICA-P); Diagnostic Infant Preschool Assessment (DIPA); Junior Eysenck Personality Questionnaire (EPQ); Functional Disability Inventory (FDI); Family Environment Scale (FES); Family Relationship Index (FRI); Full-thickness (FT); Fractures (fx); Graham and Rutter Psychiatric Assessment Interview (GRPAI); Hospital Anxiety and Depression Scale (HADS);

Human Figure Drawings (HFD); Health-Related Quality of Life (HRQoL); Denver Home Screening Questionnaire (HSQ); Impact of Event Scale (IES); Incomplete Sentences for Children (ISC); Louisville Behavior Checklist (LBC); Coddington Life Events Scale (LES); Manifest Anxiety Scale (MAS); Multidimensional Anxiety Scale for Children (MASC); Mini International Neuro-Psychiatric Interview (MINI); Manchester Scales of Social Adaptation – Self Directions Scale (MSSA-SDS); Not Described (ND); Oppositional Defiant Disorder (ODD); Postburn (PB); PTSD Checklist- civilian version (PCL-C); Post Discharge (PD); Peabody Developmental Motor Scales (PDMS); Posttraumatic Diagnostic Scale (PDS); Piers-Harris Children's Self-Concept Scale (PH); Play/ Interview technique (P/I); Profile of Mood States (POMS); Parent report (PR); Peer Relations Questionnaire for Youth (PRQY); Present State Examination - short version (PSE-SV); Parental Stress Index (PSI); Perceived Stigmatization Questionnaire (PSQ); Perceived Social Support Inventory for Families (PSS-Fa); Perceived Social Support for Friends (PSS-Fr); Posttraumatic Stress Disorder (PTSD); Posttraumatic Stress disorder Semi-Structured Interview and Observational Record for Infants and Young Children (PTSDSI); Posttraumatic Stress Symptoms (PTSS); Quick Big Five (QBF); Quality of Life (QoL); Rosenberg Self Esteem Scale (RSES); Scale for Anxiety Behavior Observation During Hospitalization (SABDH); Separation Anxiety Disorder (SAD); Stanford Acute Stress Reaction Questionnaire (SASRQ); Self Concept Form AQ (SCFA); Social Comfort Questionnaire (SCQ); Social Competence Inventory (SCI); Structured Clinical Interview for DSM (SCID); Semantic Differential (SD); Self-Drawing (S-D); Strengths and Difficulties Questionnaire (SDQ); Social Interview Schedule (SIS); Self-Perception Profile (SPP); Self-Perception Profile for Adolescents (SPP-A); Suicide Probability Scale (SPS); Self report (SR); Semi-structured Interview (SSI); Social Support Rating Scale (SSRS); State Trait Anxiety Inventory for Children (STAIC); Satisfaction With Appearance Scale (SWAP); TNO-AZL Child Quality of Life Questionnaire (TACQOL); Total Body Surface Area burned (TBSA); Teacher Report (TR); Teacher Report Form (TRF); Vineland Adaptive Behavior Scales (VABS); What Young People Believe and Do – Revised (WYPBD-R); Young Adult Behavior Checklist (YABCL); Young Adult Self-Report (YASR); Youth Quality of Life Instrument (YQOL); Youth Self Report (YSR).

^aResults of both studies are presented in one row. ^bResults of three parts are presented in one row. ^cDesign (cross-sectional/longitudinal/chart review). ^dAge at burn is presented, if the timeframe or mean time post burn was not provided. ^eSignificant findings are presented in bold typeface. ^fStatistics to examine relationship between outcome and associated variables are presented within parentheses: χ^2 for Chi Square statistics, F statistics for analysis of variance, GLM for General Linear Model, MWU for Mann Whitney U test, OR for Odds Ratio, partial r for partial correlations, r for bivariate correlation, Q for Cochran's Q, R2 multiple regression analysis, T for Student's T test.

Table 2.2 *Characteristics and Main Findings of Family Studies (22 Studies in 26 Articles)*

| Author | Sample | Design ^b and Timeframe ^c | Outcome measures | Main outcomes | Associated Factors with Negative Outcomes ^d (statistics ^e) | Remarks |
|--|---|---|------------------|---|---|---|
| Bakker et al., 2010 | 48 mothers | Longitudinal 1-2 yrs & 11 yrs | IES, SSI | 42% at 1 yr and 19% at 11 yrs scored above cut-off for PTSS. | Guilt: feelings, burn severity, guilt feelings x burn severity (R^2). | Unknown non-response. Complete data available for 29% of the original sample. |
| Blakeney, Meyer, Moore, Murphy et al., 1993* | 25 parents | Cross-sectional 0.5-10 yrs, M 5 and partly longitudinal (annual assessment) | PSI | Parents worried about the impact of the burns on family life disruption, 50% of married couples got divorced. Compared to reference data, more parental stress was attributed to child characteristics. | Time PB (r, R^2). | Unknown non-response. |
| Blakeney, Moore et al., 1993 | 120 parents (89 acute/ 31 recovery phase) | Cross-sectional Acute phase/ recovery group: 1-5 yrs | PSI | More parental stress was attributed to child characteristics (solely in the recovery group). | TBSA (r). | Unknown selection and non-response. |
| Blakeney et al., 1998* | 44 parents | Cross-sectional 0-13 yrs | PSI | Parents reported more parenting stress than a norm group. Parents attributed distress to both child and their own characteristics. | None specifically investigated. | |
| Delgado Pardo et al., 2008* | 21 parents | Cross-sectional In hospital & 1 mth | FES | Family characteristics cohesion, control, and conflict were comparable to reference data. | None specifically investigated. | Unknown non-response, small sample size. |

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|-------------------------|---|--|--------------------------------|---|---|-----------------------|
| El Hamaoui et al., 2006 | 28 mothers | Cross-sectional 0.5-5 yrs, M 2 | MINI, HDRS, HARS, GAF | 36% major depression, 54% depressive symptoms, 71% feelings of guilt. Depression was related with anxiety and global functioning. | Child gender, child age, maternal age, maternal education, low SES, TBSA, burns in > 1 child, complication of burn (T, X ²). | |
| Fukunishi, 1998* | 16 mothers | Longitudinal 1-2 wks & 4 yrs | SCID, HDS | 18.8% PTSD and/or depression at 1-2 weeks, 0% PTSD and/or depression at 4 years PB. | TBSA, facial burn, maternal feelings of guilt (r). | Small sample size. |
| Graf et al., 2011* | 61 mothers and 54 fathers of 76 children | Cross-sectional 0.3-4 yrs, M 1 | PDS | 7% of mothers and 6% of fathers met criteria for PTSD. | None specifically investigated. | |
| Hall et al., 2007 | 62 parents (87% mothers) | Longitudinal In hospital & 3 months later | PCL-C | 47% of parents reported significant PTSD at 3 months PB from ≥ 1 cluster; 38% reported ≥ 1 reexperiencing symptoms, 16% ≥ 3 avoidance symptoms, and 32% ≥ 2 arousal symptoms. | 3 pathways: 1) parent anxiety > increased parent-child conflict > parental PTSS; 2) conflict extended family and TBSA > parent dissociation > parental PTSS; 3) child PTSD > parental TBSA > child PTSD > parental PTSS (path modeling, R ²). | |
| Kent et al., 2000* | 40 mothers; 3 x 40 controls: non ill/injured, ill, fx | Longitudinal 3 days & 6 mths | HADS | Initial parental anxiety and depression rates were high in the burn and ill-group. Depression decreased, but anxiety remained comparatively high in the burn group at 6 months. | TBSA, visible scarring, time PB (F). | |
| LeDoux et al., 1998* | 35 caregivers (32 mothers/3 other) | Cross-sectional 1-5 yrs | FES, IES, BDI | More family cohesion, control, and moral religious emphasis compared to reference data. 31% in clinical range for depression, 14% for avoidance, and 29% for intrusion. | None specifically investigated. | Unknown non-response. |

Table 2.2 Continued

| Author | Sample | Design ^b and Timeframe ^c | Outcome measures | Main outcomes | Associated Factors with Negative Outcomes ^d (statistics ^e) | Remarks |
|-------------------------------------|--|--|------------------|---|---|---|
| Lehna, 2010 | 27 siblings (44% brothers, 9 yrs +) | Cross-sectional 2-21 yrs, M 6 | SSI, SRQ-R | The process of adjustment could be gradual and involved multiple domains, 'normalization' was essential. | None specifically investigated. | Unknown selection and non-response, results partly based on retrospective information and non-standardized measure. |
| Liber et al., 2006* | 28 mothers & 27 fathers of 29 children | Cross-sectional In hospital | FES | Family characteristics cohesion, control, and conflict were comparable to reference data. | Child gender, child age, TBSA (-, trend with cohesion), visible scarring (-, trend with cohesion, r). | Unknown non-response. |
| Mancuso et al., 2003 | 79 siblings (49% brothers) | Cross-sectional ≥ 4 months | CBCL, SIQ, CIBQ | Sibling problem behavior was comparable to reference data, but a decrease in social competence was noticed. Parents reported positive changes, e.g., more protectiveness (73%), more closeness (48%). | TBSA (MWU). | Unknown non-response, low response rate, results partly based on non-validated measure. |
| Mason & Hillier, 1993 ^{3a} | 57 mothers | Longitudinal In hospital & 1 wk & 2 months & 6 months | SSI, GHQ | Psychiatric morbidity in 7% prior to the injury (retrospective report), 81% in hospital, 37% at 1 week, 32% at 2 months and 14% at 6 months PB; 81% reported feelings of guilt. Common maternal responses are presented in a model. | Child age (older), SES, TBSA, LOS, scar severity, itching, visible scarring, perceived threat to child's life, history of depression, and additional financial or marital worries, being single, had experienced isolation and stigma as a result of the burn, child adjustment (χ^2, r) | Unknown non-response and results partly based on non-standardized measure. |

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|---------------------------|--|--|--|---|---|---|
| Meyer et al., 1994* | 38 mothers | Cross-sectional M age at burn 7 yrs | PSI, 8SQ | Parents reported high levels of parenting stress, compared to reference data. Emotional states and moods were comparable to reference data. | Child problem behavior (significantly related to parenting stress, depression and guilt, <i>r</i>). | Unknown non-response. |
| Phillips et al., 2007 | 15 siblings | Cross-sectional 0.2-9 yrs, M 2.6 | SR questionnaire (new) | Daily activities were not affected in most siblings (87%), 40% of siblings retrospectively reported to have felt upset seeing the burn the first time, and 40% felt not involved in care. | None specifically investigated. | Small sample size, results predominantly based on retrospective information. Non-validated measure. |
| Phillips & Rumsey, 2008 | 72 parents | Cross-sectional 4 groups: in hospital, < 6 mths, 6-24 mths, > 24 mths | HADS, FAD | Parental anxiety: 69% in hospital, 31% in < 6 months PB group, and 33% in outpatient groups respectively. Parental depression: 44%, 11% and 0-22%. Depression and anxiety were highly related. Family functioning was comparable to reference data. | Child gender, child age, maternal age (younger) , people in family home, family functioning (-) , TBSA, time PB, perceived severity, (perceived) visibility, grafts, parental factors: emotional stability, extraversion, openness/imagination, agreeableness, conscientiousness, items about social ("I worry about my child's health now") and physical aspects burns ("Child has pain", <i>R</i> ²). | Low response rate. |
| Rivlin & Faragher, 2007** | 44 mothers and 2x24 controls: healthy & children with fx | Cross-sectional 3-14 yrs | PSE-SV, GHQ, EPQ, AECOM-DP, MAS, DAQ, SIS, life events | More psychopathology than control mothers. Marital, social relationships, and life events were comparable. A higher divorce rate was found post-burn, compared to controls. | Mothers of daughters reported more guilt than mothers of sons (T). | Statistics: not controlled for multiple comparisons. |
| Rizzone et al., 1994 | 25 parents (96% mothers) | Cross-sectional 1-17 yrs, M 7 | SCID | 16% had current PTSD, and 52% had experienced PTSD at some moment after the burn. | TBSA (only with present symptoms), proximity, social support, perceived stress (<i>r</i>). | |

Table 2.2.2 Continued

| Author | Sample | Design ^b and Timeframe ^c | Outcome measures | Main outcomes | Associated Factors with Negative Outcomes ^d (statistics ^e) | Remarks |
|-------------------------|---|--|------------------|--|--|--|
| Rosenberg et al., 2007* | 93 young adults with burns | Cross-sectional M 14 yrs | FES | Family characteristics were comparable to reference data. Achievement orientation and religious emphasis were higher; involvement in intellectual-cultural events lower. | Gender, family of origin vs. significant others, young adult adjustment (<i>r</i>). | |
| Thompson et al., 1999 | 27 family members of pediatric patients | Cross-sectional Acute phase | SSI | Many family members expressed worries, e.g. about pain, skin grafting surgery, scarring, and uncertainty about the future. | None specifically investigated. | Unknown selection and non-response, results based on non-standardized measure. |

Note. Child outcomes of studies with an * are displayed in Table 1. Eight State Questionnaire (8SQ); AECOM-DP measure for Depression (AECOM-DP); Beck Depression Inventory (BDI); Changes in Behavior Questionnaire (CIBQ); Child Behavior Checklist (CBCL); Death Anxiety Questionnaire (DAQ); Discharge (d/c); Junior Eysenck Personality Questionnaire (EPQ); McMaster Family Assessment Device (FAD); Family Environment Scale (FES); Fractures (fx); Global Assessment of Functioning Scale (GAF); General Health Questionnaire (GHQ); Hospital Anxiety and Depression Scale (HADS); Hamilton Anxiety Rating Scale (HARS); Hamilton Depression Rating Scale (HDRS); Hamilton Depression Scale (HDS); Impact of Event Scale (IES); Manifest Anxiety Scale (MAS); Mini International Neuro-Psychiatric Interview (MINI); Not Described (ND); Postburn (PB); PTSD Checklist- civilian version (PCL-C); Post Discharge (PD); Posttraumatic Diagnostic Scale (PDS); Present State Examination - short version (PSE-SV); Parental Stress Index (PSI); Posttraumatic Stress Disorder (PTSD); Posttraumatic Stress Symptoms (PTSS); Structured Clinical Interview for DSM (SCID); Sibling Injury Impact Questionnaire (SIQ); Social Interview Schedule (SIS); Sibling Relationship Questionnaire - Revised (SRQ-R); Semi-structured interview (SSI); Total Body Surface Area burned (TBSA).
^aResults of three parts are presented in one row. ^bDesign (cross-sectional/longitudinal/chart review). ^cAge at burn is presented, if timeframe or mean time post burn was not provided. ^dSignificant findings are presented in bold typeface. ^eStatistics to examine relationship between outcome and associated variables are presented within parentheses: χ^2 for Chi Square statistics, F statistics for analysis of variance, MWU for Mann Whitney U test, *r* for bivariate correlation, *R*² multiple regression analysis, T for Student's T test

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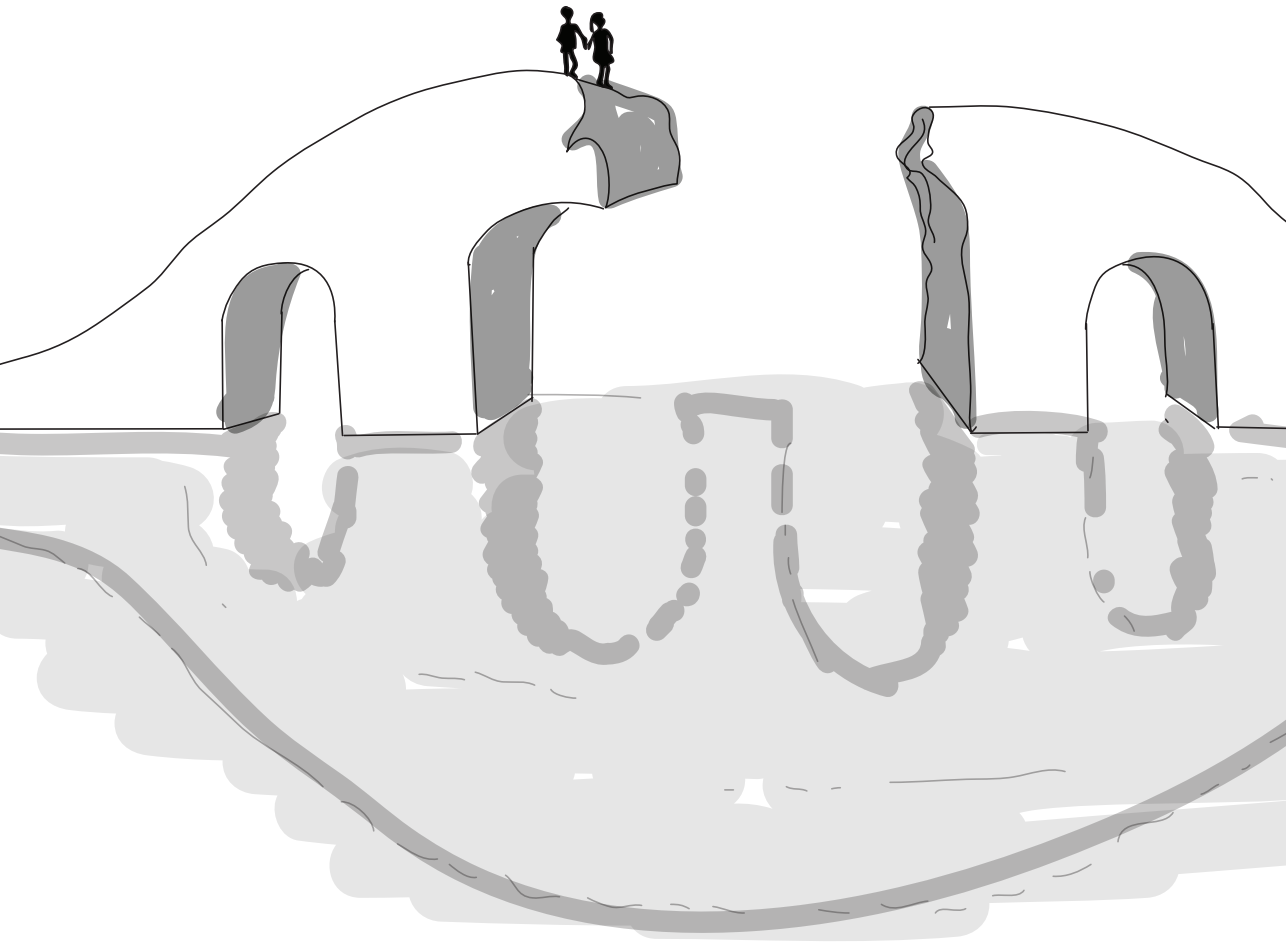
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Acute Stress Reactions in Couples After a Burn Event to Their Young Child



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ABSTRACT

Objective This multicenter study examines acute stress reactions in couples following a burn event to their preschool child. **Methods** Participants were 182 mothers and 154 fathers, including 143 couples, of 193 children (0-4 years) with acute burns. Parents' self-reported acute stress reactions and emotions regarding the burn event were measured within the first month postburn. **Results** More mothers than fathers reported clinically significant acute stress reactions. Multilevel analysis revealed that individual parent reactions were associated with parent gender and negative emotions about the burn event. Interestingly, avoidance symptoms overlapped to an important extent within couples, whereas intrusion symptoms were mainly intra-individual. Burn characteristics, such as burn size, contributed to acute stress within couples. **Conclusions** Mothers and fathers are seriously affected by their child's burn trauma and share a part of their acute stress reactions. These results emphasize the importance of a family-based approach to support adjustment after pediatric medical trauma.

Key words: burns, children, parents, posttraumatic stress

ACUTE STRESS REACTIONS IN COUPLES AFTER A BURN EVENT TO THEIR YOUNG CHILD

Young children constitute a high-risk group for sustaining burn injuries (Stoddard et al., 2006). Deep dermal burns often result in permanent scarring and physical limitations, and may cause psychological consequences in children and their families (De Young, Kenardy, Cobham, & Kimble, 2012; Graf, Schiestl, & Landolt, 2011; Noronha & Faust, 2007). Previous research on pediatric burns and other medical traumatic events has shown that child and parent psychological adjustment are often interrelated (Cox, Kenardy, & Hendrikz, 2008; Graf et al., 2011; Kazak, 1997; Noronha & Faust, 2007). Postburn adjustment may be understood from a family systems perspective, in which (the behavior of) a child is not considered at the individual level, but within the context of the broader family system (Kazak, Simms, & Rourke, 2002). The family consists, beyond the traditionally studied mother-child dyad (Seagull, 2000), of several subsystems that may interact with each other, for example, parent-parent, child-parent-grandparent (Kazak, 1997). Children are influenced by the interactions with the immediate systems surrounding them, but also by interactions within and between these different subsystems (Bronfenbrenner, 1977). From a family perspective, it is imperative to address a child's direct environment when studying psychological reactions following a potentially medical traumatic event. This might even be more the case for very young children, who heavily rely on their parents for protection in the context of stress (Scheeringa & Zeanah, 2001).

Injury or illness in children may elicit acute stress symptoms (ASS), in the short term, and posttraumatic stress symptoms (PTSS) in the longer term, in their parents, such as unwanted reliving of the traumatic event, avoidance of thoughts, people or places that remind one of the traumatic event, irritability, and difficulties concentrating (Kazak et al., 2006). Previous studies on parents of various groups of ill and/or injured children demonstrated that parents are at considerable risk for ASS and PTSS (Balluffi et al., 2004; Le Brocque, Hendrikz, & Kenardy, 2010). Research on children with burns has shown that 18.8% of parents met criteria for clinical stress in the acute phase (Fukunishi, 1998), 47% had clinical significant PTSS at 3 months (Hall et al., 2006), and 16% of parents experienced PTSD on average 7 years postburn (Rizzone, Stoddard, Murphy, & Kruger, 1994). Parental PTSS following pediatric burns was (indirectly) related to the size of the burn, with parents of children with more extensive burns having the highest level of PTSS (Bakker, Van Loey, Van Son, & Van der Heijden, 2010; Hall et al., 2006). This differs from other literature on acutely ill or injured children, where mixed results were found concerning the relationship between injury variables and subsequent parent adjustment (Le Brocque et al., 2010). Circumstances of the burn event have not been researched widely in relation to parental ad-

justment; only one study showed that parental proximity at the time of the injury was not related to PTSS (Rizzone et al., 1994). Furthermore, parents' peritraumatic anxiety and dissociation, and child reactions were linked to PTSS at 3 months postburn (Hall et al., 2006). Studies on parents of injured or acutely ill children showed that parent appraisal of life threat to the child was strongly related to ASS (Balluffi et al., 2004; Kassam-Adams, Fleisher, & Winston, 2009). In the longer term, feelings of guilt about the burn event appeared an important predictor of stress responses in parents of children with burns (Bakker et al., 2010; Cella, Perry, Kulchysky, & Goodwin, 1988), but the relationship between guilt feelings and acute symptomatology is unknown. Besides feelings of guilt, also anger has been shown to be associated with PTSS both in a large variety of trauma populations (McHugh, Forbes, Bates, Hopwood, & Creamer, 2012), and in adults with burns. The role of anger in relation to acute stress symptomatology has not yet been investigated in parents of (burn) injured children.

Past research predominantly focused on the reactions of mothers to medical trauma in their children (Phares, Lopez, Fields, Kamboukos, & Duhig, 2005). As such, there is limited knowledge on ASS and PTSS in fathers and in couples. Several researchers in the field of pediatric psychology have advocated the importance to involve the whole family (e.g., Alderfer et al., 2008; Phares et al., 2005; Seagull, 2000). Most of the few previous studies that included both mothers and fathers of acutely ill children have found PTSD more frequently in mothers than in fathers (Nelson & Gold, 2012). In contrast, PTSD prevalence rates in mothers and fathers of children with newly diagnosed diabetes were fairly similar, although co-occurrence of PTSD within couples was very low (Landolt et al., 2002). Phares and colleagues (2005) suggested, after reviewing a large body of literature in the area of pediatric psychology, that there were 'more similarities than differences between mothers and fathers of chronically ill children' (p. 636). Interestingly, Bronner and colleagues (2008) found a strong correlation between mothers' and fathers' PTSS 3 months after their child had been admitted to the pediatric intensive care unit, despite the fact that mothers had overall higher scores.

To our knowledge, no studies have specifically studied potential similarities of parental acute distress within couples after an injury in their child. This information on trauma-related family dynamics is important for optimizing family support after pediatric illness or injury (Nelson & Gold, 2012). The aim of this study was to examine subjective distress in couples in the subacute phase of recovery of their preschool child and to identify variables associated with individual parent and parent-couple traumatic stress. Parental distress in the first month after the burn is examined to gain more knowledge about this unique and highly demanding period for parents. Preschool children were focus of the study, as they constitute an important risk group for burn injuries and often share many similarities in

terms of burn etiology and event circumstances. We hypothesized that mothers would experience greater levels of distress than fathers, but that acute stress in couples would not be independent. Further, we hypothesized that individual parent factors such as parent gender and individual peritraumatic reactions would influence the parent's level of stress. Child factors, that is, factors that are the same for both parents within a couple such as severity of the burn, were thought to be modestly associated with acute stress reactions in couples.

METHOD

Participant Recruitment and Procedures

This study describes the first results of a larger prospective study that examines child and parental adjustment following a pediatric burn event. Data were gathered in three burn centers in the Netherlands and four in Belgium between October 2007 and July 2010. Families were eligible to participate if the child was between 8 months and 4 years old, the length of stay in the hospital was ≥ 24 hr, and burn severity quantified by the Total Body Surface Area (TBSA) burned was $\geq 1\%$. TBSA burned is the estimated proportion of the body with second or third degree burns. Exclusion criteria were insufficient parental Dutch language proficiency required to complete questionnaires, pre-existing severe mental disabilities in the child, and deceased children. A local researcher contacted consecutive eligible families 1-4 weeks after admission. Parents were approached while their child was still hospitalized, or were invited by telephone. The researcher explained the study purpose and offered additional written information. Two independent ethics committees in the Netherlands and Belgium, respectively, approved this study. All families signed an informed consent form.

Of 313 families that met the study criteria, 216 consented to participate (69%). Fifty-five families declined participation (18%), 26 families were missed before they could be approached (8%), and 16 families were not invited because their participation was deemed inappropriate (e.g., severely ill family members, psychiatric background, or court custody cases; 5%). Of the 216 families that consented to participate, 23 families had incomplete data, that is, the measure for parental subjective distress was not completed, and were not included in the current analyses. The final 193 participating families did not differ from the other 120 eligible families in terms of child age, gender, length of stay in the hospital, percentage TBSA, and percentage deep burns.

Participants

Parent characteristics

A total of 182 mothers and 154 fathers, including 143 couples, participated. Mean age was 32.0 years ($SD = 5.3$) for mothers and 35.8 years ($SD = 5.8$) for fathers. The majority of the parents were in a relationship (89% of mothers and 93.5% of fathers). Seventeen families reported that they also had children from previous relationships (9%). The majority of parents, 86% of mothers and 81% of fathers, were born in the Netherlands or Belgium. Education level was categorized as low (primary education, technical and vocational training until the age of 16), middle (technical and vocational training until the age of 18) or high (technical or vocational training for 18+ or university). Mothers' and fathers' degrees were as follows: 29 and 26% low, 31 and 36% middle, 40 and 38% high. Sixty-nine percent of the mothers and 90% of the fathers were currently employed.

Child characteristics

Children, 125 boys (65%) and 68 girls (35%), were 1.8 ($SD = 0.9$) years old (range 0-4). In 77% of the cases, the burn accident occurred in the home, and 91% of the burn injuries were scald burns. Mean TBSA was 7.5% ($SD = 6.5$, range 1-45), and the mean length of stay in the hospital was 11.2 days ($SD = 10.6$, range 1-55). Thirty-six percent of the children required at least one skin grafting procedure during their initial hospitalization ($M = 0.5$, $SD = 0.8$, range 0-5).

Measures

Acute stress reactions

The Impact of Event Scale (IES) is a valid and psychometrically sound 15-item self-report measure to assess two dimensions of traumatic stress reactions, that is, symptoms of intrusion and avoidance (Horowitz, Wilner, & Alvarez, 1979; Sundin & Horowitz, 2002). In adult patients with burns, the IES was demonstrated to be a good indicator for PTSD (Sveen et al., 2010). The validated Dutch version of the IES was administered within the first month postburn (Brom & Kleber, 1985). The IES was completed by parents either in the hospital, if parents could be approached while their child was still hospitalized, or at home, when the child was already discharged and parents were invited by telephone to participate. In that case, the questionnaires were sent to their home address by regular mail and returned in a pre-stamped envelope. Parents were asked to rate the frequency of symptoms they had experienced on a 4-point Likert scale (0-1-3-5). The total possible score ranged from 0-75, with higher scores representing higher levels of subjective distress. We used scores 26 and

higher on the total scale as indication of 'clinically significant stress' (Van der Velden, Burg, Steinmetz, & Bout, 1992). The two subscales, Intrusion (range 0-35) and Avoidance (range 0-40), were used as two dependent variables in the multilevel regression analysis. In our study, Cronbach's α was .86 for Intrusion and .79 for Avoidance, leading to a corrected correlation for unreliability of .70 between Intrusion and Avoidance. This finding indicates discriminant validity, that is, the two subscales can be treated as related but distinct constructs (Kenny, 2011).

Independent parent-related variables

Several parental emotions regarding the burn event were inquired. Parents were asked: "To what extent do the following emotions apply when you think about the accident that caused the burn?" Parents were asked to answer on a 5-point Likert scale, ranging from 0 "not at all" to 4 "a lot". Based on previous research, we used the emotions guilt and anger ($r = .45$, $p < .01$). Further, 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?" All information was gathered within the first month after the burn event, in the hospital if possible, or otherwise questionnaires were sent to the families' home address.

Independent child-related variables

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) were recorded from the medical file. Information regarding the place of the burn event (i.e., inside or outside the home), and the cause of the burn (e.g., hot fluids, flame, contact with hot object) were provided by the parents.

Statistical Analyses

Paired samples t tests, Chi square statistics, and bivariate correlations were used to compare scores of mothers and fathers. Further, we used multilevel regression analysis in Mplus version 6.1 to examine symptoms of Intrusion and Avoidance within couples (Muthén & Muthén, 1998-2010). As data from mothers and fathers from the same family are nonindependent, it is highly recommendable to perform dyadic analyses (Kenny, 2011). This type of analysis considers the nonindependence in the data and directly measures the magnitude of the nonindependence (Hox, 2010). Our data set has a two-level hierarchy, with two parents nested within a couple. Each predictor variable in a multilevel model only varies at one level. The lowest level comprises the parent variables (i.e., parent gender, parent age, feelings of anger and guilt, and perceived life threat to the child), and the high-

est level comprises child and burn characteristics, as these are the same for parents within a couple (i.e., child gender, child age, burn size, and circumstance of the burn event occurring in the home setting). Intraclass correlation coefficients were used to examine the distribution of unexplained variance over the two levels. In other words, this coefficient indicates the extent to which the outcome (i.e., Intrusion and Avoidance) appears in individual parents and to which extent it is shared within a couple. Individual parent-related variables and child-related variables were subsequently added to the regression model. Finally, the proportions of explained variance at the individual parent and the couple level were calculated.

RESULTS

Parental Stress Reactions in Subacute Phase of Burn Event

Fifty percent of the participating 182 mothers and 27% of the participating 154 fathers had clinically significant stress scores. Looking at complete participating couples only ($n = 143$), percentages were comparable (45% and 25% respectively, Table 3.1). There was dyadic concurrence on the presence (15%) or absence (45%) of clinical stress in most couples. In families where mothers had scores above the cut-off, 34% of the fathers also had a score above the cut-off. In families where fathers had a score above the cut-off, 61% of the mothers also scored above the cut-off. Acute stress reactions in mothers and fathers were significantly correlated ($r = .33, p < .01$). The association between parents on symptoms of avoidance ($r = .42, p < .01$) was stronger than the association on symptoms of intrusion ($r = .20, p = .02$).

Table 3.1

Clinically Significant Acute Stress Reactions in Couples ($IES \geq 26$)

| | | Fathers | | |
|---------|---------------|---------------|---------------|------------|
| | | Below cut-off | Above cut-off | |
| Mothers | Below cut-off | 64 (45%) | 14 (10%) | 78 (55%) |
| | Above cut-off | 43 (30%) | 22 (15%) | 65 (45%) |
| | Total | 107 (75%) | 36 (25%) | 143 (100%) |

On average, mothers had higher total stress scores than fathers (mean difference 9.1, 95% CI 6.5 – 11.7, $t(142) = 7.0, p < .01, r = 0.51$). Mothers and fathers without a partner did not have higher stress scores than mothers and fathers with a partner (mothers: mean difference 3.5, $t(178) = 1.1, p = 0.38$; fathers: mean difference 4.2, $t(148) =$

0.8, $p = 0.42$). Table 3.2 shows mean IES scores for all mothers and fathers, and parental individual emotions regarding the burn event.

Table 3.2

Descriptives Parental Acute Stress and Emotions Regarding the Burn Event

| Variable | Mothers ($n = 182$) | Fathers ($n = 154$) |
|--|-----------------------|-----------------------|
| IES – total, scale 0-75, M (SD) | 27.3 (14.2) | 17.5 (13.3) |
| Feelings of guilt, scale 0-4, M (SD) | 2.0 (1.5) | 1.4 (1.4) |
| Feelings of anger, scale 0-4, M (SD) | 1.4 (1.5) | 1.1 (1.3) |
| Perceived threat to life child, % yes | 18% | 9% |

Multilevel Regression Analysis

Data from 143 complete couples were used for the multilevel analysis. Intraclass correlations showed that nearly all unexplained variance of the Intrusion subscale was found at the individual parent level (93%). In contrast, for the Avoidance subscale, 64% of the unexplained variance was found at the individual parent level, and 36% was found at the couple level. This means that for Avoidance, two parents within a couple expressed more similar reactions, than two random parents of different couples.

When examining associated variables with the Intrusion subscale, parent gender (female), more feelings of guilt and anger, and in particular perceived life threat of their child were parental characteristics significantly associated with higher intrusion scores (Table 3.3). Child-related variables such as child gender and age and burn size were modestly associated with parent symptoms on the couple level. However, since only 7% of parents' intrusion symptoms were found at the couple level, these child variables play a minor role in explaining intrusions in parents at the couple level.

For the Avoidance subscale, results showed that, in line of the findings on Intrusion, parent-related variables gender and individual emotions concerning the burn event were significantly associated with higher avoidance scores. However, the associations were less strong compared with the Intrusion subscale and less variance was explained at the individual parent level (26 vs. 42%). In contrast with the findings on intrusion, two child-related variables, that is, more extensive burns and accidents that happened at home, were strongly related to parental avoidance at the couple level (Table 3.3). This means that part of the similarity in avoidance reactions within a couple was explained by characteristics of the burn and the burn event. Parent-related and child-related variables together explained 74% out of 36% unexplained variance of avoidance symptoms at the couple level.

Table 3.3*Multilevel Regression Analysis for Variables Related to Couples' Acute Stress (n = 143)*

| | Intrusion (0-35) | | | Avoidance (0-40) | | |
|--|------------------|-----------|---------|------------------|-----------|---------|
| <i>Child-related variables</i> | <i>B</i> | <i>SE</i> | β | <i>B</i> | <i>SE</i> | β |
| Child gender ^a | 1.97 | 0.97 | 0.30* | 1.45 | 0.82 | 0.28 |
| Child age | 1.11 | 0.52 | 0.32* | 0.80 | 0.43 | 0.30 |
| Burn size | 0.19 | 0.09 | 0.35* | 0.29 | 0.08 | 0.71** |
| Accident at home | 1.33 | 1.08 | 0.19 | 2.61 | 0.76 | 0.48* |
| <i>Individual Parent variables</i> | | | | | | |
| Parent gender ^a | 3.98 | 0.85 | 0.26*** | 2.47 | 0.80 | 0.19** |
| Parent age | 0.40 | 0.17 | -0.18* | -0.06 | 0.14 | -0.03 |
| Feelings of anger | 1.42 | 0.40 | 0.23*** | 1.43 | 0.46 | 0.27** |
| Feelings of guilt | 0.87 | 0.38 | 0.16* | 0.75 | 0.37 | 0.16* |
| Perceived threat to life of child ^b | 8.88 | 1.98 | 0.27*** | 4.41 | 2.08 | 0.16* |
| <i>R</i> ² Individual parent level | 42% (of 93%) | | | 26% (of 64%) | | |
| <i>R</i> ² Couple level | 32% (of 7%) | | | 74% (of 36%) | | |

^a0 = male, 1 = female. ^b0 = no, 1 = yes.* $p < .05$. ** $p < .01$. *** $p < .001$.

DISCUSSION

This is the first study demonstrating that both mothers and fathers report considerable stress reactions in the subacute aftermath of a burn event to their preschool-aged child and that avoidance of stimuli associated with the trauma is, to an important extent, shared within couples. In contrast, intrusions appear intra-individual symptoms not shared within couples.

Approximately half of the mothers and one fourth of the fathers in this study sample experienced significant acute stress in the first month after the burn. The rates we identified seemed somewhat high compared to studies that investigated (the risk for) PTSD in parents of ill or injured children (Balluffi et al., 2004; Kassam-Adams et al., 2009; Nelson & Gold, 2012), but are in line with studies on parents, predominantly mothers, of children with burns (Hall et al., 2006; Rizzone et al., 1994). Conceivably, the time frame of our study (i.e., the first month after the burn event compared to at least 3 months after the injury used in most other studies) partly explains the elevated stress scores identified in our study. Besides the time frame, the preschool age category in this study differs from other studies that included children of all ages.

Consistent with most other studies that included both parents of acutely ill or injured children, our results showed that, on average, mothers experienced more acute stress compared to fathers. This finding may be related to women's higher risk to develop PTSD (Olf, Langeland, Draijer, & Gersons, 2007), but also to the fact that mothers are often the primary caregiver (Cabizuca, Marques-Portella, Mendlowicz, Coutinho, & Figueira, 2009). However, we also found a considerable overlap within families. For example, our results showed that if one parent reported significant distress, in 34-61% of the cases the other parent as well experienced significant distress. And, in a minority of the participating families, fathers actually had higher stress scores than mothers. To speculate, this latter finding may for instance be related to pretrauma factors (e.g., prior trauma, Kassam-Adams et al., 2009), being the primary caregiver (Cabizuca et al., 2009), or circumstances of the injury.

Interestingly, this study demonstrated that on the family level mothers and fathers showed an overlap in their avoidance symptoms in the subacute phase of the burn event, in contrast to intrusion symptoms that appeared to be predominantly individual experiences. Our results support a reported association between mothers' and fathers' PTSS, 3 months after their child had been admitted to the pediatric intensive care unit 3 months before (Bronner, Knoester, Bos, Last, & Grootenhuis, 2008). Two injury-related factors, that is, burn severity and burn events occurring in the home, were associated with avoidance symptoms within couples. Although previous studies have reported the relationship between burn severity and individual parent traumatic stress (Hall et al., 2006; Rizzone et al., 1994), this study shows the impact of burn severity on acute distress in couples. We speculate that seeing their child so badly injured and in pain may create a mutual coping response in couples to temporarily withdraw from what happened. Avoidance in couples was further modestly related to injuries that occurred at home. Because the vast majority of pediatric burns in infants and toddlers concern scald burns that occur in the home (Vloemans et al., 2011), it can be an important factor in coping with a burn event in this population of parents. Ignoring thoughts about the circumstances of the accident may be a functional response for parents to modulate intense emotions in this early phase after the burn event (Horowitz, 1986). Other shared family factors may as well have influenced the similarity of responses in couples, such as similarities in the supportive network (Bronner et al., 2008).

Acute stress reactions in parents were strongly related to their emotions about the burn event. The strongest association was found between subjective distress and the thought that their child might not survive the burn injury. Previous studies support this finding in parents of children with traffic-related injuries (Kassam-Adams et al., 2009), and children that were admitted to the intensive care unit (Balluffi et al., 2004). We also found that parents' feelings of anger and guilt were related to their stress reactions. Concerning

feelings of guilt, our group found a predictive value of feelings of guilt present at 1 year postburn on traumatic stress 10 years later in mothers of children with more severe burn injuries (Bakker et al., 2010). Profound feelings of guilt may be particularly relevant when parents are faced with accidental injury in their children (Aitken, Mele, & Barrett, 2004). Compared to guilt, anger appeared even stronger related to parental subjective distress. Anger has been shown to be associated with PTSD in general trauma populations (McHugh et al., 2012); however, to our knowledge, it has not yet been reported in parents of injured children. The current findings emphasize the relevance of investigating individual emotions in the context of parental traumatic stress, as negative appraisals may interfere with healthy psychological adaptation to a traumatic event (Ehlers & Clark, 2000). Emotions about the burn event, and potential similarities or discrepancies in subjective feelings of anger or guilt, may be point of attention in monitoring parents during and after hospitalization.

Further research is needed to better understand these dynamics and the potential effect of this mutuality in couples on longer-term child and family adjustment. Important topics to address are for instance the extent to which the overlap in couples' avoidance symptoms maintains over time, and if couples that share symptoms in the acute phase run more or less risk of adequate adjustment to their child's medical trauma in the long run. Additionally, prospective information on postburn behavior of the children may provide more insight into the potential consequences of couple's stress reactions on a family level.

Findings from this study suggest that including both parents in screening and counseling is of importance, because there appears to be a shared component in their reactions to the injury of their child. In clinical practice, in the hospital but also shortly after discharge, health care workers should be aware of the presence of stress reactions in *both* parents and the potential interaction between parents' symptoms. The findings confirm the critical importance of monitoring traumatic stress reactions not only in mothers but across the entire family (Seagull, 2000). Mothers and fathers may need help for instance to contextualize and cope with intense emotions and change roles flexibly (Rolland & Walsh, 2006). In addition, parents may have significant worries about their child's health and potential functional limitations, and their child's appearance (Thompson, Boyle, Teel, Wambach, & Cramer, 1999). Approximately half of admitted children are discharged within a few days and not all of them are monitored systematically for an extended period. Parental psychoeducation during hospitalization and before discharge could include information on potential parent reactions and shared symptoms within families in order to normalize feelings and reassure couples. Further, it may be helpful to frame adaptation to the medical trauma as a challenge for all family members (Rolland & Walsh, 2006). Previous reports have also underlined the relevance of including the entire family in interventions after a pediatric medical trauma (Seagull, 2000). In the burn centers participating in this study, psychosocial sup-

port services is provided for children and their families during hospitalization and on follow-up (e.g., psychological counseling, social work, burn camps for burn survivors 8-17 years old), but no specific family counseling program or parent groups for supporting the entire family system have been developed.

Some limitations of this study should be noted. Our results concern parental reactions within the first month after their young child's burn event. Initial stress symptoms tend to gradually decline over time in most parents (Le Brocque et al., 2010). Nevertheless, this study on short-term reactions adds to our understanding of parents' experiences of the subacute phase during or shortly after hospitalization, which is a highly relevant phase with respect to clinical pediatric practice. Further, albeit not a sensitive predictor on its own, stress reactions in the acute phase may be associated with long-term posttraumatic stress reactions (Kassam-Adams et al., 2009). The IES, used in this study to measure parental subjective distress, measures only two symptom clusters of traumatic stress, that is, avoidance and intrusion, excluding hyperarousal. Furthermore, the IES does not inquire after symptoms of dissociation. As such, the IES does not provide figures concerning the prevalence of Acute Stress Disorder. Nevertheless, the IES has been validated in the Dutch population (Brom & Kleber, 1985), has proven acceptable discriminant validity between persons with and without PTSD in an adult population with burns (Sveen et al., 2010), and has been used previously in other studies on parents of injured children (e.g., Le Brocque et al., 2010). Children in this study were 0-4 years old; consequently, our results may not readily be applied to parents of older children. It would be interesting, however, to investigate if the risk for developing ASS and/or PTSS in parents of young children differs from parents of older children. With regard to the population under study, parents with insufficient proficiency in the Dutch language were not included in this study, though they were well represented in the pediatric burn population. Further, the literature reports that a significant minority of pediatric burn injuries is nonaccidental, resulting from abuse or serious neglect (Toon et al., 2011). This was not an exclusion criterion in our study, but we do not have information if these cases are present in our sample. Finally, we recognize that apart from the parental emotions related to the burn event and the child and burn characteristics we investigated in this study, factors such as previous life stressors, premorbid mental health problems, and additional circumstances of the burn event, may also have influenced stress reactions in couples.

Despite these limitations, this study has substantial strengths. Most importantly, we included both mothers and fathers of children with acute burns admitted to all burn centers in the Netherlands and all burn centers in the Dutch-speaking region of Belgium. In two-thirds of the sample, both parents participated, which makes this a considerably large and unique study sample. We used advanced statistical modeling to properly study our

dyadic data (Kenny, 2011). By doing so, we surpassed the traditional practice of either studying differences between mothers and fathers or statistically treating parents of the same child as independent caregivers.

In conclusion, this study with a large sample of mothers and fathers showed that acute stress reactions were highly prevalent in both parents after a burn event to their young child. On average, mothers reported more distress than fathers, but a significant overlap in avoidance symptoms within couples was found. Information on individual parent emotions regarding the burn event, such as the perceived threat to the life of the child, anger, guilt, and injury severity may be helpful in identifying parents and couples who are most at risk for acute traumatic stress. Follow-up care should not only systematically monitor scar evolution, but also systematically address mothers' and fathers' emotions and subjective distress in response to the burn event. We therefore recommend the integrated screening of both caregivers and the potential interplay in couples as part of a more comprehensive family support system after pediatric medical trauma.

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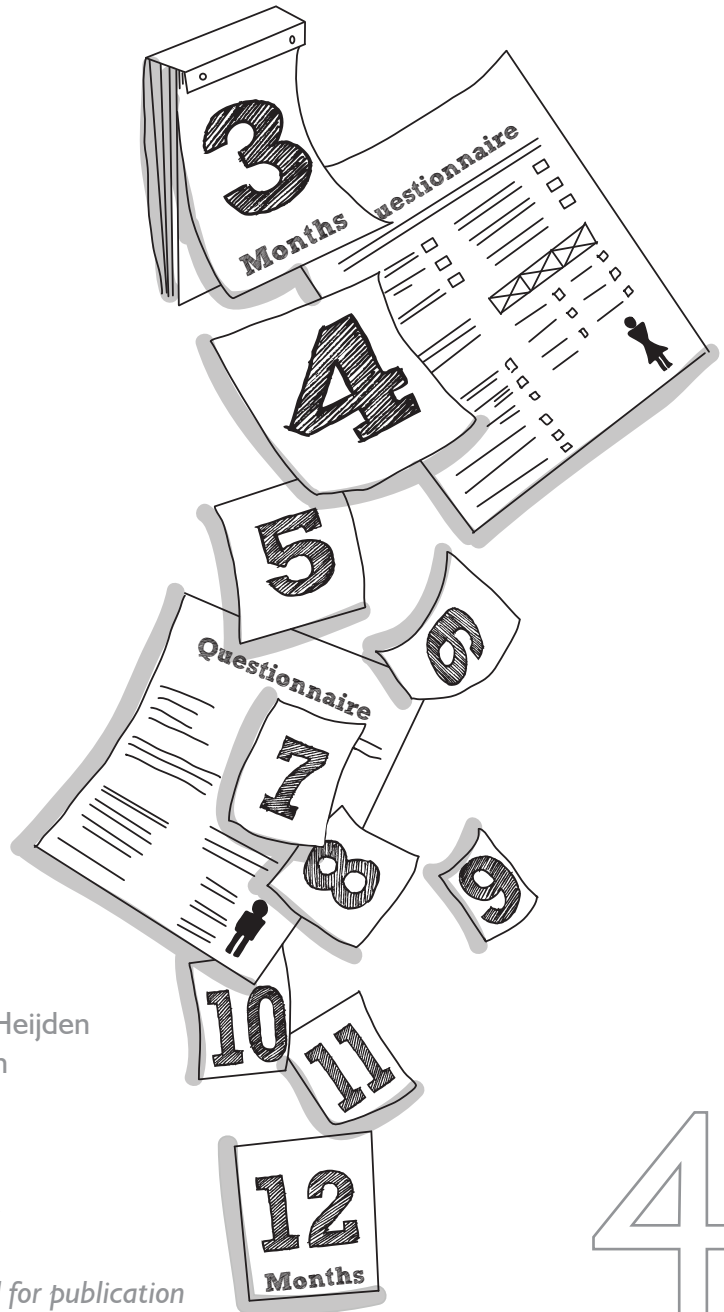
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The Relationship between Behavioral Problems in Preschool Children and Parental Distress after a Pediatric Burn Event



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ABSTRACT

Objective This study examines mother- and father-rated emotional and behavior problems in and worries about 0-4 year old children at 3 and 12 months after a burn event and the relation with parental distress. **Methods** Mothers ($n = 150$) and fathers ($n = 125$) representing 155 children participated. Child emotional and behavior problems and parental worries about the child were assessed with the Child Behavior Checklist at both time points. Parents' level of acute subjective distress was assessed within the first month after the burn event with the Impact of Event Scale. **Results** Mothers and fathers held comparable views of their child's emotional and behavioral problems, which were generally within normal limits. Parents' own acute stress reactions were significantly related to parent rated child behavior problems at 3 and 12 months postburn. A substantial part of mothers' and fathers' worries about the child concerned physical and emotional aspects of the burn trauma, and potential future social problems. Parents with high acute stress scores more often reported burn-related concerns about their child at 3 and 12 months postburn. **Conclusions** Health care professionals should be informed that parents' distress in the sub-acute phase of their child's burn event may be related to subsequent worries about their child and to (parent-observed) child emotional and behavioral problems. The authors recommend a family perspective, with particular attention for the interplay between parents' distress and parent-reported child behavior problems and worries, in each phase of pediatric burn care.

Key words: burns, children, behavioral problems, parental distress, fathers, interparental agreement

THE RELATIONSHIP BETWEEN BEHAVIORAL PROBLEMS IN PRESCHOOL CHILDREN AND PARENTAL DISTRESS AFTER A PEDIATRIC BURN EVENT

Burns are among the most common causes for injuries in children (Stoddard & Saxe, 2001), and in particular children under the age of 5 are at increased risk to sustain burn injuries (Vloemans et al., 2011). Rapid motor and cognitive development during early childhood contribute to a high incidence of predominantly scald burns in this young population (Brusselaers, Monstrey, Vogelaers, Hoste, & Blot, 2010; Vloemans et al., 2011). Commonly reported mechanisms for scald burns are for instance reaching for a cup on the edge of a counter, a pan on a stove, or pulling a table cloth (Dissanaike & Rahimi, 2009). Because children have a thinner and therefore more vulnerable skin than adults, seemingly modest accidents with hot fluids may result in severe burns with permanent scarring. Burns have been described as one of the most serious and traumatic injuries a child may experience (De Young, Kenardy, Cobham, & Kimble, 2012; Landolt, Grubenmann, & Meuli, 2002). The potential life threatening character of the injuries, pain, hospitalization and/or frequent visits to the hospital, and aspects of the medical treatment, such as repeated wound dressing changes, scar management, and in some cases skin grafting procedures are significant additional stressors. In the longer run, rehabilitation and reconstructive surgeries may be necessary. Permanent alterations to the child's appearance, functional limitations, and issues in social life may be further challenges for children (De Young et al., 2012) and may elicit parental worries about the future of their child (Thompson, Boyle, Teel, Wambach, & Cramer, 1999).

Serious medical events, such as burn injuries, may evoke a range of psychological reactions in both children and parents (Kazak et al., 2006). Previous studies in preschool children with burns have described considerable rates of short-term behavior disturbances between one and six months postburn (De Young et al., 2012; Mason & Hillier, 1993a), increased levels of internalizing problem behavior at an average of 1 year postburn (Meyer, Robert, Murphy, & Blakeney, 2000), and traumatic stress symptomatology in the first months (De Young et al., 2012; Stoddard et al., 2006), and at an average of 1 year postburn (Graf, Schiestl, & Landolt, 2011). In a Dutch-Belgian study, 25% of 2-14 year old children displayed internalizing problems during hospitalization (Liber, List, Van Loey, & Kef, 2006). Differently, a prospective study at 6 months postburn (Kent, King, & Cochrane, 2000) and a cross-sectional study at 1 year postburn on average (Graf et al., 2011) did not find significant group differences in terms of behavioral problems compared to reference data. Explanations for the discrepancy in findings may include variety in study outcomes, measures, timeframe, and sample characteristics (e.g., severity of injuries, socioeconomic background). So far, no studies prospectively followed children beyond the first 6 months post-

burn. Moreover, study samples were relatively small (n 's between 17 and 76), with the exception of one Australian study on 130 young children with minor burn injuries. As was noted in pediatric psychology (Phares, Lopez, Fields, Kamboukos, & Duhig, 2005; Seagull, 2000) and developmental psychopathology literature (Phares, Fields, Kamboukos, & Lopez, 2005), mothers were the principal informant on child postburn emotional and behavioral outcome in virtually all pediatric burn studies (Bakker, Maertens, Van Son, & Van Loey, 2013). Moreno and colleagues (Moreno, Silverman, Saavedra, & Phares, 2008) have argued that "the scarcity of father involvement in psychological research has likely yielded an incomplete picture of the familial context involved in child and adolescent psychopathology, especially in the assessment of youth's internalizing and externalizing behavior problems" (p. 915). Mothers and fathers may hold a different view of their child's behavior (Moreno et al., 2008), although it has been found that mothers and fathers overall show moderate to high levels of correspondence concerning their child's internalizing and externalizing behavior problems (Duhig, Renk, Epstein, & Phares, 2000). Up to now, studies on children with burns did not address the degree of interparental agreement or discrepancy on ratings of child internalizing and externalizing behavior problems.

Apart from a potential adverse effect on children, pediatric burns may as well seriously affect parents (Bakker, Maertens, et al., 2013). Studies, predominantly in mothers, reported for instance considerable rates of depression (El Hamaoui, Yaalaoui, Chihabeddine, Boukind, & Moussaoui, 2006), anxiety (Phillips & Rumsey, 2008), acute stress symptoms (Bakker, Van Loey, Van der Heijden, & Van Son, 2012), posttraumatic stress (Hall et al., 2006; Rizzone, Stoddard, Murphy, & Kruger, 1994), and worries about the child's health, scarring and appearance, and social issues (Phillips & Rumsey, 2008; Thompson et al., 1999). Only two studies reported separate data about posttraumatic stress in fathers after their child's burn injury (Bakker et al., 2012; Graf et al., 2011). In correspondence with a relational perspective on trauma in early childhood (Scheeringa & Zeanah, 2001) and in line with previous child trauma literature (Alisic, Jongmans, van Wesel, & Kleber, 2011), reactions of children and mothers were often found to be interrelated in the aftermath of a burn event (Graf et al., 2011; Mason & Hillier, 1993b; Stoddard et al., 2006). Information on the mutual relationship between reactions of children and their fathers is limited, as only one burn study specifically investigated the relationship between father and child postburn outcome (Graf et al., 2011). This study among parents of 1-4 year old children found that the mother's but not the father's PTSD symptoms in the aftermath of the child's burn event were related to the child's symptoms. However, mothers were the single informants to report on child posttraumatic stress and behavioral functioning in that study. The authors suggested that the absent relationship between the father's PTSD symptoms and the child's outcome might in fact be due to the single use of the

mother's rating of the child's functioning (Graf et al., 2011). In child developmental literature, a somewhat stronger relationship between maternal psychopathology and the child's internalizing problems was found in comparison to paternal psychopathology, but generally both mothers' and fathers' psychological functioning are described to be associated with child internalizing and externalizing problems (Connell & Goodman, 2002). A prospective study on school-aged children with injuries or newly diagnosed cancer or diabetes and their parents indeed showed that mothers' and fathers' posttraumatic stress symptoms in the subacute phase influenced the child's symptoms at one year later to an equal extent (Landolt, Ystrom, Sennhauser, Gnehm, & Vollrath, 2012). Contrarily, a meta-analysis suggested that the relationship between mother and child posttraumatic stress was stronger than the relationship between father and child posttraumatic stress across various types of potentially traumatic events in school-aged children (Morris, Gabert-Quillen, & Delahanty, 2012).

In summary, a burn event is a potentially traumatic event for both children and their parents and there is a lack of prospective research that extends beyond the period of hospitalization. In addition, the traditional research focus on mothers limits our understanding of the father's perspective on child functioning and father-child associations in terms of postburn outcome. In order to gain a rich perspective on the family context of child post-injury adjustment, this study included both mothers and fathers as informants of child behavior problems and parental worries at 3 and 12 months after a pediatric burn event. Compared to reference data, children with burns were hypothesized to show elevated levels of behavioral problems at 3 months postburn, in particular in the internalizing domain. Mothers and fathers were hypothesized to show a moderate to high level of agreement in terms of their rating of internalizing and externalizing problem behavior in the child. Worries concerning their child's health were expected to be present in mothers as well as in fathers and concordance of worries within couples was explored. Finally, this study investigated the prospective relationship between acute mother and father distress on the one hand, and child behavior problems and parental worries about the child on the other hand. We expected a positive relation between parental acute stress and subsequent parental worries and child behavior problems in mothers as well as in fathers.

METHODS

Procedure

This study is part of a larger prospective study on child and parental adjustment following a pediatric burn event. Data were collected in three Dutch and four Belgian burn centers. In previous articles, we reported on acute stress and the course of parental stress symptoms

in parents of young children with burns (Bakker et al., 2012; Bakker, Van Son, Van der Heijden, & Van Loey, 2013). Data for the current study concerning child behavioral and emotional problems were collected at 3 months (T1) and 12 months postburn (T2). Parent acute subjective distress, a predictor variable, was collected within the first month postburn.

Families were eligible to participate if the child was between 8 months and 4 years old, length of stay in the hospital was ≥ 24 h, and the Total Body Surface Area (TBSA) burned was $\geq 1\%$. TBSA is a percentage used to express the estimated proportion of the body with second or third degree burns. Exclusion criteria were insufficient parental Dutch language proficiency, and mental retardation in the child. Families were enrolled between October 2007 and July 2010. A local researcher contacted eligible families 1–4 weeks after admission. The researcher explained the study purpose and offered additional written information; informed consent was obtained from each of the participants. Two independent ethics committees in the Netherlands and Belgium, respectively, approved this study.

Of 313 families that met the study criteria, we could use data of 155 families that completed at least one questionnaire on behavior problems either at 3 or at 12 months postburn. Sixty-one families gave their informed consent to participate, but dropped out before 3 months postburn, 55 families declined the invitation, 26 families were missed before they could be approached, and 16 families were not invited because their participation was deemed inappropriate (e.g., severely ill family members, psychiatric background, or court custody cases). The 155 participating families did not differ from the other eligible families ($n = 158$) in terms of child age, gender, length of stay in the hospital, percentage TBSA, and percentage deep burns.

Participants

In total, 150 mothers and 125 fathers participated and in 77% of the cases, both parents participated. Table 4.1 shows child demographic and burn characteristics. Mean age of the mothers and fathers was 32.2 (SD 5.2) and 36.0 (SD 5.5) years. The majority of participating parents was employed (73% of mothers, 93% of fathers), and had a partner (90% of mothers, 95% of fathers).

In the course of the study, 25 families (23 mothers, 16 fathers) dropped out. We found no differences between families that participated at T1 and T2, and families that participated only at T1, in terms of child gender and age, burn characteristics, and mother-report of child behavior problems at T1. However, the 16 fathers that dropped-out after T1 reported more T1 behavior problems in their child, than the 95 fathers that participated at T1 and T2, $M = 50.5$ (SD = 10.0) vs. $M = 45.0$ (SD = 9.0), $t(109) = 2.2$, $p = .03$. Finally, 16 families participated only at T2 (16 mothers and 14 fathers) because their child was

younger than 18 months at T1. Behavior problems at T2 did not significantly differ between mothers/fathers that participated at T1 and T2 and mothers/fathers that participated only at T2.

Table 4.1

Participants: Child Demographic and Burn Characteristics (n = 155)

| | <i>M</i> | <i>SD</i> | <i>range</i> |
|-----------------------------------|----------|-----------|--------------|
| Child age (yrs) | 1.8 | 0.9 | 0-5 |
| TBSA (%) | 7.7 | 6.8 | 1-45 |
| Length of stay in hospital (days) | 11.3 | 10.8 | 1-55 |
| | <i>n</i> | <i>%</i> | |
| Child gender (boys) | 101 | 65 | |
| Skin grafting procedure (yes) | 57 | 37 | |
| Site of accident | | | |
| Inside the home | 113 | 73 | |
| Somewhere else inside | 27 | 17 | |
| Outside | 15 | 10 | |
| Aetiology | | | |
| Hot fluid | 137 | 88 | |
| Hot object | 8 | 5 | |
| Flame | 7 | 5 | |
| Other | 3 | 2 | |

Measures

Child behavior problems

The Child Behavior Checklist (CBCL) 1½-5 is a 100-item standardized measure of parental perception of their young child's emotional and behavioral problems (Achenbach & Rescorla, 2000). For this study, *both* parents completed the validated Dutch version of the CBCL 1½-5 (Verhulst & Ende, 2000). The CBCL is extensively investigated and validity and reliability are excellent (Achenbach & Rescorla, 2000). In this study, Cronbach's alphas for mother- and father-report of Internalizing, Externalizing and Total symptoms range between .79-.94. Following the manual (Achenbach & Rescorla, 2000), scale scores were not computed if parents missed more than 8 out of 99 problem items. Missing items (0.13%) for the other forms were substituted by zero (no problems).

Broad band scales 'Internalizing problems', 'Externalizing problems', and 'Total problems' were used as dependent variables in the analyses. Raw scores were transformed

to *T* scores, with possible scores ranging between 29-100 for Internalizing problems and 28-100 for Externalizing and Total problems (higher scores represent more problems). *T* scores 60-63 refer to the subclinical range, and scores ≥ 64 to the clinical range of behavior problems (Achenbach & Rescorla, 2000). CBCL reference data were derived from the multicultural manual in which both the Netherlands and Belgium, together with 16 other countries including the United States of America, are represented in the middle group (Achenbach & Rescorla, 2010).

Parental concerns

Parental concerns about the child were assessed through an open-ended CBCL question: "What concerns you most about the child?".

Parental acute subjective distress

The Impact of Event Scale (IES) is a valid and psychometrically sound 15-item self-report measure used to assess two dimensions of subjective distress related to traumatic events, that is, symptoms of intrusion and avoidance (Horowitz, Wilner, & Alvarez, 1979; Sundin & Horowitz, 2002). Both parents completed the validated Dutch version of the IES (Brom & Kleber, 1985) within the first month postburn. Parents were asked to rate the frequency of symptoms they had experienced in relation to their child's burn event on a 4-point Likert scale (0-1-3-5). The total possible score ranged from 0-75, with higher scores representing higher levels of distress. Scores 26 and higher were used as an indication of clinically significant stress symptoms. Cronbach's alpha for the total IES was .86 for mothers and .87 for fathers respectively.

Demographic and injury variables

Child gender, age, and burn characteristics (i.e., percentage TBSA, number of surgeries during initial hospitalization, and length of stay in the hospital) were recorded from the medical file. Information regarding the cause of the burn, hot fluid, contact with a hot object, flame, or other, and the site of the accident was provided by parents within the first month postburn.

Statistical Analyses

First, *T* scores were used to represent child behavior problems at each stage. Child behavior problems in this sample were compared with published reference data by means of one-sample *t* tests. Intraclass correlation coefficients were calculated to determine interparental agreement for child internalizing and externalizing behavior problems.

Second, to interpret parental worries about the child, parents' answers on the open-ended CBCL question "What concerns you most about the child?" were screened for overarching themes. After this initial screening, two researchers (AB and NVL) independently from each other categorized all parental answers into four themes: (a) physical aspects of burn injury recovery, (b) emotional and behavioral consequences of the burn injury, (c) concerns about the future and reactions from others related to the burn injury, and (d) 'general' developmental or behavioral issues not related to the burn. Across the respective stages, 224 parents described one or more concern. There was interrater consensus in 87% of the cases. In case of discrepancy, consensus was reached through discussion. Within-couple differences in terms of having or not having burn-related concerns and the relationship between acute parental distress (below or above cut-off) and the presence of subsequent burn-related concerns were tested with Chi square statistics.

Third, the course and predictors of child behavioral problems were investigated in a multilevel regression model. We used multilevel analysis as it can deal with multiple predictors in a dependent multilevel data structure. Our data set has a three-level hierarchy with time (3 and 12 months), nested within an observing parent (mother and father), nested within a child. An advantage of multilevel analysis concerns the ability to deal with missing data. Multilevel analysis considers all observations where information is available on the outcome level, using a missing at random assumption for the missing data (Hox, 2010).

Separate multilevel regression analyses for internalizing and externalizing problems were performed in MLWIN (Rasbash et al., 2000), using consecutive steps described by Hox (Hox, 2010). First, intraclass correlations were calculated to examine which proportion of the variance in internalizing and externalizing problems was located at the time level (differences over time), parent level (differences between mother- and father-report), and child level (differences between children) respectively. Child gender, age, and burn severity were included in the model as covariates. To examine if mothers and fathers hold different views of their child's adjustment and to examine the influence of parental stress on parent-reported child behavioral problems, parent gender and parent acute subjective distress were added to the model. An interaction term for 'parent gender' times 'parental distress' was tested in order to examine whether the influence of parental distress on child internalizing and externalizing symptoms differed between mothers and fathers. Finally, we checked whether the course of internalizing and externalizing symptoms differed between children ('random slopes') and we explored if this randomness could be attributed to child gender, age, and extent of the burn injury by means of cross-level interactions between time and child factors. *T* scores for internalizing and externalizing problems were used as dependent variables. All continuous independent variables (i.e., parent acute stress, child

age, and burn size) were centred using the grand mean and dichotomous predictors were labelled 0-1 (i.e., gender).

RESULTS

Prevalence of Child Behavior Problems

Parent ratings indicated that 9.0-15.7% of the children had behavior problems in the (sub)clinical range at 3 months and 5.5-13.4% of children had behavior problems in the (sub)clinical range at 12 months after the burn event (Table 4.2). Total behavioral problem scores were significantly lower than published reference data (Achenbach & Rescorla, 2010).

Table 4.2

Sample Means (T scores) and Prevalence (Sub)Clinical Child Behavioral Problems

| | 3 months postburn (T1) | | | | | | 12 months postburn (T2) | | | | | |
|---------------|------------------------|--------|-------|----------------|-------|-------|-------------------------|--------|-------|----------------|-------|------|
| | Mother-report | | | Father-report | | | Mother-report | | | Father-report | | |
| | <i>n</i> = 134 | | | <i>n</i> = 111 | | | <i>n</i> = 127 | | | <i>n</i> = 109 | | |
| | M | (SD) | ≥T60 | M | (SD) | ≥T60 | M | (SD) | ≥T60 | M | (SD) | ≥T60 |
| Internalizing | 45.6 | (10.9) | 11.2% | 44.7 | (9.5) | 9.0% | 43.9 | (9.8) | 5.5% | 43.2 | (9.9) | 5.5% |
| Externalizing | 48.9 | (9.6) | 15.7% | 47.8 | (9.0) | 10.8% | 46.4 | (10.6) | 13.4% | 46.3 | (9.6) | 6.4% |
| Total | 47.3 | (10.1) | 11.9% | 45.8 | (9.3) | 9.0% | 44.7 | (10.1) | 7.9% | 44.0 | (9.6) | 6.4% |

Note. Of all T2 parents, 16/127 mothers and 14/109 fathers did not participate at T1.

Intraclass correlations between mother- and father-report for internalizing symptoms were .59 and .58, and for externalizing symptoms .67 and .68, at 3 and 12 months respectively.

Parental Concerns

Between 33-57% of parents described one or more concerns with regard to their child at 3 and 12 months postburn, respectively. Table 4.3 shows the distribution of parental answers across the four themes: physical aspects of burn injury recovery, emotional and behavioral consequences of the burn injury, concerns about the future and reactions from others, and 'general' developmental or behavioral concerns.

Examples of parental burn-related concerns were: “.. that the scar will remain visible” (physical aspects of burn, mother, T1) “..will the skin grow along” (physical aspects of burn, father, T2), “.. [my child] has imaginary friends since the burn...” (emotional or behavioral consequences of burn, mother, T1), “how the outside world, future classmates will respond” (future and social aspects of burn, father, T2).

Table 4.3*Parental Concerns*

| | 3 months postburn | | 12 months postburn | |
|---|---------------------------|---------------------------|---------------------------|---------------------------|
| | Mothers <i>n</i> = 134 | Fathers <i>n</i> = 111 | Mothers <i>n</i> = 127 | Fathers <i>n</i> = 109 |
| Parents with ≥ 1 concern related to: | | | | |
| Burn event/burn injury | 42 (31%) | 34 (31%) | 24 (19%) | 16 (15%) |
| Physical aspects | 25 (19%) | 23 (21%) | 14 (11%) | 10 (9%) |
| Emotional or behavioral aspects | 10 (7%) | 7 (6%) | 6 (5%) | 0 (0%) |
| Future and social aspects | 8 (6%) | 7 (6%) | 6 (5%) | 8 (7%) |
| Behavior/development | 39 (29%) | 21 (19%) | 35 (28%) | 21 (19%) |

Note. Each parent could describe more than one concern. Percentages in each cell are expressed as proportions of the total number of participating parents at the respective stages.

Although a comparable proportion of mothers and fathers reported burn-related concerns, that is, 31% at 3 months and 15-19% at 12 months, concurrent presence of concerns *within couples* was low (3 months: $X^2(1) = 24.1, p < .01$; 12 months $X^2(1) = 17.2, p < .01$).

Association Parental Distress and Parental Concerns about the Child

Forty-seven percent of the mothers and 26% of the fathers had acute stress symptoms in the clinically significant range ($IES \geq 26$). Cross-tabs showed that the number of parents with burn-related concerns at 3 and 12 months postburn was approximately twice as high among highly symptomatic parents (Table 4.4). In contrast, symptomatic parents did not report more general behavior concerns about their child (results not shown).

Child Behavior Problems from the Mother's and the Father's Perspective

Multilevel regression analysis showed that two parents had very similar observations of problem behavior in their child: 3% of internalizing and 1% of externalizing symptoms' variance was located at the parent level. The major part of variance in child symptoms was found at the child level (56% for internalizing and 59% for externalizing problems) and another large part of the variance occurred at the time level (41% for internalizing and 40% for externalizing problems). This indicated that children's problem behavior differed from each other, and, that children's scores changed over time.

Table 4.4*Contrast of Parental Concerns Between Parents with Low and High Levels of Acute Stress Symptoms*

| | Low acute parental distress | High acute parental distress | X ² |
|--|--------------------------------|---------------------------------|------------------|
| Proportion of mothers with ≥ 1 burn-related concern | | | |
| 3 months | 23% | 39% | 4.3* |
| 12 months | 14% | 26% | 2.7 [†] |
| Proportion of fathers with ≥ 1 burn-related concern | | | |
| 3 months | 24% | 45% | 4.3* |
| 12 months | 10% | 31% | 7.1** |

* $p < .05$. ** $p < .01$. [†] $p < .10$.

For internalizing problems, results showed that older children in the preschool range experienced more symptoms (Table 4.5). Parental acute stress symptoms ($M = 27.1$ [$SD = 14.0$] for mothers; $M = 16.9$ [$SD = 12.7$] for fathers) were associated with internalizing behavior problems across the first year postburn, such that children of more acutely distressed parents were reported to have more internalizing behavioral problems at 3 and 12 months later. This relationship between parental acute stress and child internalizing symptoms was comparable for mothers and fathers. The relation between time and internalizing behavior problems was random, indicating that not all children displayed the same decrease in behavior problems. One child factor was identified that partly explained the different patterns over time. That is, girls tended to show more internalizing problems (2.19 points higher than boys), but they also showed a greater decline in problems over time (a decrease of 3.58 points for girls versus a decrease of 0.16 points for boys).

For externalizing problems, parental acute subjective distress was related to more child externalizing problems (Table 4.5). Child factors age, gender, and burn extent were not significantly related to the level of externalizing behavioral problems. Over time, there was a decrease in externalizing problem behaviors which appeared random. However, in contrast to internalizing problem behavior, we could not find child factors that significantly contributed to the variance in children's courses of externalizing symptoms.

Table 4.5*Multilevel Regression Analyses Internalizing and Externalizing Behavior Problems*

| | Internalizing problems | | Externalizing problems | |
|------------------------------------|------------------------|------|------------------------|------|
| | B | SE | B | SE |
| <i>Time variables</i> | | | | |
| Intercept | 45.29*** | 0.95 | 48.88*** | 0.98 |
| Time | -0.16 ^c | 0.84 | -1.17 ^c | 0.87 |
| <i>Parent variables</i> | | | | |
| Parent gender ^a | -1.23 | 0.74 | -0.57 | 0.70 |
| Acute stress symptoms ^b | 0.14** | 0.05 | 0.09* | 0.05 |
| Parent gender × Acute stress | 0.08 | 0.06 | 0.01 | 0.06 |
| <i>Child variables</i> | | | | |
| Child gender ^a | 2.19 | 1.46 | 0.41 | 1.53 |
| Child age | 2.59*** | 0.75 | 1.03 | 0.79 |
| Burn size | 0.15 | 0.10 | 0.08 | 0.11 |
| <i>Interaction variables</i> | | | | |
| Time × Child gender | -3.42* | 1.49 | -2.39 | 1.55 |
| Time × Child age | -0.23 | 0.79 | -0.72 | 0.82 |
| Time × Child burn | -0.17 | 0.10 | -0.10 | 0.11 |
| <i>Explained variance</i> | | | | |
| At the child level | 28% (of initial 56%) | | 2% (of initial 59%) | |
| Of random slopes ^c | 12% | | 4% | |

^a0 = male, 1 = female. ^bScale 0-75. ^cRandom at child level.* $p < .05$. ** $p < .01$. *** $p < .001$ (two-sided tested)

DISCUSSION

By including both mother's and father's perspective on child internalizing and externalizing behavior problems and both mother's and father's self-reported acute distress, this study provides a novel and comprehensive family perspective on child postburn adjustment. Results showed that overall child behavioral and emotional problems within the first year after the burn event were well within normal limits. However, 6-16% of the children were described to experience behavior problems in the (sub)clinical range. Additionally, a substantial proportion of parents reported concerns related to physical and emotional aspects of their child's injury. The findings further indicated an association between mothers' and fathers' own distress shortly after the burn event and child adjustment and parental worries across the first year after the burn event. The results point at the importance of incorpo-

rating a family systems perspective when supporting, educating, and monitoring families after a pediatric burn event.

Although a small decrease in children's symptoms over the first year was noticed, children in our sample did not display more internalizing or externalizing behavioral problems at either time point after the burn event in comparison to multinational reference data. Behavior ratings from both parents showed that mothers and fathers held generally comparable views of their child's adjustment, which was consistent with our hypothesis. The prevalence of behavior problems, based on the CBCL, differed from a US study on toddlers with severe burns (Meyer et al., 2000), but is in line with two European studies on preschool children with minor to moderate burns (Graf et al., 2011; Kent et al., 2000). Apart from this difference regarding burn severity, the socioeconomic background of the children in the current and the Swiss study seemed quite good (Graf et al., 2011), in contrast to the children in the US study that predominantly came from lower socioeconomic groups (Meyer et al., 2000). Moreover, while information concerning abuse was not gathered in the current and the Swiss study (Graf et al., 2011), and injuries that were (suspected) nonaccidental were an exclusion criterion in a British study (Kent et al., 2000), 12% of the burn injuries in the US study were documented to have resulted from abuse and as much as 73% of the children were considered at high-risk for potential abuse (Meyer et al., 2000). These differences across study samples may suggest that there may already have been pre-existing differences in terms of behavior problems. Finally, although the current findings suggest a generally favourable behavioral outcome for young children with burns, results from recent diagnostic interview studies with parents have shown considerable rates of posttraumatic stress disorder in very young children with burns (De Young et al., 2012; Graf et al., 2011; Stoddard et al., 2006). Perhaps, clinical parent interviews that focus on posttraumatic stress responses, such as intense psychological distress at cues related to the event, avoidance of stimuli related to the trauma, or sleep problems, are more sensitive to detect particular problematic domains for these young children with burns.

The participation of fathers in this study provides additional insights in postburn mechanisms of family adjustment to a pediatric burn event, which may as well apply to other young trauma populations. In accordance with our hypothesis, child behavior problems at 3 and 12 months postburn, in particular internalizing behavioral problems, were related to both mothers' and fathers' symptoms of acute stress. Moreover, the strength of the relationship between parental and child adjustment in our study was comparable in mother-child and father-child dyads. To our knowledge, this had not been reported before in preschool injured children. Our findings were consistent with a study on school-aged children and their parents after a medical traumatic event (Landolt et al., 2012), but differed from a previous study that only found a relationship between child and maternal

adjustment after a pediatric burn event. However, it should be mentioned that the father's perspective on child adjustment in that study was absent (Graf et al., 2011). The literature describes different explanations concerning the interrelatedness between child and parent distress following trauma. First, it is possible that children and parents respond in a similar way to the same event. Shared factors related to the event and injury and a shared biological vulnerability might contribute to this phenomenon (Langeland & Olf, 2008). Moreover, it has been hypothesized that parents who are traumatized themselves may fall short in providing an emotionally safe environment and adequate parenting practices for the child resulting in poorer child recovery of trauma (De Young, Kenardy, & Cobham, 2011). Scheeringa & Zeanah (2001) hypothesized that behavior of family members may exacerbate the responses of other family members. Apart from resemblance and potential dynamics within the family in terms of posttrauma reactions, it may be conceivable that parents who are more distressed themselves observe more behavioral and emotional problems in their child. General child psychopathology literature for instance reported that parental characteristics, such as depression (De Los Reyes & Kazdin, 2005; Muller, Achtergarde, & Furniss, 2011) and anxiety (De Los Reyes & Kazdin, 2005), may influence parent ratings of psychopathology in the child. After medical trauma, it was found that highly distressed parents tended to overestimate traumatic stress symptoms in their school-aged child, whereas less distressed parents actually underestimated their child's symptoms in comparison to the child's self-report (Kassam-Adams, Garcia-Espana, Miller, & Winston, 2006). To what extent the interrelatedness between parental distress and child adjustment may partly be explained by observer bias remains to be elucidated in future research.

This study identified two child factors that were associated with postburn internalizing behavioral problems. Internalizing symptoms were more strongly present in older children in the preschool age range, while age differences concerning internalizing symptoms in the general population of 1.5-5 year olds are minimal (Achenbach & Rescorla, 2000). Previous burn studies with preschool children did not find an association between child age and postburn total behavior problems (Graf et al., 2011; Kent et al., 2000). Developmental factors may influence particular important aspects of the experience of a traumatic event, such as comprehension of what is happening, prior knowledge, and emotion regulation (Salmon & Bryant, 2002). These factors may have been less present in the youngest children in this study, perhaps resulting in less internalizing responses in this group. Another explanation may be that these symptoms are better observable in toddlers compared to infants, resulting in higher scores in older children. Related to this issue, the measure used in this study, albeit specifically designed for 1.5-5 year olds, is perhaps more sensitive to detect behavioral changes in the older age range of preschool children. With

respect to the decrease of internalizing symptoms, results showed that this pattern was different for boys and girls. Where girls tended to show more overall internalizing problems than boys, they also showed a greater decrease in symptoms. Although one study reported that young traumatized girls exhibited somewhat more PTSD symptoms than boys (Green et al., 1991), overall there seems no consistent evidence for gender differences regarding trauma reactions in preschool traumatized children (De Young et al., 2011). The CBCL manual reports no general gender effects (Achenbach & Rescorla, 2000). In contrast to internalizing symptoms, the variables under study explained only a minor part of externalizing symptoms and we could not find specific factors that contributed to the decrease in externalizing symptoms over time. Other factors beyond the scope of this study, such as family functioning (Graf et al., 2011), parenting behavior (De Young et al., 2011), and, although speculative, parent's posttraumatic symptoms of hyperarousal after the burn event, might have contributed stronger to the child's externalizing symptoms.

A substantial group of mothers and fathers in this study expressed concerns about their child's adjustment to the burn trauma, relating to physical, social, and emotional aspects. This is in line with a qualitative study among family members of pediatric patients with burns that found many burn-related concerns already shortly after hospitalization (Thompson et al., 1999). Specific reports about father's worries had not been described before. The content of parental worries suggests a need for comprehensive psychoeducation for parents about physical as well as emotional aspects of wound healing and scar formation as an essential part of postburn aftercare. Although mothers and fathers within couples had quite comparable views of their child's behavior problems, parents did not report the same burn-related worries about their child. As we found a clear relation between parents' own distress and their subsequent burn-related worries, the low concordance on worries may partly be explained by the low concordance on traumatic stress within parent couples that we previously found (Bakker et al., 2012). Awareness about the relationship between parents' stress reactions in the subacute phase of the injury and long-term worries and questions about the child's recovery is warranted and the needs of both parents in this perspective should be an on-going focus of monitoring.

This prospective multicenter study has a number of important strengths, including a longitudinal design and a large sample of preschool children with burns. We used a standardized and well-validated instrument to examine child behavioral and emotional problems from both the mother's and the father's perspective, and advanced statistical modelling to adequately study family data over time. Limitations of this study include the lack of information on pre-injury behavioral functioning that prevented to examine a causal relationship between the burn event and postburn child problems. In other studies after accidental trauma (Cox, Kenardy, & Hendrikz, 2008; Meyer et al., 2000), pretrauma behavior was

strongly linked to behavior after traumatic injuries. In general, it is difficult to gather reliable (parent-reported) information concerning child pre-injury behavior problems once admitted to the hospital, but it should nevertheless be a point of attention. Future studies may consider a comparison or control group in order to assess the unique consequences of pediatric burns as well as to gain more insight in recovery processes. Concerning the prevalence rate of (sub)clinical problem behavior, we used reference data from a multicultural, but US-based, normative sample (Achenbach & Rescorla, 2010). No separate norm data are available for Belgium and the Netherlands. It is remarkable that the prevalence rates we found in this study were much more in line with a sample of Swiss preschool children with burns (Graf et al., 2011) than with published norms. Notably, five percent of eligible children were excluded because of problematic family conditions, and fathers that dropped out in the course of the study indicated slightly more problem behavior in their child, so prevalence rates of behavior problems might actually be higher. With regard to the population under study, insufficient proficiency in the Dutch language was an exclusion criterion, though these families were well represented in the pediatric burn population. Future studies may benefit from a longer follow-up than 1 year, as one study identified burn-related factors to be associated with maternal symptoms of traumatic stress over a 10-year period (Bakker, Van Loey, Van Son, & Van der Heijden, 2010), raising questions to what extent these factors might affect the child's long-term functioning. Finally, research on family dynamics should give more insight how parents' reactions and young children's behavior reciprocally influence each other in the aftermath of a medical traumatic event.

Results from this study may inform European clinical burn practice where young children -predominantly with scald burns- and their parents are frequently seen. Our findings showed that both parents hold fairly comparable views of their child's behavior following the burn event. Health care workers should be aware that, as in the normal population, a subgroup of children presents with clinical behavior problems. Parents' concerns about their child's burn, which were related to physical, emotional, and potential future social aspects, provide suggestions for several important themes for psycho-education materials. In addition, parents within couples did not express the same concerns, indicating the importance of inquiring after concerns of mother as well as of fathers. Parents may struggle with intense emotions or traumatic stress reactions, which may also relate to (their observation of) their child's behavior problems and to parental worries about the child. Information about a range of normative parental reactions to stressful events may be helpful and supporting for both parents. Finally, considering the interrelatedness between the child and both parents in terms of postburn outcome, we recommend a broad family perspective on child adjustment and aftercare in the aftermath of a pediatric medical traumatic event.

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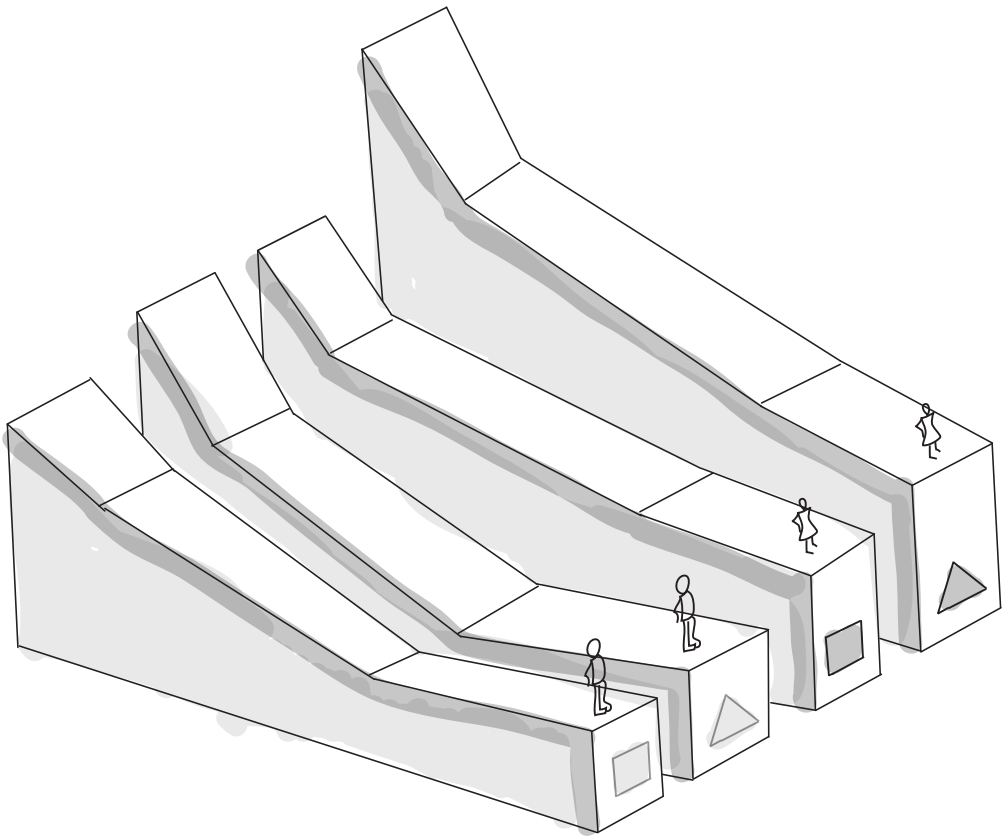
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CHAPTER 4

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Course of Traumatic Stress Reactions in Couples after a Burn Event to Their Young Child



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ABSTRACT

Objective This study examines traumatic stress reactions in couples that were followed prospectively for 18 months after a burn event to their child. **Methods** The participants included 186 mothers and 159 fathers of 198 preschool children. Parents' self-reported traumatic stress reactions were measured with the Impact of Event Scale (IES). Predictors included parental emotions and the perceived life-threatening character of the child's injury. **Results** Rates for clinically significant symptoms ($IES \geq 26$) decreased from 50% within the first month to 18% at 18 months postburn for mothers and from 27% to 6% for fathers. The decline in symptoms was not entirely linear. Mothers had higher scores than fathers, but the discrepancy in intrusion symptoms among couples diminished over the course of time. Early appraisal of life threat and emotions about the burn event were significant predictors. **Conclusions** Both mothers and fathers are seriously affected by a burn event of their young child. Despite a general decrease over time, a subgroup of parents is at risk for chronic symptoms. The results call for the integration of prolonged parent support in family-centered pediatric burn aftercare programs.

Key words: burns, parents, traumatic stress symptoms, appraisal, guilt

COURSE OF TRAUMATIC STRESS REACTIONS IN COUPLES AFTER A BURN EVENT TO THEIR YOUNG CHILD

Being confronted with a serious illness or injury in their child is among the most devastating and life-impacting experiences a parent couple may face. A serious medical condition in loved ones qualifies as a traumatic event and may consequently evoke symptoms of post-traumatic stress disorder (PTSD), such as intrusive thoughts, avoidance of stimuli related to the trauma, and hyperarousal. Past research has found considerable rates of PTSD symptoms in parents across a variety of medical conditions (e.g., Bronner et al., 2010; Kassam-Adams, Fleisher, & Winston, 2009; Kazak et al., 2004; Rizzone, Stoddard, Murphy, & Kruger, 1994). While the importance of a family systems framework in pediatric psychology practice is highly acknowledged (Kazak et al., 2006; Kazak, Simms, & Rourke, 2002), information on the adjustment of fathers and couples to their child's medical event is scarce and, in particular, *longitudinal* data of couples is almost nonexistent. The current study aims to address these gaps in the literature by investigating the course of posttraumatic stress symptoms (PTSS) in mothers and fathers of young children with burns and by focusing on the differences and similarities between parents from a family system's perspective.

Pediatric burn injuries are characterized by their unexpectedness, sudden onset, potential threat to the child's life, acute hospitalization, pain, invasive medical procedures such as wound dressing changes and skin grafting procedures, scarring, and the potential loss of functionality. Pediatric burns occur relatively often in young children under the age of five (Vloemans et al., 2011), an age category in which children are particularly dependent on their parents. Burn events in preschool children often share many similarities in terms of burn etiology (i.e., scalds caused by hot fluids) and event circumstances (i.e., burn events occurring at home). A recent review indicated a considerable prevalence of maternal PTSS in cross-sectional studies both shortly after and long after the burn event (Bakker, Maertens, Van Son, & Van Loey, 2013).

Many parents will experience some symptoms of traumatic stress shortly after their child's illness or injury. These symptoms generally decline as time passes (Bronner et al., 2010; Le Brocque, Hendrikz, & Kenardy, 2010; Martin-Herz, Rivara, Wang, Russo, & Zatzick, 2012), but not in all parents. Identifying early risk factors of prolonged symptoms is thus warranted. Ehlers & Clark's (2000) cognitive model for PTSD suggests that individuals' negative appraisals about the trauma and/or its sequelae play an important role in the maladjustment to trauma. Pediatric medical trauma studies support the belief that parents' subjective experiences predominate the objective characteristics in valuing an experience as traumatic (Kazak et al., 2006). For example, parents who had perceived their child's life to be in danger after traffic-related injuries (Kassam-Adams et al., 2009) or burn injuries

(Bakker, Van Loey, Van der Heijden, & Van Son, 2012) had elevated levels of acute stress symptoms. With regard to pediatric burns, parental emotions related to appraisals about the trauma, such as feelings of guilt (Bakker et al., 2012; Bakker, Van Loey, Van Son, & Van der Heijden, 2010; Cella, Perry, Kulchysky, & Goodwin, 1988) and anger (Bakker et al., 2012) were also found to predict the parents' levels of PTSS.

Although individual appraisals about the child's medical trauma may explain the occurrence and persistence of PTSS in both mothers and fathers, differences within couples may also be expected, as women are more likely to report negative appraisals about traumatic events than men (Olf, Langeland, Draijer, & Gersons, 2007). Moreover, women use emotion-focused coping strategies more than men (Tamres, Janicki, & Helgeson, 2002), which may affect their reactions to the trauma (Olf et al., 2007). In pediatric studies, mothers are generally found to experience more (symptoms of) posttraumatic stress than fathers after an illness or injury in their child (for overviews see Cabizuca, Marques-Portella, Mendlowicz, Coutinho, & Figueira, 2009; Nelson & Gold, 2012). However, the mechanism underlying this difference between mothers and fathers has not yet been a topic of investigation. This study hypothesizes that mothers experience a higher level of PTSS than fathers partly because mothers experience a more negative appraisal (i.e., perceived threat to the child's life) and stronger emotions (i.e., feelings of guilt and anger) pertaining to the traumatic event. Furthermore, as negative appraisals or emotional responses may produce a current sense of threat and consequently hamper healthy adaptation to the traumatic event (Ehlers & Clark, 2000), parents with stronger emotions are expected to retain a higher level of stress symptoms over the course of time.

Although gender differences may be expected when studying PTSS in mothers and fathers, a family systems framework necessitates the incorporation of the interrelatedness within couples. Studying the dyadic subsystem of parents may prove helpful in ultimately gaining more insight into family functioning as a whole (Kazak, 1997). Previous studies noted an association within couples regarding symptoms of PTSD following a medical event in their child (Bakker et al., 2012; Bronner, Knoester, Bos, Last, & Grootenhuis, 2008; Landolt, Ystrom, Sennhauser, Gnehm, & Vollrath, 2012). This association does not imply that both parents have the exact same level of symptoms; the association rather refers to a pattern of similarity within couples that may be explained in part by sharing the same family system. The results from a study in the subacute aftermath of a pediatric burn event showed that child characteristics (i.e., a female child, an older age) and burn characteristics (larger burns and burn events occurring in the home setting) contributed to a shared part of avoidance symptoms in parent-couples (Bakker et al., 2012). Currently, it is unclear how these symptoms in couples evolve in the ensuing months.

The current study aims to extend our understanding of a couple's development of PTSS following a burn trauma in their preschool child with an 18-month follow-up. Based on the extant literature (e.g., Kazak et al., 2006; Le Brocque et al., 2010), a cognitive model for PTSD (Ehlers & Clark, 2000) and known gender differences in the context of PTSD (Olff et al., 2007), the following hypotheses were formulated: (a) parental symptoms generally decline over time; (b) mothers show a persistently higher level of stress symptoms than fathers throughout the study period, which may partly be explained by differences in appraisal and emotions about the burn event; (c) symptoms in parents *within* couples are more similar than symptoms *between* couples, partly because parents share factors related to their child, that is, the child's gender (girls) and age (older), and the child's burn injury, that is, a larger burn size and burn events occurring in the home setting (cf. Bakker et al., 2012).

METHOD

Participants

Parent characteristics

A total of 186 mothers and 159 fathers, including 147 couples representing 198 children, participated in the study. The mean age was 31.9 years ($SD = 5.3$, range 20–45 years) for mothers and 35.7 years ($SD = 5.8$, range 23–55 years) for fathers. The majority of the parents were in a relationship (88% of mothers and 95% of fathers), and a minority was single (11% of mothers, 5% of fathers) or widowed (1% of mothers, none of the fathers). Seventeen families reported that they also had children from previous relationships (9%). The majority of the parents, 83% of mothers and 81% of fathers, were 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; 29% of mothers, 26% of fathers), middle (technical and vocational training until the age of 18; 29% of mothers, 35% of fathers), or high (technical or vocational training for ages 18 and older or university; 42% of mothers, 39% of fathers). Seventy percent of the mothers and 90% of the fathers were currently employed.

Child characteristics

The children, 129 boys (65%) and 69 girls (35%), were, on average, 1.8 years old ($SD = 0.9$, range 0.7–4.6 years). In 77% of the cases, the burn event occurred in the home, 8% of the burn events occurred outside, and 15% took place somewhere else inside, mostly with family members such as grandparents. Ninety percent of the burn injuries were scald

burns. The average Total Body Surface Area (TBSA) burned, the estimated proportion of the body with second or third degree burns, could be classified as mild to moderate with a mean TBSA of 7.5% ($SD = 6.4$, range 1-45%), which is representative for 0-4 year old children in Dutch burn centers (Vloemans et al., 2011). The mean length of stay in the hospital was 11.2 days ($SD = 10.4$, range 1-55 days). Thirty-six percent of the children required at least one skin grafting procedure during the initial hospitalization ($M = 0.5$, $SD = 0.8$, range 0-5).

Participant Recruitment and Procedures

This study is part of a larger prospective study that examines child and parental adjustment following a pediatric burn event. Other articles report on parental acute stress (Bakker et al., 2012) and child behavior problems at 3 and 12 months after the burn event (Bakker, Van der Heijden, Van Son, Van der Schoot, & Van Loey, 2013). Data for the current study were collected within the first month after the burn event (T1) and subsequently at 3 (T2), 12 (T3), and 18 months postburn (T4).

Data were gathered in three burn centers in the Netherlands and four burn centers in Belgium between October 2007 and July 2010. Families were eligible to participate if the child with burns was between 8 months and 4 years old and had survived the burn event, the length of stay in the hospital was ≥ 24 hr, and the burn extent was $\geq 1\%$ TBSA. Exclusion criteria were as follows: insufficient parental Dutch language proficiency required to complete questionnaires, mental retardation in the child, and deceased children. A local researcher contacted consecutive families that met the study criteria within the first month after admission. Parents were approached while their child was still hospitalized or were invited by telephone if they had been discharged. The researcher explained the purpose of the study and offered additional written information. Two independent ethics committees in the Netherlands and Belgium approved this study. All families signed an informed consent form.

Of the 313 families that met the study criteria, data from 198 families, from which at least 1 parent per family completed an outcome measure for parental traumatic stress symptoms on at least one study occasion, were used. Fifty-five families declined to participate, 26 families were missed before they could be approached, 18 families consented to participate but did not complete a measure on parental traumatic stress, and 16 families were not invited because their participation was deemed inappropriate (e.g., severely ill family members, psychiatric background, or court custody cases). The 198 participating families did not differ from the other 115 eligible families in terms of child age, gender, length of stay in the hospital, percentage TBSA, and percentage deep burns.

Drop-out Analysis

In comparison with the total number of participating parents (186 mothers and 159 fathers from 198 families), participation rates at Times 1 to 4 (T1 to T4) were 98%, 82%, 68%, and 69% for mothers and 97%, 80%, 69%, and 68% for fathers. Sixty-two percent of the participating mothers and 63% of the participating fathers completed all four measures. The missing data were inspected for potential patterns in terms of demographics, burn characteristics, traumatic stress reactions, and predictors as assessed at T1. Parents that did not participate in all the study occasions had higher T1 scores for feelings of anger about the burn event (mothers: 1.7 vs. 1.3, $t(177) = 2.1$, $p = .04$; fathers: 1.4 vs. 1.0, $t(143) = 2.0$, $p = .04$) and T1 traumatic stress reactions, particularly symptoms of avoidance (mothers: 12.9 vs. 9.1, $t(180) = 3.1$, $p < .01$; fathers: 8.5 vs. 5.8, $t(152) = 2.2$, $p = .03$). There were no differences in demographics and burn characteristics (i.e., age, gender, TBSA burned, or accident at home) between the families that completed the study and the families that dropped out after certain time points.

Measures

Traumatic stress reactions

The Impact of Event Scale (IES) is a validated, psychometrically sound 15-item self-report measure used to assess two dimensions of traumatic stress reactions, that is, symptoms of intrusion and avoidance (Horowitz, Wilner, & Alvarez, 1979; Sundin & Horowitz, 2002). In adult patients with burns, the IES was demonstrated to be a good indicator for PTSD (Sveen et al., 2010). The validated Dutch version of the IES (Brom & Kleber, 1985) was administered at all four study occasions. Parents were directed to rate the frequency of symptoms they had experienced specifically in reaction to their child's burn event on a 4-point Likert scale (0-1-3-5). The total possible score ranged from 0-75, with higher scores representing higher levels of subjective distress. Based on Dutch¹ and Australian² research, scores ≥ 26 on the total scale were used as an indication of 'clinically significant stress'. The two subscales, Intrusion (range 0-35) and Avoidance (range 0-40), were used as dependent outcome variables. Cronbach's alpha for Intrusion ranged from .80 to .87 for mothers and fathers at the four time points, and the alpha for Avoidance ranged from .77 to .86.

¹ Van der Velden, Burg, Steinmetz, & Bout (1992) used scores of 26 and higher to indicate severe stress reactions based on the 80th percentile in their sample of victims of bank robberies.

² Le Brocque et al. (2010) used scores of 27 and higher to classify the parents of injured children that are likely to have PTSD.

Parental appraisal and emotions

All parent-related predictors were gathered within the first month after the burn event. 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?" Parental emotions regarding the burn event were ascertained with the question: "To what extent do the following emotions apply when you think about the accident that caused the burn?" Answers were rated on a 5-point Likert scale ranging from 0 "not at all" to 4 "a lot". In line with our previous findings (Bakker et al., 2012), the impact of the emotions of guilt and anger on the initial level and on the course of the traumatic stress reactions was investigated (correlation between guilt and anger in mothers: $r = .44$, $p < .01$ and in fathers: $r = .45$, $p < .01$).

Child- and burn characteristics

Researchers recorded 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) from the medical file. Information regarding 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) was provided by the parents at T1.

Statistical Analyses

Student's t tests for continuous variables (e.g., age and TBSA) and Chi-square statistics for categorical variables (e.g., gender and burn etiology) were used to compare participating and nonparticipating families and to examine families that dropped out. Parents with IES scores ≥ 26 were counted to determine the proportion of parents with clinically significant symptoms. Differences between parents within couples were tested with Chi-square statistics (e.g., perceived threat) or paired samples t tests (e.g., feelings of guilt and anger). The relationships between parental-perceived life threat and emotions at T1 and subsequent stress symptoms at T1, T2, T3, and T4 were investigated with bivariate correlations.

The course and predictors of parents' symptoms were investigated in a multilevel regression model. Multilevel analysis (MLA, performed with MLwiN [Rasbash et al., 2000]) was employed, because it can address multiple predictors in a dependent data structure. Our data set had a three-level hierarchy with time on the first level (four time points), parents on the second level (mother or father), and couples on the third level. The predictor variables in our study varied either at the individual parent or at the couple level. MLA allows for missing data on the outcome level by using a missing at random (MAR) assumption. MAR assumes that the development of parents with missing data is identical to the

development of parents without missing data (Hox, 2010). The analyses were conducted with all available information using a full information maximum likelihood estimator.

Because different patterns for the symptom clusters Intrusion and Avoidance were found in the subacute phase of the burn event (Bakker et al., 2012), two separate analyses were performed. The general course of symptoms in mothers and fathers was studied in models with time (coded as 0, 3, 12, and 18 months), time squared, and parent gender. To examine if mothers and fathers varied in their changes in symptoms over time, so-called random slopes for the regression parameter for time were included in the model. In the case of evidence for random slopes, it was investigated whether parent gender was related to this variation by including an interaction between time and parent gender.

Predictors measured at the parent level (i.e., individual parental appraisal and emotions regarding the burn event) and at the couple level (i.e., child and burn characteristics) were entered into the model. Interactions between parent gender and appraisal/emotions were tested to investigate whether the relationship between appraisal/emotions and stress symptoms differed between mothers and fathers. The interaction terms were entered separately. Only interaction terms that demonstrated at minimum a trend for significance ($p < .10$) were retained in the final models. All continuous independent variables were centered on their grand mean, and dichotomous variables were coded 0/1.

RESULTS

Prevalence of Parental Stress Symptoms

Table 5.1 shows the mean IES scores for mothers and fathers and the number of parents scoring above the cut-off for clinically significant symptoms (IES score ≥ 26). For the families in which the mother's data as well as the father's data were available, *both* parents had stress scores in the clinical range in a small number of cases: 15% at T1, 8% at T2, 3% at T3, and 1% at T4. The number of families with at least one family member with a stress score in the clinical range was considerable: 55% at T1, 29% at T2, 16% at T3, and 18% at T4.

Appraisal, Emotions, and Stress Symptoms

More mothers (18%) than fathers (9%) had perceived their child's life to be in danger, a difference that was significant within couples ($\chi^2(1) = 31.9, p < .01$). Mothers had higher scores for early feelings of guilt ($M = 2.0, SD = 1.5$) and anger ($M = 1.4, SD = 1.5$) than fathers ($M = 1.4, SD = 1.4$ for guilt; $M = 1.1, SD = 1.3$ for anger), which was significant within couples for guilt feelings ($t(132) = 3.1, p < 0.01$) but not for anger ($t(131) = 0.64, p$

= .52). Table 5.2 shows the bivariate correlations between parental-perceived life threat and emotional responses at T1 and stress symptoms at T1-T4. In the subacute period, the relationship between parental-perceived life threat/emotions and parental stress symptoms was significant in mothers and fathers. However, whereas the relationship between acute appraisals/emotions and stress symptoms persisted in mothers, it diminished in fathers.

Table 5.1*Parental Stress Symptoms*

| | 1 st month | 3 months | 12 months | 18 months |
|------------------------|-----------------------|----------------|----------------|----------------|
| <i>Mothers</i> | <i>n</i> = 182 | <i>n</i> = 152 | <i>n</i> = 127 | <i>n</i> = 129 |
| IES – Total (M, SD) | 27.3 (14.6) | 19.9 (14.5) | 16.1 (13.8) | 14.4 (12.7) |
| IES - Intrusion | 16.8 (8.2) | 12.1 (7.6) | 9.7 (7.6) | 8.4 (6.8) |
| IES - Avoidance | 10.5 (8.2) | 7.8 (8.5) | 6.4 (7.7) | 6.0 (7.3) |
| % of mothers ≥ cut-off | 50% | 30% | 16% | 18% |
| <i>Fathers</i> | <i>n</i> = 154 | <i>n</i> = 127 | <i>n</i> = 109 | <i>n</i> = 108 |
| IES - Total | 17.4 (13.3) | 11.8 (10.7) | 8.7 (9.1) | 8.2 (9.0) |
| IES - Intrusion | 10.6 (7.7) | 6.9 (5.8) | 5.3 (5.4) | 5.0 (5.1) |
| IES - Avoidance | 6.8 (7.1) | 4.9 (6.4) | 3.5 (5.2) | 3.1 (4.8) |
| % of fathers ≥ cut-off | 27% | 10% | 7% | 6% |

Note. IES = Impact of Event Scale.

Unexplained variance

A model with time and time squared showed that the unexplained variance was located at the time level (34% for Intrusion, 29% for Avoidance), at the individual parent level (48% for Intrusion, 24% for Avoidance) and at the couple level (18% for Intrusion, 47% for Avoidance).

Course of stress symptoms in mothers and fathers

Mothers had higher scores on both subscales compared to fathers (Intrusion: $B_{\text{parent gender}} = 6.289$ [$SE = 0.707$]; Avoidance $B_{\text{parent gender}} = 2.684$ [$SE = 0.486$]). A general decline in intrusion ($B_{\text{time}} = -0.757$ [0.086]) and avoidance symptoms ($B_{\text{time}} = -0.447$ [0.075]) was observed in all parents, but a small quadratic term for time indicated that this decrease in symptoms was not strictly linear (intrusion: $B_{\text{time} \times \text{time}} = 0.028$ [0.005]; avoidance $B_{\text{time} \times \text{time}} = 0.016$ [0.004]). Parents within couples did not have the same course of symptoms over time ('random slopes'). For symptoms of intrusion, the difference between mothers and fathers became smaller over time ($B_{\text{time} \times \text{parent gender}} = -0.144$ [0.045]), whereas for avoid-

ance, differences over time were not associated with parent gender. Figure 5.1 illustrates the course of intrusion and avoidance symptoms for mothers and fathers based on this model (estimated means).

Table 5.2
Associations Appraisal, Emotions, and Stress Symptoms

| | 1 st month | 3 months | 12 months | 18 months |
|------------------------------|-----------------------|--------------------|--------------------|-------------------|
| <i>Mothers</i> | <i>n</i> = 176-177 | <i>n</i> = 144-146 | <i>n</i> = 121-122 | <i>n</i> = 125 |
| Intrusion ~ perceived threat | .30** | .25** | .24** | .36** |
| Intrusion ~ guilt feelings | .39** | .23** | .24** | .27** |
| Intrusion ~ anger | .41** | .20* | .13 | .14 |
| Avoidance ~ perceived threat | .33** | .29** | .30** | .35** |
| Avoidance ~ guilt feelings | .38** | .34** | .43** | .39** |
| Avoidance ~ anger | .37** | .24** | .37** | .35** |
| <i>Fathers</i> | <i>n</i> = 139-144 | <i>n</i> = 114-118 | <i>n</i> = 98-102 | <i>n</i> = 96-100 |
| Intrusion ~ perceived threat | .23** | .13 | .20* | .23* |
| Intrusion ~ guilt feelings | .34** | .14 | .24* | .13 |
| Intrusion ~ anger | .39** | .25** | .22* | .11 |
| Avoidance ~ perceived threat | .18* | .11 | .07 | .15 |
| Avoidance ~ guilt feelings | .24** | .27** | .18 | .18 |
| Avoidance ~ anger | .39** | .33** | .11 | .10 |

Note. Trauma appraisal and emotions were assessed at T1, Intrusion and Avoidance were assessed at T1-T4. The range of the sample size is noted for mothers and fathers at each time point separately.

* $p < .05$. ** $p < .01$.

Course and Predictors of Parental Stress Symptoms

Explanatory variables

For Intrusion, the final model with explanatory variables showed that apart from parent gender, perceived threat to the child's life ($B = 3.29$, $SE = 0.95$) and parental feelings of guilt ($B = 0.71$, $SE = 0.24$) affected the level of symptoms throughout the entire study period (Table 5.3). For early feelings of anger, the results showed an initial influence on symptoms of intrusion ($B = 1.47$, $SE = 0.27$), but this influence diminished as time passed

($B_{\text{time} \times \text{anger}} = -0.08, SE = 0.02$). The relationship between appraisal/emotions and intrusion symptoms was comparable in mothers and fathers. Parent gender explained 43% and individual appraisal and emotions explained an additional 13% of the 48% of the unexplained variance located at the parent level. The cross-level interactions between parent gender and time and between feelings of anger and time explained 34% of the random slopes at the parent level. The final model explained 8% of the 18% of the unexplained variance that was located at the couple level. There was no evidence for random slopes between couples.

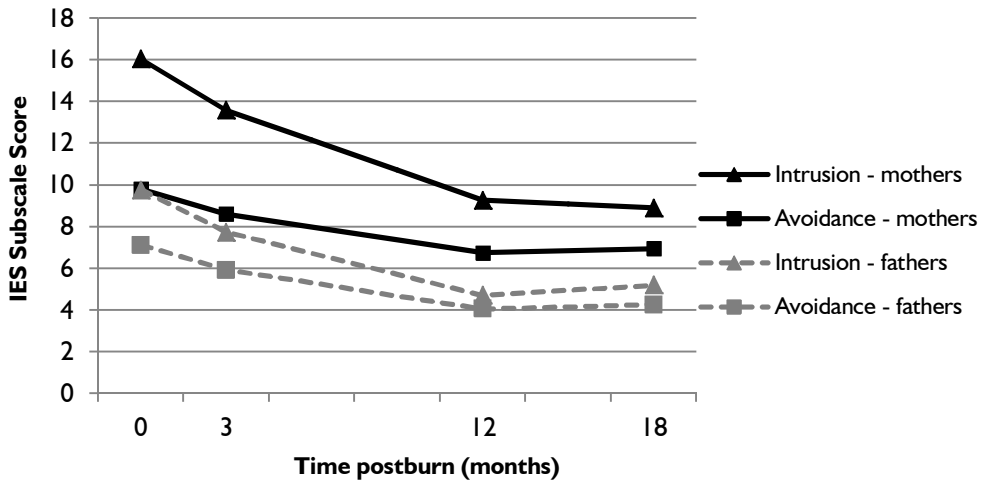


Figure 5.1 Longitudinal Course of Intrusion and Avoidance Symptoms. Estimated means are based on a model with time, time squared, and parent gender. Scales range between 0-35 for Intrusion and between 0-40 for Avoidance. IES = Impact of Event Scale.

The final model for Avoidance showed that anger ($B = 1.13, SE = 0.23$) consistently affected the level of symptoms other than the effect of parent gender (Table 5.3). The effects of guilt feelings and perceived threat on avoidance symptoms differed between mothers and fathers; the influence of guilt feelings and perceived threat on avoidance symptoms was stronger in mothers than in fathers. The development of avoidance symptoms over time was similar for mothers and fathers and was not dependent on subjective appraisal and emotions. Individual parent-related variables explained 37% (parent gender: 24%; appraisal/emotions: 13%) of the 24% unexplained variance at the parent level and 33% of the initial 47% unexplained variance at the couple level. Child gender (girls > boys), child age (parents of older children reported tentatively more avoidance symptoms),

and the size of the burn explained an additional 9% of the avoidance symptoms at the couple level. The results did not demonstrate evidence for a different course of symptoms between couples.

Table 5.3*Predictors of Intrusion and Avoidance in Multilevel Regression Analysis*

| | Intrusion ^a | | Avoidance ^b | |
|-----------------------------------|------------------------|------|------------------------|------|
| | B | SE | B | SE |
| <i>Time level</i> | | | | |
| Intercept | 8.88*** | 0.90 | 5.41*** | 0.90 |
| Time ^c | - 0.77*** | 0.09 | - 0.45*** | 0.08 |
| Time × Time | 0.03*** | 0.01 | 0.02*** | 0.00 |
| <i>Individual parent factors</i> | | | | |
| Parent gender (female = 1) | 5.22*** | 0.65 | 1.79*** | 0.50 |
| Feelings of guilt | 0.71*** | 0.24 | 0.10 | 0.31 |
| Feelings of anger | 1.47*** | 0.27 | 1.13*** | 0.23 |
| Perceived threat to life child | 3.29*** | 0.95 | 0.56 | 1.49 |
| Parent gender × Feelings of guilt | | | 0.91** | 0.37 |
| Parent gender × Perceived threat | | | 2.28 [†] | 1.55 |
| <i>Couple factors</i> | | | | |
| Child gender (female = 1) | 1.56* | 0.72 | 2.17** | 0.77 |
| Child age | 0.76* | 0.40 | 0.59 [†] | 0.43 |
| Burn size | 0.09 [†] | 0.06 | 0.14** | 0.06 |
| Accident at home | 0.45 | 0.84 | 1.08 | 0.90 |
| <i>Time interaction variables</i> | | | | |
| Time × Parent gender | - 0.12** | 0.04 | | |
| Time × Feelings of anger | - 0.08*** | 0.02 | | |
| <i>Explained variance</i> | | | | |
| At couple level | 8% (of initial 18%) | | 42% (of initial 47%) | |
| At individual parent level | 56% (of initial 48%) | | 37% (of initial 24%) | |
| Of random slopes at parent level | 34% | | 0% | |

Note. In sum, 993 completed questionnaires (Impact of Event Scale), from 173 mothers and 139 fathers, were analyzed in the multilevel regression analyses.

^aScale 0-35. ^bScale 0-40. ^cRandom at individual parent level.

* $p < .05$. ** $p < .01$. *** $p < .001$. [†] $p < .10$ (all one-sided tested).

DISCUSSION

To our knowledge, this is the first study that includes four consecutive self-reports from both mothers and fathers covering the first 18 months after their child's acute burn injury. The results from this study including a considerably large sample of parents of preschool children with burns show that stress symptoms may be more prevalent in mothers, but a substantial proportion of fathers of young children with burns are deeply affected as well over a considerable time period. Our results support the importance of parental subjective appraisal and emotions in relation to subsequent symptoms of posttraumatic stress. Furthermore, differences were found between mothers and fathers regarding appraisal and stress over the course of time, while concurrently appreciating interdependence within a family system.

The level of parental PTSS gradually declined over the first 18 months post injury in accordance with our hypothesis and pediatric medical trauma literature (Bronner et al., 2010; Le Brocque et al., 2010; Martin-Herz et al., 2012). The course of avoidance symptoms seemed more stable across time, as opposed to the sharper decrease in terms of intrusion symptoms. The prevalence of clinically significant symptoms seemed stable between 12 and 18 months postburn, suggesting a risk for chronic symptoms at this point if problems are left untreated. The prevalence of symptoms at 18 months, 18% of mothers and 6% of fathers, was lower than previous cross-sectional studies on parents of children with burns (Bakker et al., 2010; Rizzone et al., 1994) but was largely in line with other longitudinal studies after pediatric burns (Cella et al., 1988; Hall et al., 2006) or unintentional injury (e.g., Landolt et al., 2012; Le Brocque et al., 2010). The results from two-parent families indicated that in approximately one fifth of the families, at least one parent is at risk for persistent stress symptoms. Although mothers were at an increased risk for severe stress reactions, the results emphasize that fathers should not be overlooked and call for ongoing monitoring of both parents after a pediatric burn event.

As expected, mothers had higher stress scores than fathers throughout the course of the study. In accordance with the cognitive model for PTSD by Ehlers & Clark (2000), individual parent appraisal and emotions about the burn event were linked to subsequent stress reactions. Hence, the difference between mothers and fathers may be because the mothers more frequently perceived their child's injury as life threatening and they had stronger short-term emotions pertaining to the burn event compared to the fathers. Shortly after the burn event, appraisals and emotions about the child's burn injury were associated with PTSS in mothers as well as in fathers, indicating similar mechanisms underlying parents' initial stress reactions. Over time, however, these associations were stable in mothers, whereas the associations diminished in fathers. Mothers may more frequently use

particular emotion-focused coping strategies (Tamres et al., 2002) that ultimately prolong their stress symptoms. Alternatively, mothers' higher scores may have resulted from their primary caregiver role (Cabizuca et al., 2009) or the possibility that more mothers directly witnessed their child's accident and/or hospital experiences. However, these explanations remain speculative.

Apart from differences between mothers and fathers, particular family system mechanisms or commonalities between parents may result in similarities within couples in terms of PTSS. Whereas intrusions were mainly intra-personal and decreased over time, a more stable pattern and a considerable overlap in symptoms of avoidance within couples was observed. Fathers' symptoms of avoidance were not influenced by intra-personal mechanisms as much as seems the case in mothers' symptoms, but inter-personal processes might play an important role. Grief studies have for instance shown that attempts by parents to protect their partner by avoiding conversations about the loss and by holding in their grief paradoxically resulted not only in more grief for themselves but also for their partner (Stroebe et al., 2013). In this line of reasoning, the avoidance reactions of one parent with regard to the burn event, injury, or scarring of the child may influence the other parent's avoidance behaviors. The overlap of symptoms within couples was partly attributed to child- and burn-related variables. Parents of daughters indicated more stress symptoms than parents of sons, which concurs with a study that found more guilt feelings among mothers of daughters compared to mothers of sons (Rivlin & Faragher, 2007). Furthermore, parents of older children within the preschool age range reported more PTSS, which was in agreement with another study on mothers of young children with burns (Mason & Hillier, 1993). Couples of more severely injured children expressed more avoidance symptoms throughout the course of the study, which has also been found previously in some burn studies (Bakker et al., 2010; Hall et al., 2006; Rizzone et al., 1994), but is not a consistent finding in other pediatric injury populations (Le Brocque et al., 2010). Although speculative, appraisals about the *consequences* of the burn injuries, such as scarring, may become increasingly important as time elapses after the burn event, possibly maintaining a pattern of avoidance within families.

The current study adds to the field of family adjustment after pediatric medial trauma, but several questions warrant further investigation. Future studies should address the potential differences between mothers and fathers in the context of the hypothesized interrelatedness between (persistent) emotions, perceived scar severity, coping strategies, and chronic traumatic stress reactions. The interpersonal dynamics and parallels within families after a serious injury or illness in their child also require more detailed investigation. Examples include mutual influencing patterns between mothers and fathers over time and parents' subjective perceptions about coping with their child's burn injury as a couple and

as a family. The current results suggest that a family perspective may be particularly relevant when studying avoidance reactions. Little is known about the impact of couple adjustment on the child's functioning or coping with the burn injury.

This study has some limitations that should be considered. First, our results are exclusively based on parents of children with burns. Although parents were specifically asked for reactions with reference to their child's burn event, future studies may consider to include a comparison group to contribute knowledge about the unique impact of the child's burn injury and event circumstances on subsequent parental responses. Second, although the variables studied could explain a substantial part of parental PTSS, other variables may have contributed to the outcomes. For instance, medical procedures or (suspected) cases of abuse or serious neglect might have affected the results. Psychosocial support was available during hospitalization in all burn centers, but information on individual parental psychological treatment was not collected. Other pediatric injury studies found that parents with previous life stress (Bronner et al., 2010), premorbid mental health problems (Le Brocque et al., 2010), or additional post injury traumatic or stressful life events (Martin-Herz et al., 2012) were more likely to experience persistent stress symptoms. Third, parents that dropped out of the study had higher scores for avoidance in the subacute phase of their child's burn event. Consequently, the actual long-term prevalence rates of clinically significant PTSS may have been higher than reported. Examination of the course of avoidance symptoms in parents that completed all 4 time points showed that parents with T1 avoidance scores above the median had higher scores at all 4 time points, but they displayed a larger decrease in symptoms over time than parents with T1 avoidance scores below the median. The influence of this drop-out information on our predictive model of PTSS was thoroughly examined. As similar analyses on datasets with all cases, only full cases, or cases without high-avoidance scores at T1, generated comparable results; drop-outs are believed to not have affected the results concerning risk factors for long-term PTSS. Finally, the IES is not an instrument to diagnose PTSD and results with cut-offs should therefore be carefully interpreted. Nevertheless, the IES has been validated in the Dutch population (Brom & Kleber, 1985), has proven acceptable discriminatory validity between individuals with and without PTSD in an adult population with burns (Sveen et al., 2010), and has been used previously in other studies on parents of injured children with a comparable cut-off score (Le Brocque et al., 2010).

The current results may provide suggestions for pediatric burn care and may be applied more widely to other families that are confronted with a potentially traumatic event in their child. The persistence of PTSS in a subgroup of mothers and fathers shows the need for clinical attention from a broad family systems perspective (Seagull, 2000). Follow-up of the child's scarring and well-being may offer an important opportunity to

simultaneously and systematically monitor parental adjustment. A family systems approach seems especially warranted when treating avoidance problems in parents. Intrusion symptoms appeared to be more of an individual experience throughout the course of time and may be treated as such. A multidisciplinary aftercare program is recommended, because burn center professionals have knowledge about common postburn adjustment processes and emotions. Finally, the occurrence of strong parental emotions concerning the burn event and their long-term impact on PTSS may call for clinical initiatives. For example, parents may benefit from meeting and discussing their emotions concerning the burn event in a support group with other parents (Frenkel, 2008). Severe and persistent feelings of guilt may require (group) therapy including components of cognitive restructuring of negative thoughts and social comparison with other parents to normalize feelings (Nixon & Singer, 1993). As the literature has clearly shown, parental emotional well-being is interrelated with child postburn adjustment (Bakker, Maertens, et al., 2013), and efforts to better understand and help parents after a high-impact event are believed to ultimately result in benefits for the entire family.

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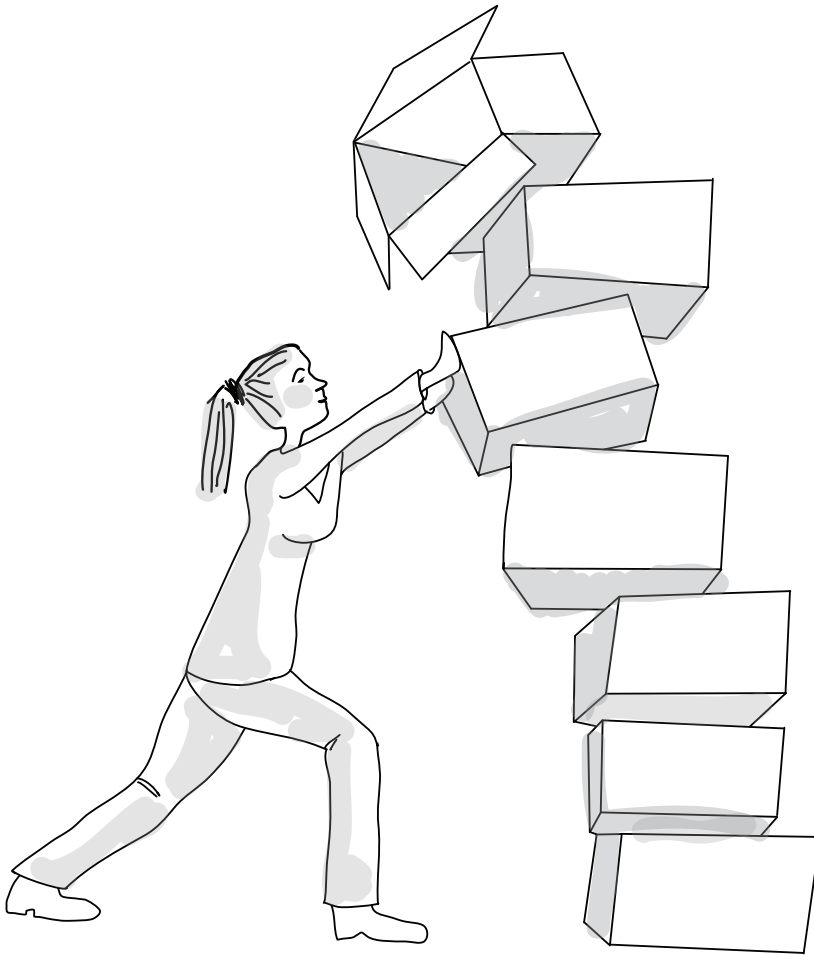
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Brief Report: Mothers' Long-term Posttraumatic Stress Symptoms Following a Burn Event of Their Child



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ABSTRACT

Objective This prospective longitudinal study examines the course of posttraumatic stress symptoms (PTSS) in mothers of children with burns between 1 and 11 years after the burn event and the role of burn severity and feelings of guilt on this course. **Method** Self-reported PTSS of 48 mothers were measured with the Impact of Event Scale. Guilt feelings were assessed during an in-depth interview 2 years after the burn event. Eleven years after the burn event, mothers marked their child's scars at the present time on a drawing. **Results** Over a period of 10 years, maternal PTSS decreased. Multiple regression analysis showed that the interaction between guilt and burn severity predicted the course of PTSS. **Conclusions** Although PTSS substantially decreases through the years, a subset of mothers, in particular mothers who feel guilty about the burn event and whose children have more extensive permanent scarring seem at risk for longer-term PTSS.

Keywords: burns, children, longitudinal research, parents, posttraumatic stress

BRIEF REPORT: MOTHERS' LONG-TERM POSTTRAUMATIC STRESS SYMPTOMS FOLLOWING A BURN EVENT OF THEIR CHILD

Each year approximately 1 million children are involved in a burn event in the United States (Noronha & Faust, 2007). Severe burns are among the most serious injuries a child can experience (Landolt, Buehlmann, Maag, & Schiestl, 2009). The actual burn event contains adverse and frightening aspects for both a child and the family. Additionally, the subsequent hospitalization, daily painful medical procedures, and long-lasting rehabilitation can evoke feelings of fear, uncertainty, and uncontrollability as well. Generally, there is a concern for the psychological adjustment and quality of life of children with burns and their families. However, there is little consensus regarding psychological adjustment of children after a burn event (Noronha & Faust).

Research in various pediatric populations has shown that children and their parents may display traumatic stress reactions following a pediatric illness or injury (Kahana, Feeney, Youngstrom, & Drotar, 2006; Nugent, Ostrowski, Christopher, & Delahanty, 2007, Stoddard & Saxe, 2001). Kazak et al. (2006) conceptualize these reactions in a comprehensive model for pediatric medical traumatic stress (PMTS). This model describes posttraumatic stress responses in the acute phase, the early and ongoing phase, and the longer-term phase after a pediatric medical event. The model comprises characteristic posttraumatic stress symptoms (PTSS), such as reexperiencing, avoidance, numbing of general responsiveness, and increased arousal, yet it is not restricted to the psychiatric diagnosis posttraumatic stress disorder (PTSD).

A growing body of evidence supports the relevance of the PMTS model for children with burns and their parents (Kazak et al., 2006). With regard to children with burns, PTSD prevalence rates between 6.7% (on average 8.9 years postburn) and 19% (on average 4.4 years postburn) have been reported, with the separate symptom clusters being even more prevalent (Landolt et al., 2009). As for parents of children with burns, self-reported PTSS and diagnosed PTSD within the first year after the burn event range between 19% and 52% (Cella, Perry, Kulchysky, & Goodwin, 1988; Fukunishi, 1998; Hall et al., 2006; Rizzone, Stoddard, Murphy, & Kruger, 1994). Longer-term results are scarce and inconsistent. Reported prevalence rates of PTSD were 0% at 4 years after the burn event in a sample of mothers of mildly injured children (Fukunishi) and 16% on average 7 years after the burn event in a sample of mothers of children with severe burns (Rizzone et al.).

Identifying factors that are associated with PTSS is important, since medical events are not by definition traumatic for all children and families. Kazak et al. (2006) describe that both pre-existing factors and characteristics of the event may contribute to an event being perceived as traumatic. Generally, objective medical characteristics seem to be not strongly

associated with PMTS. In burn literature, divergent results have been reported concerning the predictive value of burn severity on psychological outcome for parents of children with burns. While one study found a significant relation (Rizzone et al., 1994), another found a mediated relation through a parent's dissociative symptoms (Hall et al., 2006), and a third study reported no association between burn severity and parental posttraumatic stress (Cella et al., 1988). An explanation for the contrasting findings may be derived from Hall et al. who demonstrated that burn severity was mediated by other characteristics, such as dissociative symptoms. Another explanation could be that burn severity interferes with stress reactions only with the course of time (Van Loey, Maas, Faber, & Taal, 2003).

Another conceivable predictor of parental PTSS of particular interest in this population is the subjective feelings of guilt many parents experience about the burn event (Mason, 1993). Cella et al. (1988) found that initially perceived guilt strongly predicted persistent distress at 6 months after the burn event. Mason speculated about the relationship between scarring and guilt feelings, and their possible impact on subsequent maternal psychological responses. However, there is no empirical evidence for these hypothesized relationships.

The present study examined mothers' PTSS at 1 and 11 years after the burn event by means of a longitudinal prospective study design. We hypothesized that on average PTSS would decrease. Furthermore, we aimed at identifying associates of PTSS. We proposed a positive relationship between feelings of guilt and the course of PTSS and we tested the moderating effect of burn severity on this relationship.

METHOD

Participant Recruitment and Procedures

This study was conducted in the Netherlands as part of a broader study which aimed at investigating satisfaction with aftercare for children with burns and their families, children's psychological outcome and parents' PTSS. Data were collected 1 year (T1, $n = 167$ mothers), 2 years (T2, $n = 109$ mothers), and 11 years after the burn event (T3, $n = 72$ mothers). For the purpose of this article, we used the data of 48 mothers who participated in all data collections.

The initial sample was selected from the National Medical Surveillance files, which cover all Dutch hospitals, of 1994 and 1995. Seventy-nine percent of the hospitals, general hospitals as well as the three Dutch burn centers, agreed to participate. Families were eligible to participate if the child with burns was hospitalized in 1994 and/or 1995 and younger than 16 years of age when discharged from the hospital. Burn injury had to be the main discharge diagnosis.

At T1, the participating hospitals distributed questionnaires with pre-stamped envelopes to the eligible families, which yielded 167 returned questionnaires. Of the participants, 83% agreed to participate in follow-up research. Following this first questionnaire, in-depth semistructured interviews were conducted by graduate level trained interviewers in the respondent's home setting (T2). At T3, 10 years after the initial study program, the addresses of families who had agreed to participate in follow-up research were verified through telephone directories and registrations of local authorities. Several families could not be traced due to emigration to other countries and nonresponse of local authorities. The 126 families that could be traced received a letter explaining the aim of the follow-up study. Ten families returned a form indicating that they did not wish to participate, of whom four indicated that their child had no scars left, and one mother informed the researchers that her child had died. The remaining 116 families were provided with questionnaires with prestamped return envelopes and were informed that they would receive a small present if they returned the questionnaires. This study was approved by the Ethics Committee of the Martini Hospital in Groningen, the Netherlands, which is a legally qualified Dutch Ethics Review Committee.

Completers, that is, mothers who completed T1, T2, and T3, were compared to mothers who completed T1 only, with regard to stress scores. Additionally, completers were compared to mothers who completed T1 and T2, but not T3, with regard to mother's age, marital status, presence of guilt feelings, T1 stress score, child's age and gender, etiology of the burns, child's length of stay in the hospital, and the number of surgical procedures. Results showed that completers had significantly higher stress scores than mothers who completed T1 only (mean difference 5.61, $t(165) = 2.40$, $p = .018$, C.I. = 0.99 – 10.24). There were no differences between completers and mothers who only completed T1 and T2, but not T3.

Participants

Characteristics of the mothers

At the time of the burn event, the 48 mothers were on average 32.33 years old ($SD = 4.07$), and 85% of the mothers were married or lived together with a partner. The current socioeconomic status (SES) was low for 12%, middle for 52% and high for 36% of the families. Compared to the distribution of Dutch households, families with low SES are underrepresented. Thirty-six mothers (75%) were present in the physical neighborhood of their child when the burn event took place, although not all mothers actually witnessed the event.

Characteristics of the child

The sample comprised 28 boys (58%). Mean age at burn was 3.00 years ($SD = 2.76$), range 0-13. Causes of the burns were hot fluid (73%), flame (17%) or other (10%). The average length of stay in the hospital was 13.02 days ($SD = 15.44$), range 1-77.

Measures

Posttraumatic stress symptoms

The Impact of Event Scale (Horowitz, Wilner, & Alvarez, 1979) is a 15-item self-report inventory to assess two dimensions of PTSS, that is, symptoms of intrusion and avoidance. Answers are given on a 4-point Likert scale and total score ranges from 0-75. Higher scores represent higher levels of stress and a score of ≥ 26 is considered an indicator of a clinically significant stress reaction (Van der Velden, van der Burg, Steinmetz, & van den Bout, 1992). For this study, the validated Dutch version was administered at both measurements (Brom & Kleber, 1985). The dependent variable is the difference between the two PTSS scores, that we therefore refer to as "course of PTSS".

Guilt feelings and burn severity

The presence of guilt feelings was measured during the in-depth interview approximately 2 years after the burn event. One section of the interview included questions on several feelings about the burn event, such as guilt feelings. More specifically, mothers were asked whether they had feelings of guilt regarding the burn event. The response was noted by the interviewer as No (73%) or Yes (27%).

Burn severity was specified by the extent of permanent physical skin damage 11 years after the burn event. At that point, each mother was asked to mark her child's scars at the present time on a picture of a human body. Subsequently, the body was divided into 20 zones. On average 2.60 body zones ($SD = 2.28$, range 0-12) were scarred, which can predominantly be conceived of as mild to moderate burn severity. Pearson's correlations of .74 ($p < .001$) with the number of surgical procedures and .72 ($p < .001$) with the number of days hospitalized suggest that the number of scarred body zones is a valid indicator of burn severity.

Statistical Analyses

Data were analyzed with Statistical Package for Social Sciences, version 16.0 (SPSS Inc., Chicago). An alpha level of .05 was set for all statistical tests. There were no data missing regarding PTSS at T1, guilt feelings, and burn severity. At T3, 3 respondents had each one item missing at the IES (0.42%). Scale scores were computed assuming that the stress on

these items was absent, in order to prevent overestimation of the stress score. Paired (within mothers) and unpaired (between mothers) *t* tests were used to compare continuous variables and chi-square tests were used for categorical variables. Correlations were analyzed with Pearson's correlation coefficients. A multiple regression approach was applied to investigate the predictive value of guilt feelings, burn severity and the interaction between guilt feelings and burn severity on the course of PTSS. Finally, posthoc probing of significant moderator effects was computed as recommended by Holmbeck (2002).

RESULTS

PTSS I and 11 years after the Burn Event

A paired *t* test demonstrated that mean total stress scores decreased significantly from 23.83 (*SD* = 14.67) at 1 year to 12.50 (*SD* = 13.48) at 11 years after the burn event, $t(47) = 6.18$, $p < .001$, C.I. = 7.64 – 15.02. Symptoms of intrusion were significantly more prevalent than symptoms of avoidance at 1 year after the burn event, $t(47) = 6.62$, $p < .001$, C.I. = 4.93 - 9.24, as well as at 11 years after the burn event, $t(47) = 3.88$, $p < .001$, C.I. = 1.50 – 4.75.

One year after the burn event, 42% of the mothers had a total stress score of ≥ 26 , and 11 years after the event significantly fewer mothers (19%) scored above the cut-off ($\chi^2[1, N = 48] = 10.16$, $p = .001$). The majority of the mothers did not report clinically significant symptoms at either measurement (56%). One fourth of the mothers had high stress scores only at 1 year after the event, and 17% reported clinically significant stress at 1 as well as at 11 years after the burn event. One mother showed delayed onset (2%).

Relation between Feelings of Guilt, Burn Severity and PTSS

Mothers who experienced guilt feelings reported higher stress scores 11 years after the burn event (mean difference = 10.07, $t[46] = 2.42$, $p = .020$, C.I. = 1.69 - 18.46). The total number of scarred body zones was not significantly related to PTSS at T3 ($r = .21$, *ns*). Child's burn severity did not differ between mothers with or without guilt feelings (mean difference = 0.12, $t[46] = 0.16$, *ns*).

A significant multiple regression model, $F(3, 44) = 3.07$, $p = .038$, explained 17% of the variance in the course of PTSS (Adjusted $R^2 = .12$). Significant predictors were feelings of guilt and the interaction between feelings of guilt and scars (see Table 6.1). The significance level of the interaction variable ($p = .013$) indicated that the course of PTSS from mothers with guilt feelings significantly differed from the course of PTSS from mothers without guilt feelings. Significance tests for the separate slopes indicated that the simple

slope for the mothers without guilt feelings was not significant ($t[47] = 1.63$, *ns*) and the simple slope for mothers with guilt feelings was significant ($t[47] = -2.08$, $p = .043$).

Table 6.1

Summary of Simultaneous Multiple Regression Analysis for Variables Predicting Course of Mothers' PTSS (N = 48)

| Variable | r^a | B | SE B | β | p |
|--|-------|-------|------|---------|------|
| Feelings of guilt (Yes = 1) | .20 | 19.55 | 6.63 | .69 | .005 |
| Burn severity | .09 | 1.37 | 0.84 | .25 | .111 |
| Feelings of guilt \times Burn severity | -.02 | -5.18 | 2.01 | -.63 | .013 |

^aPearson's correlation between predictors (rows) and dependent variable (course of PTSS).

DISCUSSION

To our knowledge, this is the first prospective longitudinal study with a uniform large time interval of 10 years to address long-term PTSS in mothers of children with burns. In line with the longer-term phase of the PMTS model (Kazak et al., 2006) our results show that a burn event of a child may be stressful for a parent during a long period. The prevalence rates of clinically significant symptoms we found are comparable to other studies on parents of children with burns (Cella et al., 1988; Fukunishi, 1998; Hall et al., 2006, Rizzone et al., 1994).

An interesting finding of this study is that the child's permanent scarring appeared to moderate the relationship between mothers' guilt feelings and PTSS. Although our model accounted for a modest proportion of the variance ($R^2 = 17\%$, Adjusted $R^2 = 12\%$), it is remarkable that the effect exists over a ten-year period. This empirical finding supports Mason's hypothesis (1993) that remaining scars and protection failure linked to guilt together impact maternal responses. Furthermore, it concurs with findings of others that injury severity, an objective characteristic of the medical event, may be related to traumatic stress through other factors (Hall et al., 2006). Similarly, it is possible that perhaps not initially, but as time passes, injury severity becomes more important as the permanent character of the injury arises (Van Loey et al., 2003). A suggestion for future research in predictors of PTSS may be to involve multiple conditions simultaneously and test moderating effects in order to unravel the mechanisms underlying longer-term stress responses.

Some implications may be derived from our study. First, the long-term negative outcome for a significant minority of the mothers may indicate the relevance of a monitoring program for parents, linked to the child's follow-up aftercare. The impact of guilt feelings, if replicated, may be one point of attention in screening for risk of persistent parental

PTSS. This might even be more essential when, based on the nature of the injury, permanent physical sequelae in the child are to be expected. Second, the findings may be a focus for clinical interventions. A promising direction for treating guilt may be derived from a group intervention, designed to reduce self-blame and guilt in parents of children with severe disabilities (Nixon & Singer, 1993). In addition to cognitive restructuring, the social comparison part of the intervention, in which parents could validate and normalize feelings, seemed to contribute to the reduction of self-blame and guilt.

This study contributes to the literature on pediatric burns and families' reactions and might add understanding in the maintenance of parental PTSS. However, some limitations merit note. First, data in this study are derived from a larger study which aimed at investigating aftercare for children with burns and their families. Because the initial study's focus differed from the current study, the measurement of some constructs, such as guilt, may have been too narrow. Desirably, guilt feelings would have been measured at all points in time. In addition, it can be argued that a single item with two categories might not fully meet the complex concept of guilt. However, Burisch (1997) suggested that lengthening a scale does not always increase and sometimes actually weakens its validity. Nonetheless, further research is needed to clarify whether it would be more appropriate to address a broader range of guilt-related aspects and to use gradations in order to capture the more complicated nature of the emotion guilt.

Second, this study sample may not be representative for all parents of children with burns, allowing limited generalization. Although all parents of children with burns hospitalized in 1994-1995 were eligible for the initial study program, certain groups, such as parents with low proficiency of the Dutch language and families with low SES, might not be adequately represented in this study sample. As it was not known how many questionnaires were actually distributed, it was not possible to determine the response rate. In addition, comparison between completers and noncompleters showed that completers had higher stress scores. In conclusion, because of drop-outs of less symptomatic mothers and unknown response biases, the reported prevalence rates should be cautiously interpreted. Moreover, our results concern mothers only and may not simply be applied to fathers or other caretakers.

The limitations notwithstanding, these longitudinal data over a period of 10 years contribute to the literature on parental long-term PTSS and further support the relevance of the PMTS model in parents of children with burns. Additionally, our results yield valuable directions for future research in medical traumatic stress aiming at identifying predictors within and across the different phases of the model. Although the burn population has specific characteristics, the impact of subjective guilt feelings on posttraumatic stress and

the moderating effect of permanent physical sequelae are interesting findings that might also be clinically relevant for other pediatric populations.

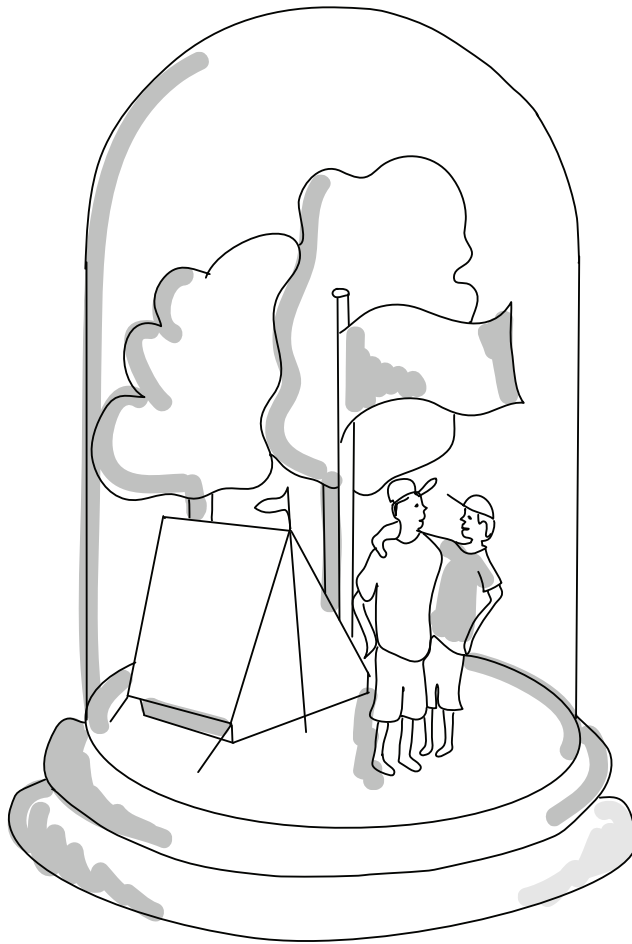
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Impact of Pediatric Burn Camps on Participants' Self-Esteem and Body Image: An Empirical Study



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ABSTRACT

Objective This study focuses on possible effects of specialized summer camps on young burn survivors' self-esteem and body image. **Method** Quantitative as well as qualitative measures was used. To study possible effects, a pretest-posttest comparison group design with a follow-up was employed. Self-report questionnaires were used to measure self-esteem and body image in a burn camp group ($n = 83$, 8-18 years) and in a comparison group of children with burns who did not attend a burn camp during the course of the study ($n = 90$, 8-18 years). Additionally, burn camp participants and parents completed an evaluation form about benefits derived from burn camp. **Results** A small positive short-term effect of burn camp participation was found on the 'satisfaction with appearance' component of body image. Overall, participants and parents showed high appreciation of the burn camps and reported several benefits, particularly concerning meeting other young burn survivors. **Conclusions** Albeit statistically modest, this is the first quantitative study to document on a significant short-term impact of burn camp on young burn survivors' body image. Implications of this result for future research and burn camp organization were discussed, including the strengths of residential camps for young burn survivors.

Key words burns, children, burn camp, intervention, body image

IMPACT OF PEDIATRIC BURN CAMPS ON PARTICIPANTS' SELF-ESTEEM AND BODY IMAGE: AN EMPIRICAL STUDY

Originating in the US in the 1980's, specialized summer camps for children with burn injuries have been organized for many years. Nowadays, numerous camps for pediatric burn survivors exist throughout world (Maslow & Lobato, 2010). Although locations and themes vary, the overall aims seem similar: to provide children with the opportunity to meet other children with burns in a warm and safe environment, to experience success, and to enhance self-esteem through challenging activities (Rimmer et al., 2007). Although most burn camps do not provide structured psychological interventions, they do offer companionship and a challenging program on top of pleasure and fun, and there are believed to be or may be psychosocial benefits from attending camp.

Several research initiatives to document potential psychological and social effects for participants have been performed. The outcomes from previous qualitative and quantitative studies are not uniform (Maslow & Lobato, 2010). Qualitative reports, based on focus groups on burn camps, or evaluation forms from participants, parents, and staff completed shortly after camp, clearly indicate psychological benefits of attending camp. Positive experiences were for instance reported in self-confidence or self-esteem related topics, social skills, for instance developing new relationships or working in a team, and burn scars or appearance-related topics, such as more confidence to show scars, putting their scars in perspective, integrating scars in overall self image, and enhanced coping with a burn injury (Cox, Call, Williams, & Reeves, 2004; Gaskell, 2007; Gaskell et al., 2009; Maertens & Ponjaert-Kristoffersen, 2008; Rimmer et al., 2007; Williams, Reeves, Cox, & Call, 2004). As most quantitative studies that often investigated short-term effects on self-esteem in relatively small samples could not confirm these positive statements (Arnoldo, Crump, Burris, Hunt, & Purdue, 2006; Biggs, Heinrich, Jekel, & Cuono, 1997; Gaskell, 2007), there is an ongoing research challenge to document potential benefits of pediatric burn camps (Gaskell, 2007).

Gaskell (2007) proposed possible explanations for quantitative studies' failure to find significant effects from pediatric burn camps. First, she argued that some children do benefit from burn camp, but others do not, because they may be doing well already before camp. Second, the questionnaires used may have been too general to grasp the particular changes that participants, parents, and staff members observe. Third, one might question whether a weeklong experience can, in the short, have such a substantial impact on a highly internalized complex construct as self-esteem. A longer-term follow-up could possibly reveal, if present, a more gradual process. Last, a randomized controlled design may be a

more appropriate design to study effects, but such a design would raise ethical issues since a control group would have to wait a year for burn camp participation.

The current study adopted some of the aforementioned suggestions and explored the effect of burn camp on self-esteem and body image. Self-esteem was selected as an outcome to enable comparison with previous research and to study potential longer-term effects. Although global self-esteem in children with burns is generally reported to be comparable to norm populations or sometimes even more positive (Blakeney et al., 1993; LeDoux, Meyer, Blakeney, & Herndon, 1996), suggestions are also made that particular subdomains of self-esteem might be impaired (Robert et al., 1999).

Additionally, we selected “satisfaction with appearance” as a quantitative outcome measure of body image. Body image has been described as the “inside view” people have of their appearance, that is, a multidimensional concept referring to a package of perceptions, feelings, responses, and evaluations about the body (Cash, 2004). The few available studies describe an overall satisfying body image for children with burns (Jessee, Strickland, Leeper, & Wales, 1992; Pope, Solomons, Done, Cohn, & Possamai, 2007), but also for instance a relationship between more severe scarring and a more negative body image (Pope et al., 2007). Several qualitative studies addressed the positive impact of burn camps on appearance-related topics (Cox et al., 2004; Gaskell et al., 2009; Williams et al., 2004), however, no quantitative data have been reported concerning this topic.

Qualitative as well as quantitative measures were employed in the current study, since previous research clearly showed merit of using both methods together. Further, our research design included measurements before, shortly after, and well after burn camp to detect potential short-term and long-term changes. Multiple statistical methods were employed to accurately study possible effects of burn camp. Last, without randomization, an intervention group and a comparison group were composed following the naturalistic line of invitation procedure for Dutch pediatric burn camps. By means of this comprehensive research approach and the inclusion of another outcome measure besides self-esteem, that is, satisfaction with appearance that may be more susceptible to change, we attempted to grasp potential effects of burn camp participation.

METHOD

Burn camp

Characteristics Dutch burn camps

In the Netherlands, three camps are held each year in springtime: a burn camp for children (ages 8-11), teenagers (ages 11-14), and adolescents (ages 14-18). The camps vary in length

from 5 to 6 days. The Dutch burn camps are financially supported by the Foundation Child and Burn, making contribution for participants very low. All camp staffs consist of one or two coordinators, two cooking staff members, and approximately 10 volunteers. Most volunteers work in burn centers (e.g., medical doctors, physiotherapists, (liaison) nurses), have experienced a burn event themselves, or have for instance a scouting or fire-fighting background or a relative with burns.

Central features of the Dutch burn camps for participants include meeting other young burn survivors, and learning from each other and staff members about coping with scars. Various activities allow participants to experience success and extend themselves. Activities such as swimming and body painting have a body image-related background. Having fun and feeling safe are considered of paramount importance.

Selection procedure Dutch burn camps

The Foundation Child and Burn holds a database containing basically all Dutch burn injured children treated in one of the three specialized Dutch burn centers. Aftercare nurses from the burn centers, familiar with all children hospitalized in their burn center, recommend children (8-18 years) from the database to be invited for burn camp. Selection criterion includes having difficulties with respect to the burns and/or the expectation that the child may benefit from burn camp participation. However, having problems is not a prerequisite to be invited and the selection is not based on standard criteria. Each year, approximately half of the invited children accept the invitation. Reasons for declining are diverse, for example interference with school or holiday, or not feeling like participating, while in many cases the reason to decline is not known to the organizers. Apart from invited children originating from the burn centers, one or two children, for instance from peripheral hospitals, apply for burn camp on their own initiative.

Study Participant Recruitment and Procedures

This study was part of a larger study designed to evaluate the Dutch pediatric burn camps and was conducted in the Netherlands in 2008 and partly in 2009. The Ethics Committee North-Holland, the Netherlands, a legally qualified Dutch Ethics Review Committee, approved this study. All participating children and caregivers signed an informed consent.

Burn camp group

Written information regarding the research project was sent by regular mail 3 weeks prior to camp to all 2008 camp participants and parents ($N = 80$). The mailing also included the first questionnaires and a stamped return envelope. Children were promised a gift voucher for their participation in the research project. One week after the initial mailing, brief re-

minders were sent to encourage children and parents to participate. In the last week before camp, families who had not returned the questionnaires yet, were contacted by telephone to make sure that families willing to participate could still return the questionnaires in time. In sum, 72 families (T0, 90%) completed the first questionnaires.

Of the 72 respondents in 2008, only 25% joined a burn camp for their first time. Since we wanted to be able to examine a possible “first time” effect from burn camp, all 2009 new burn camp participants were invited to participate in the research project as well. Of 18 new burn camp participants in 2009 who were eligible to participate, 11 completed the first questionnaire (61%). The 83 final study participants (72 in 2008 and 11 in 2009) did not differ from the 15 nonparticipants (8 in 2008 and 7 in 2009) in terms of age and gender, but had more frequently attended a burn camp before (66% vs. 27%, $\chi^2(df = 1) = 8.31, p < .01$).

The second (T1) and third questionnaire (T2) were sent by regular mail, respectively, 1 week and 16 weeks after the last day of camp. Brief postal reminders were sent 1 week after each mailing and resulted in a response rate of 92% at T1 and 93% at T2 compared to T0.

Comparison group

All children from the Foundation Child and Burn database, who did *not* join a burn camp in 2008 were invited in 2008 to participate in this study's comparison group. Seven children could not be invited for various reasons, for instance severe mental disability, and 38 families could not be traced. In sum, 278 of 323 families were sent a study invitation at the same point in time as the 2008 camp participants of the same age. Ninety families (32%) returned the first questionnaire. Of them, 47% had declined an invitation for 2008 burn camp. There were more boys among the nonparticipants (65%) than among the participants (52%, $\chi^2(df = 1) = 4.18, p = .04$). There were no differences between participants and nonparticipants in the comparison group regarding age and number of previous burn camp attendances. For T1 and T2, the same procedure as for the burn camp study group was followed. Compared to T0, response rates for the comparison group were 88% at T1 and 85% at T2.

Measures

Burn characteristics

Parents answered questions about the date of the burn event and the etiology of the burns. Participants marked their still present scars on a drawing of a human body. Subsequently, the body was divided in 20 zones (Bakker, Van Loey, Van Son, & Van der Heijden, 2010).

This method provides an indication of both the extent and the visibility of the current scarring. Visible scars were defined as scars on hands, face or neck. Regarding burn camp characteristics, participants endorsed all previous years they had attended a burn camp. Further, children answered how many other children with burns they knew.

Self-esteem

A global perception of self-worth was measured with a Dutch version of the Rosenberg Self-esteem Scale (RSES), a widely used self-report instrument (Rosenberg, 1965). The RSES consists of 10 items, answered on a four-point Likert scale ranging from strongly agree to strongly disagree. Item scores were summed up to a total scale ranging from 0 to 30, where a higher score represents a higher self-worth. The RSES is developed for adolescents, but has been used in pediatric burn camp studies in children from 6 years onwards (Arnoldo et al., 2006; Biggs et al., 1997). Internal consistency in this study was good, with Cronbach's alpha at T0 of .86.

Body image

The Satisfaction with Appearance Scale (SWAP) was used as an indicator of body image (Lawrence et al., 1998). It is the only questionnaire available that is specifically developed for populations with disfigurements or deformities. It is originally used for adult burn survivors and has not yet been validated for younger populations. However, Pope et al. (2007) have used the SWAP in a population of young burn survivors (aged 11-19 years). In their study, young burn survivors reported less satisfaction with the appearance of burned body parts as compared to nonburned body parts and mean burn size was positively associated with overall higher dissatisfaction about appearance (Pope et al., 2007). The SWAP consists of 14 items, answered on a seven-point Likert scale ranging from strongly disagree to strongly agree. The SWAP contains four subscales: dissatisfaction with facial body parts, dissatisfaction with nonfacial body parts, perceived social impact, and social discomfort. Validity and reliability of the SWAP were reported to be good, internal consistency for the total scale was high (Cronbach's alpha .87, Lawrence et al., 1998).

For the purpose of this study, two investigators translated the original version into Dutch, with approval of the author. The wording was adapted to make sentences shorter, that is, "Because of changes in my appearance caused by my burn"... was changed into "Because of the scars". After reaching consensus, the Dutch version was back-translated into English by an independent native speaker, professional translator. Final consensus was reached among all three involved. From this point, the adapted and translated version of the SWAP will be referred to as SWAP-Child-Dutch (SWAP-C-D).

Principal component analysis (PCA) did not show the four factor solution that was described by Lawrence et al. (1998). However, comparable to Heinberg et al. (2007) who adapted the SWAP for patients with scleroderma, a PCA confirmed the two *initially hypothesized* components Subjective Dissatisfaction with Appearance and Social Behavioral Impact of Burn Scars. The two factors accounted for 53% of the variance and both factors had an eigenvalue greater than 1. Internal consistencies were good (T0 Cronbach's alpha Factor Social Behavioral Impact of Burn Scars .78 and T0 Cronbach's alpha Factor Subjective Dissatisfaction with Appearance .87). A higher score represents more social behavioral impact, respectively more dissatisfaction with appearance. A squared root (sqrt) transformation was performed on the adapted SWAP-C-D subscales to correct for skewness. This transformation resulted in a normal distribution (posttransformation skewness of Social Behavioral Impact -0.15, min=0, max=5; posttransformation skewness of Dissatisfaction With Appearance -0.09, min=0, max=7).

Evaluation burn camp

Evaluation forms, based on Gaskell's Evaluation Forms (Gaskell, 2007) were used to investigate children's and parents' opinions about burn camp. The burn camp study group completed the evaluation forms at T1 (sent to home address, 1 week after burn camp¹). Questions for children included how much they had enjoyed camp, how much coming to camp had helped them, and how much they had learned. Responses were given on Likert scales ranging from 1 (not at all) to 7 (a lot/ very much). In addition, answers of parents are shown concerning their opinion about their child's personal benefit from camp and the answers of children how coming to burn camp had helped them, and what they had learned from burn camp. Children and parents could give more than one answer on these open-ended questions, so frequencies can exceed the number of participants.

Statistical Analyses

First, regarding demographic characteristics, the camp group and comparison group were compared with independent samples *t* tests (age, years postburn, number of scarred body zones) or Chi square tests (gender, etiology, presence of visible scars, previous burn camp attendance).

Second, to investigate short-term and long-term differences in self-esteem and body image, paired samples *t* tests were performed separately for the burn camp group and the comparison group. Then, new variables were computed for short-term and long-term changes (i.e., T1-T0 and T2-T0, respectively) and multiple regressions were utilized

¹ The comparison group did not complete this burn camp evaluation form.

to test whether these changes significantly differed between the burn camp group (1) and the comparison group (0). If at least a trend effect of group appeared, gender, age, number of scarred body zones, visibility of the burns, and number of previous camp attendances were entered to the model. To prevent loss of power, the variables were added separately and not simultaneously. Data were analyzed with Statistical Package for Social Sciences, version 17.0 (SPSS Inc., now IBM, Chicago, 2008). An alpha level of .05 was set for all statistical tests, but results were also screened for trends ($p < .10$), because of a limited sample size and because we expected to find only small effects.

Additionally, Reliable Change Indices (RCI's, Maassen, 2004) were calculated for the RSES and both subscales of the SWAP-C-D (before squared root transformation) to determine the percentage of children whose scores had substantially changed between T0 and T1. For the RSES, SWAP-C-D Social Behavioral Impact, and SWAP-C-D Dissatisfaction With Appearance, reliability coefficients (Cronbach's alpha) of .87, .83, .88, and standard deviations of 5.1, 6.7, and 9.2 of the comparison group at T0 and deviations of 5.4, 6.8, and 9.6 of the comparison group at T1 were used to determine the standard error of measurement of difference scores. Improvement and deterioration were defined as $RCI \geq 1.96$, meaning that a change of 6 points or more on the RSES, 8 points or more on SWAP-C-D Social Behavioral Impact, and a change of 10 points or more on SWAP-C-D Dissatisfaction With Appearance were likely to represent a real change (95% CI). Subsequently, linear trends were used to test whether the number of children whose scores had substantially improved, remain unchanged, or deteriorated between T0 and T1, differed between the burn camp group and the comparison group.

Last, modal responses and percentages of agreement (scores 5-7 on a scale of 1-7, conform Gaskell et al. (2009) were calculated for the questions on how much children had enjoyed camp, how much coming to camp had helped them, and how much they had learned. Answers on open-ended questions on the evaluation forms were categorized according to themes described by Gaskell et al. After discussing the content of these themes and applicability for the current study, two researchers (AB, NVL) independently categorized the answers of parents on the question what they thought their child had gained from coming to camp. Inter-rater reliability was good (Cohen's kappa .83). In case of disagreement between the raters, consensus was reached through discussion. Subsequently, the other open-ended questions were analyzed by one researcher (AB).

Drop-out Analysis

Children who only completed T0 ($n = 13$) did not differ from children who completed multiple measurements ($n = 160$) in terms of age, gender, burn characteristics, number of previous burn camp attendances, and outcome variables as measured on T0.

RESULTS

Participants

Table 7.1 shows demographic, burn, and burn camp characteristics of all study participants. Children in the burn camp group had more body zones with scars, more of them had visible scars, and more of them had attended a burn camp before, compared to children in the comparison group. There were no differences with regard to gender, age, number of years postburn, and etiology of the burns.

Table 7.1

Characteristics burn camp group ($n = 83$) and comparison group ($n = 90$)

| Variable | Burn camp group | Comparison group | p |
|---------------------------------------|--------------------|--------------------|------|
| Male gender (%) | 52 | 52 | .96 |
| Age (years) | 12.3 (± 2.8) | 13.1 (± 2.8) | .07 |
| Years postburn | 6.2 (± 4.1) | 6.1 (± 4.0) | .85 |
| Etiology: flame/ hot fluid/ other (%) | 36/ 40/ 24 | 29/ 47/ 24 | .55 |
| Number of scarred body zones (0-20) | 5.0 (± 3.3) | 3.7 (± 2.8) | <.01 |
| Presence of visible scars (%) | 58 | 41 | .03 |
| No previous burn camp attendance (%) | 35 | 76 | <.01 |

Quantitative Data

Short-term effects

Paired samples t tests showed that SWAP-C-D Dissatisfaction With Appearance significantly decreased in the burn camp group ($T0 = 2.85 \pm 1.55$, $T1 = 2.50 \pm 1.74$, $t(72) = 2.48$, $p = .02$, $r = .28$), but not in the comparison group ($T0 = 2.46 \pm 1.78$, $T1 = 2.64 \pm 1.72$, $t(74) = -1.31$, $p = .19$). For the RSES, $T1$ scores did not differ from $T0$ scores, neither for the camp group ($T0 = 23.33 \pm 4.81$, $T1 = 23.16 \pm 4.38$, $t(75) = 0.43$, $p = .67$), nor for the comparison group ($T0 = 23.20 \pm 5.12$, $T1 = 23.53 \pm 5.35$, $t(74) = -0.70$, $p = .49$). The same applied for the scores on SWAP-C-D Social Behavioral Impact, both for the camp group ($T0 = 2.47 \pm 1.46$, $T1 = 2.35 \pm 1.37$, $t(72) = 0.84$, $p = .40$) and for the comparison group ($T0 = 1.95 \pm 1.52$, $T1 = 2.03 \pm 1.46$, $t(74) = -0.57$, $p = .57$).

Because a significant short-term decrease in SWAP-C-D Dissatisfaction With Appearance was found in the burn camp group, and not in the comparison group, we used multiple regressions to further investigate the relationship between this short-term decrease and burn camp participation. A significant model emerged that explained a small

amount of the variation in the decrease in SWAP-C-D Dissatisfaction With Appearance ($F(1, 146) = 7.28, p < .01, R^2 = .05, \text{adjusted } R^2 = .04$).

Next, background variables that differed between the burn camp group and the comparison group were added separately to the model, to test whether other conditions besides burn camp participation (partly) explained the decrease in SWAP-C-D Dissatisfaction With Appearance scores (Table 7.2). It appeared that, besides the additionally entered variables, burn camp participation remained a significant predictor of the decrease in dissatisfaction with appearance. No other predictors included in this study had a significant relationship with a decrease in SWAP-C-D Dissatisfaction With Appearance.

Improvement versus deterioration

To determine whether more children in the burn camp group than in the comparison group showed substantial improvement shortly after burn camp, reliable change indices were calculated for the different outcomes.

Linear trends demonstrated that relatively more children in the camp group than in the comparison group had improved scores on SWAP-C-D Dissatisfaction With Appearance (trend value, Table 7.3). The number of children whose scores substantially changed on the RSES and SWAP-C-D Social Behavioral Impact did not significantly differ between the camp group and the comparison group (data not shown).

Long-term effects

Paired samples *t* tests showed no significant long-term changes on the RSES in both groups (burn camp group $T0\ 23.23 \pm 4.93, T2\ 23.21 \pm 5.55, t(76) = 0.05, p = .96$; comparison group $T0 = 23.49 \pm 4.86, T2 = 23.46 \pm 4.81, t(73) = 0.06, p = .95$). Similarly, there were no statistically significant long-term changes, neither on SWAP-C-D Social Behavioral Impact (burn camp group $T0\ 2.50 \pm 1.46, T2\ 2.34 \pm 1.41, t(75) = 1.02, p = .31$; comparison group $T0\ 1.92 \pm 1.54, T2\ 1.89 \pm 1.58, t(73) = 0.18, p = .86$), nor on SWAP-C-D Dissatisfaction With Appearance (burn camp group $T0\ 2.86 \pm 1.65, T2\ 2.66 \pm 1.65, t(74) = 1.28, p = .21$; comparison group $T0\ 2.50 \pm 1.76, T2\ 2.53 \pm 1.63, t(73) = -0.21, p = .84$). Summarizing, no long-term effects of burn camp participation were found on self-esteem or body image.

Qualitative Data

Nearly all participants reported enjoying the camp (96% endorsed responses 5-7, modal response 7). One participant gave a neutral answer and two participants reported that they did not enjoy the camp. They indicated a specific activity (dancing) or teasing as negative aspects of camp. Seventy percent of the participants reported that camp had helped them

Table 7.2

Multiple regression models

| Short-term change | | B | SE B | β | Sig. | R² | ANOVA |
|--|-------------------------------------|----------|-------------|---------------------------|-------------|----------------------|-------------------|
| dissatisfaction with appearance^a | | | | | | | |
| Model | Constant | 0.18 | 0.14 | | .20 | .05 | F(1,146) = 7.28** |
| Burn camp | Participation ^b | -0.53 | 0.20 | -0.22 | <.01 | | |
| Model | Constant | 0.06 | 0.49 | | .27 | .05 | F(2,145) = 3.93* |
| Burn camp + | Participation ^b | -0.06 | 0.20 | -0.23 | <.01 | | |
| age | Age | -0.03 | 0.04 | -0.06 | .44 | | |
| Model | Constant | 0.04 | 0.19 | | .04 | .07 | F(2,143) = 5.16** |
| Burn camp + | Participation ^b | -0.48 | 0.20 | -0.20 | .02 | | |
| extent scars | Extent scars | -0.06 | 0.03 | -0.14 | .10 | | |
| Model | Constant | 0.33 | 0.17 | | .05 | .07 | F(2,143) = 5.10** |
| Burn camp + | Participation ^b | -0.50 | 0.20 | -0.20 | .01 | | |
| visible scars | Visible scars ^c | -0.03 | 0.20 | -0.13 | .10 | | |
| Model | Constant | 0.09 | 0.40 | | .83 | .05 | F(2,145) = 3.65* |
| Burn camp + | Participation ^b | -0.51 | 0.22 | -0.21 | .02 | | |
| previous participation² | Previous participation ^d | 0.05 | 0.22 | 0.02 | .80 | | |

^aDependent variable is difference score: $Tl_{\text{sqrt}} - T0_{\text{sqrt}}$ ^b0 = no burn camp participation (comparison group), 1 = burn camp participation^c0 = no visible scars, 1 = visible scars^d0 = no previous burn camp attendance, 1 = ≥ 1 previous burn camp attendances* $p < .05$. ** $p < .01$.**Table 7.3**

Short-term substantial change according to Reliable Change Index

| Dissatisfaction with appearance | Improvement | No change | Deterioration | p |
|--|--------------------|------------------|----------------------|----------|
| Camp Group | $n = 7$ | $n = 63$ | $n = 3$ | .05 |
| Comparison group | $n = 1$ | $n = 71$ | $n = 3$ | |

Note. p value indicates significance level of linear trends test (one-tailed)

² The relationship between a decrease in SWAP-C-D Dissatisfaction With Appearance and the interaction term "Burn Camp \times Previous Participation" was also examined to investigate the potential effect of a "first time" burn camp experience. However, this relationship was not significant ($p = .69$).

in some way (modal response 7) and 81% of the participants reported that they had learned from burn camp (modal response 6). Figures 7.1, 7.2, and 7.3 reflect themes of participants' and parents' opinion about the participant's personal benefits derived from burn camp.

A significant amount of the answers of children and parents was classified within the theme "Shared experience of having a burn" and "Coping skills around burns". The majority of these answers related to companionship: meeting other children with scars and learning that there are other children with a comparable experience (e.g., "That I'm not the only one with burns").

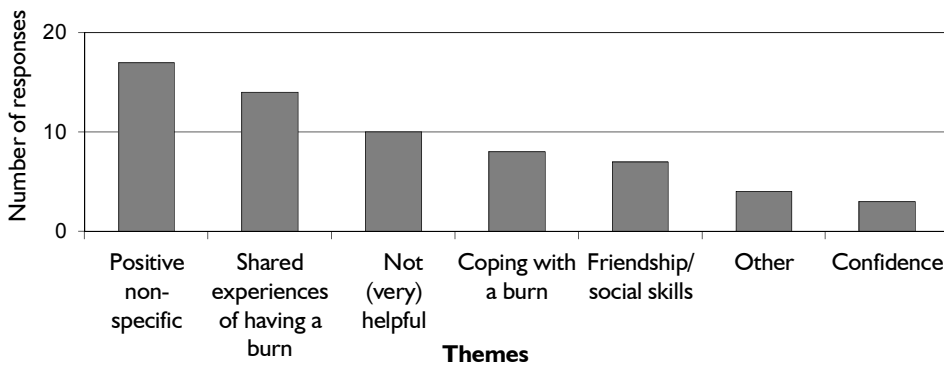


Figure 7.1 Bar chart illustrating children's responses about how coming to burn camp helped them (n = 76)

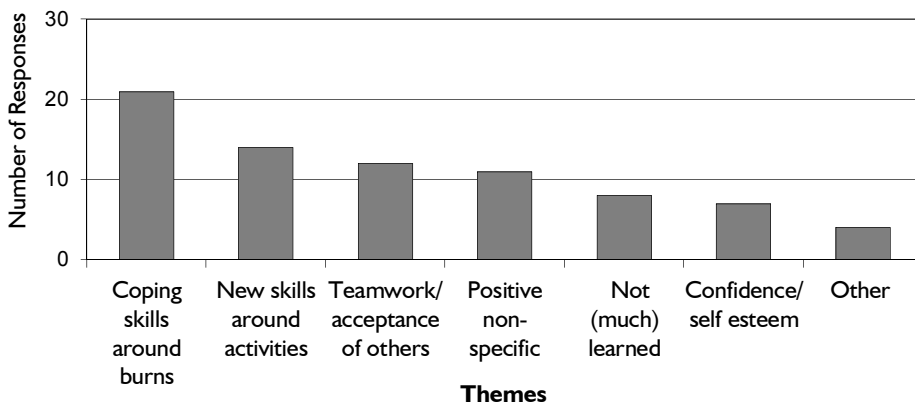


Figure 7.2 Bar chart illustrating children's responses about what they have learned from burn camp (n = 76)

Numbers clearly illustrate the strength of pediatric burn camps of enabling children with burn scars to meet other children who have experienced a burn. In this study, the majority of children who had not previously attended a burn camp reported to know no or just one other child with burns, whereas children who had already attended a burn camp before knew on average 11 other children with burns.

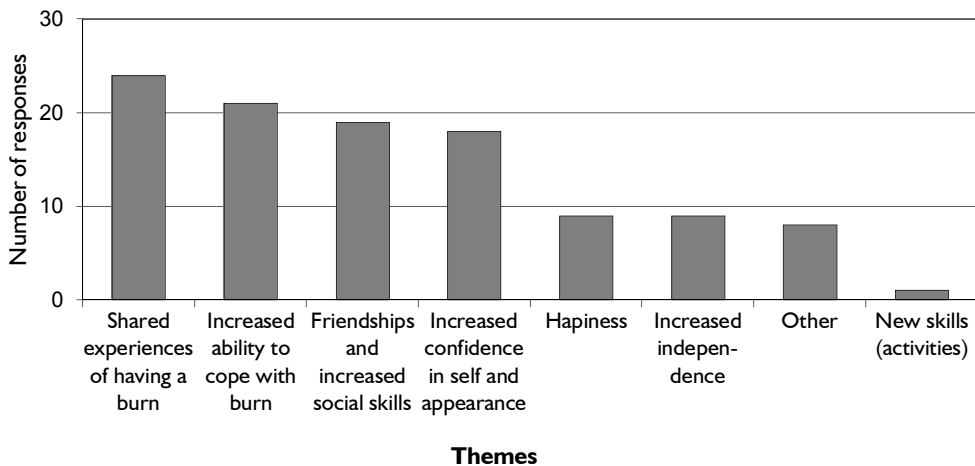


Figure 7.3 Bar chart illustrating parents' responses about what their child had gained from attending burn camp ($n = 74$)

Another significant part of the answers concerned appearance-related issues, for example, "Now, I wear a T-shirt [...], without 'an awkward feeling'" (child), "That I don't have to be ashamed of my scars" (child), "To put the scars in perspective" (parent), "She isn't insecure about her scars anymore and does no longer hide them" (parent).

It should be mentioned that a considerable part of the children gave quite general answers. Children stated that burn camp had helped them "very much", or "very good". There were also children that noted burn camp had not specifically helped them. Some children added they already dared to do everything, that this was not their first burn camp attendance, or that they just had a fantastic time. Finally, there were also children who could not come up with ways how camp had helped them or what they had learned from burn camp ($n = 10-13$, not included in bar charts).

DISCUSSION

This is one of the few quantitative studies to report on a positive impact of burn camps regarding psychological outcome in young burn survivors, and the first study that docu-

ments a significant short-time change in satisfaction with appearance. This finding may be useful for future development of burn camp programs. As reported in other studies (e.g., (Gaskell et al., 2009), participants and parents were very positive about the burn camp experience and personal benefits for the children, and no effect of burn camp was found on self-esteem (Arnoldo et al., 2006; Biggs et al., 1997).

Interestingly, our results indicate a small short-term improvement of burn camp participants' satisfaction with appearance, a change that could not be observed in the comparison group. Of notice, burn camp participation could only explain a small amount of the variance and none of the other predictive factors included in this study were significantly related to the observed decrease. Nonetheless, contrary to self-esteem that has often been reported to be fairly stable, this finding suggests a beneficial effect of burn camps on a more specific and burn-related concept such as satisfaction with appearance.

This result concerning appearance satisfaction, although modest, has straightforward support from the existing qualitative literature that reported on a positive impact of burn camp on participants' body image or appearance-related confidence. Studies reported for instance that participants had learned to integrate the scars as being part of themselves, felt comfortable to show their scars, and had gained confidence to wear less covert clothes in their everyday live situations (Cox et al., 2004; Gaskell, 2007; Gaskell et al., 2009; Williams et al., 2004). Qualitative results in the current study also indicated that, for a subgroup of participants, burn camp was supportive regarding their appearance-related confidence.

Regarding self-esteem, no changes were found in the burn camp group, nor in the comparison group, which strongly suggests that burn camp participation did not enhance participants' self-esteem. So far, only one study reported an average significant short-term increase in self-esteem for all participants (Rimmer et al., 2007), but most studies failed to find an overall effect of burn camp on self-esteem (Arnoldo et al., 2006; Biggs et al., 1997). Explanations for the lack of an effect on self-esteem may relate to methodological shortcomings, child characteristics, or intervention characteristics as put forward by Gaskell (Gaskell, 2007). In comparison to the study of Rimmer et al. (2007) that showed improvement, pre-camp scores in the current study were already higher than post-camp scores in the aforementioned study. Perhaps, the high pre-camp scores in this study prevented children from improving more on self-esteem. However, considering most other available evidence, it is more likely that burn camp did not influence participants' global self-esteem.

Appreciation of the burn camps appeared, in line with other studies, very high and participants and parents pointed out various aspects that were positively influenced through burn camp participation. The opportunity to meet other young burn survivors, endorsed by many children and parents, seemed to benefit participants the most. We be-

lieve that this companionship, together with a strong program, a competent staff, and a positive atmosphere, make up the uniqueness of residential burn camps. Furthermore, we believe that satisfaction is an important prerequisite to attain an effect, and should be considered a complementary condition to the effect. Future studies that wish to quantify the benefits of these unique camps should for that reason focus at potential effects as well as satisfaction with the burn camps.

Some methodological limitations of this study merit note. First, study participants were not randomly assigned to either a control group or a camp group, which may have been a more ideal design for investigating effects. For ethical reasons, we choose not to deviate from the naturalistic invitation procedure. Still, we believe it is valuable to have included a comparison group to adjust for changes that may occur in children apart from any intervention. Further, results may be biased, because only children, and/or the caretakers, in favor of burn camps attend a burn camp. This “self-selection” does not cause difficulties for this study, but should be considered when generalizing the results from this study to all young burn survivors. Second, the questionnaire used in this study (SWAP-C-D) has not been validated for this age category yet, nor has a Dutch version been validated before. However, the SWAP has been used before in young burn survivors and our exploration of the psychometric properties seemed promising and resembled that of another study (Heinberg et al., 2007). Nonetheless, more research may be indicated to further determine the instrument’s validity and the appropriateness for assessing changes following burn camp in this population. Third, separate cross-age burn camps were currently considered one experimental condition. We feel that in spite of methodological objections that obviously could be raised and developmental considerations that were presently not taken into account, the camps had ample similarities to treat them as one. All Dutch burn camps share essential basic elements like swimming, campfire, and companionship with other young burn survivors. Elaborating on this, Gaskell et al. (2009) observed that even between five cross-regional burn camps many likenesses were found, indicating that “there is something generic about the burn camp experience itself” (p. 517). Finally, although the response rate in our study was satisfactory, this study may suffer from power problems. To detect the modest effects that may be expected from a summer camp, which is not designed as a therapy, a larger sample size may be required. However, most burn camps are organized for a limited number of participants, repeatedly generating this statistical power problem. Notwithstanding the methodological drawbacks intrinsic to combining several burn camps, larger study initiatives like the Pan-European study (Gaskell et al., 2009) are to be welcomed.

Despite the limitations, we believe this study adds to our understanding of burn camps’ potential influence in the rehabilitation of young burn survivors. First, the results

suggest that appearance-related confidence could be a more powerful construct than self-esteem (Arnoldo et al., 2006; Biggs et al., 1997) for tapping the positive effects of burn camp. Through the repeated use of uniform open-ended questions in this study and others (Gaskell, 2007; Gaskell et al., 2009; Maertens & Ponjaert-Kristoffersen, 2008), several variables impacted by burn camps can now be distinguished, such as coping skills around burns, appearance-related confidence, social skills, and increased independence. Future burn camp evaluations that wish to study potential effects may incorporate these recurring categories to compose an eligible, sensitive, and standardized quantitative research tool.

In addition, the results may direct future initiatives to extend the magnitude and duration of burn camps' impact on psychological outcomes. By now, there is a growing body of evidence on the potential positive effect of burn camps in appearance-related areas (Cox et al., 2004; Gaskell, 2007; Gaskell et al., 2009; Williams et al., 2004). Burn camps bring young burn survivors together in a fun and informal atmosphere, where principles of social learning (Bandura, 1977), such as observational learning and the use of role models, are already naturally embedded. These principles could be expanded and other approachable elements could be added to the burn camp programs. Components of the short-term social skills training based on *Changing Faces* (Blakeney et al., 2005), or cognitive-behavioral techniques applied in therapies that aim to improve body-related cognitions may for instance provide examples of effective elements that could be transferred to a burn camp setting.

Towards participants, parents, and organizers, it remains important to document in what respect children potentially benefit from burn camps. Research shows that burn camp is a pleasant experience for the large majority of participants, which is an important result as it is. Results from this study regarding appearance-related confidence need replication, but may serve future plans for research initiatives and burn camp programs. Without interfering with the fun and safe environment a burn camp is, innovations could maximize the strengths and opportunities of these unique camps for young burn survivors.

ACKNOWLEDGEMENTS

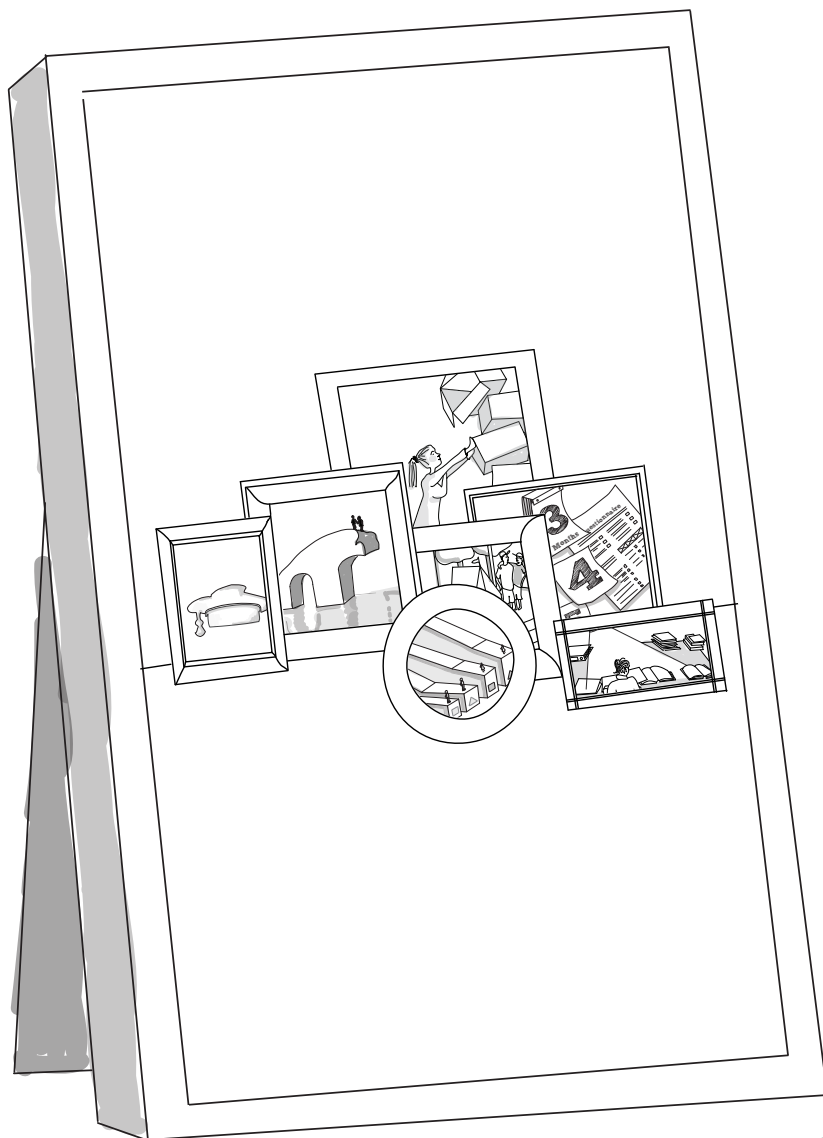
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Summary and general discussion



INTRODUCTION

This dissertation focused on the psychological consequences of pediatric burns on children and their parents. We conducted several studies in order to gain an understanding of possible psychological problems following pediatric burn injuries in children and their families, posttraumatic stress symptoms shortly and well after a pediatric burn event, the interrelatedness within families in terms of posttrauma outcome, and the potential benefits for children (8-17 years) with burns from participating in a weeklong burn camp program. We will first summarize the main findings of this dissertation and then discuss some overall themes concerning the impact of a pediatric burn event.

SUMMARY OF MAIN FINDINGS

In order to inform clinical practice about the extent of psychological, behavioral, and social consequences of pediatric burns for children and their families, and factors associated with negative outcomes, we started this dissertation with an overview of the empirical literature published between 1991-2011 (**Chapter 2**). A total of 75 articles were reviewed for their main outcomes, predictors of child and family outcomes, and methodological quality. The synthesis of the research findings revealed that the majority of children with burns showed good postburn adjustment. However, problems with depression, anxiety, and social functioning in a subgroup of young survivors indicated the need for clinical attention. Recent prospective studies found traumatic stress reactions in one third of preschool- and school-aged hospitalized children. Peritraumatic factors such as separation anxiety and pain were related to development of later posttrauma symptoms. The extent of the burn injury was in most cases not associated with the extent of problems. However, findings of recent studies suggest that burn extent may indirectly influence psychological outcome, for instance through parent symptoms or through pain. Family studies found that mothers were seriously affected by their child's burn event and many experienced anxiety, feelings of guilt, depression, and worries about their child. Family functioning in general did not seem to be affected by the burn event. Family factors, such as maternal posttrauma reactions and characteristics of the family, were consistently reported to be associated with child outcome. Although we noticed that the quality of studies published in the past two decades had certainly progressed, the synthesis of methodological artifacts showed the need for prospective studies with sufficient sample sizes enabling investigation of the longitudinal course of problems and detection of early predictors of later outcome. Second, topics in need of further investigation were suggested, such as appearance-related concepts and

social life matters. Third, the extant literature showed the need for a more broad family perspective in addition to the experiences of mothers.

In **Chapter 3**, we described the first results of our large scale prospective study on preschool children (0-4 years) with acute burns and their parents. This part of the study focused on acute stress symptoms in couples. Within the first few weeks after the child's burn event, 182 mothers and 154 fathers, representing 193 preschool-aged children, self-reported on their symptoms of traumatic stress and emotions pertaining to the burn event. We found that half of the mothers and one fourth of the fathers experienced traumatic stress reactions in the clinical range. Considering traumatic stress in the marital subsystem, we found that in 15% of the couples both parents had high traumatic stress scores. However, in 55% of all couples *at least* one parent, not all mothers, reported clinically significant stress symptoms.

When studying parental stress reactions in a family model, it became apparent that symptoms of intrusion, such as intrusive memories about the event, were predominantly individual experiences for mothers and fathers. Parental appraisal of the trauma (i.e., the perceived life-threatening nature of the child's injury) and particular emotions linked to the burn event (i.e., feelings of guilt and anger) were associated to the individually experienced symptoms of traumatic stress. In other words, parents that had thought that their child would not survive the burn injuries and parents that experienced feelings of anger and guilt had more symptoms of traumatic stress. Interestingly, symptoms of avoidance, such as avoiding conversations or objects that reminded about the burn event, had a substantial shared component within couples: two parents of a couple responded more alike than two random parents. Part of this 'shared pattern' was related to factors that were the same for both parents, such that couples of more severely injured children and couples of whom the child's accident had happened in the home setting reported more avoidance reactions.

With this knowledge on the high impact of a pediatric burn event on parents and couples and the hypothesized importance of the family system when studying child post-burn adjustment, in **Chapter 4** we investigated how parental acute stress symptoms were related to internalizing and externalizing behavioral problems in children in the first year after the burn event. Previous studies had shown that internalizing problems and traumatic stress symptoms were well prevalent in preschool children with burns and that child post-burn adjustment was often related to the mother's symptoms of posttraumatic stress. However, these studies were limited by a follow-up of 6 months at the most and mothers were the participating parent in virtually all studies. Consequently, a longer-term view and the father's perspective on the child's problems and the potential relation with his own symptoms was missing.

For this part of our study, 150 mothers and 125 fathers, representing 155 preschool children, reported on their child's behavior problems and about their worries concerning the child at 3 and 12 months postburn. The relationship between mother-rated and father-rated behavioral problems and worries on the one hand, and mother- and father self-reported acute stress symptoms on the other hand was examined. Results showed that mothers and fathers held quite comparable views of their child's functioning. Children in this sample had generally lower behavioral problem scores in comparison to published multinational norm data. Study criteria and sample characteristics may have contributed to this positive result. Whilst parents reported concerns about their child's behavior and development in general (e.g., eating, language problems), they were equally concerned about the physical and emotional aspects of their child's burn injury, such as the final appearance of the scars, the psychological impact of the burn event, and potential future problems in social life. Parent's own symptoms of distress were related to (parent-reported) behavioral problems of the child and to burn-related worries about the child (but not to general worries about the child). This association was not only found within the mother-child dyad, but also within the father-child dyad, stressing the importance of including both parents in research and clinical follow-up.

In **Chapter 5**, we performed a follow-up of the parents of preschool children until 18 months after the burn event. In other studies on parents of injured children, a general decrease of symptoms was found after the first months after the injury. As most studies so far focused on mothers, the longitudinal course of symptoms for fathers and couples is not well-known. Moreover, there is little research on parental distress beyond the first year post injury.

Parents' self-reported symptoms of intrusion and avoidance were assessed within the first month (Chapter 3), and then at 3, 12, and 18 months after the burn event. We focused on differences between mothers and fathers, but we also paid attention to overlap or similarities within couples. The results confirmed the general decrease in symptoms in the first year postburn, but this decrease seemed to decline after the first year. At 18 months postburn, still 18% of mothers and 6% of fathers had high levels of posttraumatic stress symptoms. Importantly, the decrease in symptoms was not the same for all parents. For instance, the decrease in intrusion symptoms was larger in mothers than in fathers. Nonetheless, the mother's level of symptoms remained higher than the father's level of symptoms. The course of avoidance symptoms was more stable in both parents and a parallel course of symptoms was noticed within couples. In line with the results on the subacute phase of the injury, parental appraisal of life threat and emotions about the burn event were associated with symptoms of intrusion. Interestingly, the influence of feelings of anger diminished in the course of time. So, parents with angry feelings about the burn

event initially experienced, for example, more intrusive memories or nightmares, but this was no longer the case at later time points. For symptoms of avoidance, we found a persistent influence of appraisal and emotions about the burn event throughout the course of the study. The influence of guilt feelings and perceived life threat on subsequent avoidance symptoms was stronger in mothers than in fathers. Apart from this different relation between appraisal/ emotions and avoidance in mothers and fathers, the longitudinal results again pointed at a shared component of avoidance symptoms within families that was partly explained by child- and burn-related characteristics. Furthermore, potential family mechanisms that may as well have influenced this shared pattern within couples were discussed.

Chapter 6 presents a long-term follow-up study at approximately 11 years after the burn event in which the role of permanent scarring and guilt feelings in the persistence of maternal posttraumatic stress symptoms were investigated. In 1994-1995, a group of parents whose child had been treated for burn injuries in a specialized burn center or in a general hospital reported on their symptoms of traumatic stress. Approximately 2 years after the burn event, parents were interviewed more into detail about their experiences including their subjective feelings of guilt regarding their child's burn event. At 11 years after the burn event, parents were once more invited to participate and report on their symptoms of traumatic stress. In sum, 48 mothers participated at all three waves of data collection.

At 2 years after the burn event, 27% of the mothers in this sample indicated they experienced feelings of guilt regarding their child's burn event. These mothers had significantly higher stress scores approximately 10 years later. We then investigated the influence of guilt feelings on the *course* of traumatic stress symptoms between 1 and 11 years after the burn. Results showed that the extent of permanent scarring moderated the relationship between guilt feelings and traumatic stress symptoms. This means that guilt feelings significantly influenced the course of traumatic stress symptoms in mothers whose child had more extensive scarring, but not in mothers whose child had less extensive scarring. Although it should be noted that guilt feelings in this study were assessed at 2 years after the burn and should therefore be considered chronic guilt feelings, the results clearly indicated that guilt feelings are important to monitor in parents of children with burns and that the child's scars may influence the impact of guilt feelings on long-term stress reactions.

In **Chapter 7**, we describe the evaluation of Dutch burn camps for children (8-17 years) with burns. Dedicated burn camps are organized worldwide in order to support children with burns and to facilitate them to meet other children with burns. Although the content of programs and composition of the staff varies across the world, participants are hypothesized to benefit from burn camps in terms of self-esteem and coping with burn-related matters. Previous research into the effects of burn camps noted high satisfaction

among participants, but failed to find effects in terms of enhanced self-esteem. We designed a pre-test post-test comparison group design to explore possible benefits of burn camp participation on self-esteem, social impact, and satisfaction with appearance. Eighty-three participants of the 2008 burn camps completed questionnaires before, two weeks after, and 4 months after burn camp. The comparison group consisted of 90 children with burns that did not join a burn camp in 2008. Additionally, burn camp participants and their parents completed an evaluation form about strengths of the burn camps and subjectively perceived gains from burn camp participation.

Children in the burn camp group were more positive about their appearance shortly after camp than before camp, while scores in the comparison group remained stable. In the long run, appearance satisfaction was not significantly different from appearance satisfaction prior to burn camp. Self-esteem and the social impact of burns did not change in the course of the study; neither in the burn camp group nor in the comparison group. Qualitative results showed high appreciation with burn camps and participants described several benefits from their participation. Many children, and their parents, commended the burn camps for facilitating children to meet other young people with burns. This enabled them to learn from other survivors in terms of coping with having burns and made them realize that they were not the only ones with burns. Children in the comparison group that had never attended a burn camp indicated to know no or just one other child with burn injuries. Another theme that emerged from the qualitative data was related to an increased confidence in their appearance and in themselves. Although the effect suggested by the quantitative results seemed modest in comparison to the qualitative findings, this study was one of the first to quantify the often reported benefits from burn camp participation. The results suggested that body image and appearance-related confidence may be appropriate outcome parameters to tap into the potential benefits from burn camp participation.

GENERAL DISCUSSION

In this final section of the dissertation we discuss four themes concerning the psychological consequences of pediatric burns reflecting central issues, along with clinical implications and directions for future research, that emerged from this dissertation: (a) research challenges to capture short- and long-term postburn adjustment, (b) the severe impact of pediatric burns on parents, (c) the importance of family (sub)systems in the aftermath of a pediatric burn event, and (d) a bio-ecological perspective on supporting child postburn recovery.

The Acute and Chronic Character of Pediatric Burns: Research Challenges

Pediatric burns may at first be considered an acute medical traumatic event that shows commonalities with other unintentional pediatric injury populations, such as the sudden onset of the injury, pain, and acute hospitalization. Reports from parents of children with burns indicated that apart from the traumatic nature of the injury itself, their children's traumatic stress symptoms were as well related to aspects of the burn treatment, such as the dressing changes (Graf, Schiestl, & Landolt, 2011). Psychological reactions that were found in children with burns during and shortly after hospitalization, in particular acute- and posttraumatic stress symptoms (Bakker, Maertens, Van Son, & Van Loey, 2013), indeed seem to resemble reactions of other pediatric populations (e.g., Bronner, Knoester, Bos, Last, & Grootenhuis, 2008; Kassam-Adams, Garcia-Espana, Miller, & Winston, 2006; Kazak et al., 2006; Landolt, Vollrath, Ribi, Gnehm, & Sennhauser, 2003). As in other pediatric medical trauma populations, a trauma informed health care system (Stuber, Schneider, Kassam-Adams, Kazak, & Saxe, 2006), support for children and their families emanating from the family's existing strengths (Walsh, 2003), and continuous assessment of the family's psychosocial needs are recommended. Moreover, adequate pharmacological and non-pharmacological pain interventions are imperative due to the severe painful character of the injuries and the daily recurrent procedures.

After the initial acute phase of the burn event, the permanent physical consequences of burns may render pediatric burns a chronic character that may demand ongoing adjustments. This process may be related to the experience of repeated medical procedures, such as reconstructive surgery, but as well to continuous challenges regarding living with scars. These challenges may emerge from an outside perspective on appearance, for instance social interactions, as well as from an inside perspective on appearance, such as self-perception (Thompson & Kent, 2001). Results from a review of the literature on children with burns seem to point at an overall positive longer-term adaptation in young burn survivors (Bakker, Maertens, Van Son, & Van Loey, 2013). At least two important issues should be raised, however, before concluding that pediatric burns do not have a significant long-term impact on children. First, the majority of studies had a cross-sectional design. These studies indicate how children with burns function at an average time point after the injury and have shown that pediatric burns not by definition cause psychosocial problems. However, the rather static character of these studies leave many questions unanswered about the process children might go through, developmental issues, and particular vulnerable periods in their lives. Second, the vast majority of studies so far have used quite generic instruments to assess 'postburn adjustment'. These generic concepts may not tell the whole story.

We argue that longitudinal studies with different outcome measures are needed to describe longer-term challenges and strengths of children with burns. Systematic follow-up of children in aftercare practice may offer the opportunity to monitor children and timely intervene whenever necessary and may simultaneously provide highly valuable research information regarding the course of postburn adjustment. While in the acute phase of the injury, the pediatric burn population shows similarities with other injury populations, the long-term consequences of pediatric burns may show parallels with other children with disfigurements or 'visible differences' (Rumsey & Harcourt, 2007). For instance, recent studies have shown the importance of challenges concerning perceived stigmatization in children with visible differences (Masnari et al., 2013), experiences with appearance-related bullying among children with burns (Rimmer et al., 2007), the relationship between hand burns and motor functioning domains of health-related quality of life (Dodd et al., 2010; Palmieri et al., 2012), the influence of facial burns on psychosocial domains of health-related quality of life (Warner et al., 2012), and the relationship between scarring and appearance-related satisfaction (Pope, Solomons, Done, Cohn, & Possamai, 2007). Children that participated in burn camps indicated that meeting with other young burn survivors helped them to cope with their burn injuries and burn camp participation may (modestly) benefit their appearance-related satisfaction (Bakker, Van der Heijden, Van Son, Van de Schoot, & Van Loey, 2011). These outcomes suggest that issues related to appearance perception and social life are more sensitive to grasp specific, but not by definition more, difficulties for young burn survivors. Furthermore, the overall positive adjustment of children with burns described in the literature suggests that many survivors recover well or are resilient and encourages clinicians and scholars to look beyond negative outcomes of pediatric burns as was previously suggested in child trauma literature (Alisic, Jongmans, van Wesel, & Kleber, 2011).

The Severe Impact of Pediatric Burns on Mothers and Fathers

A burn event in a child undoubtedly severely affects the parents. Results from our studies indicated a serious prevalence of posttraumatic stress symptoms in mothers and fathers, both short- and long-time after the burn event (Bakker, Van Loey, Van der Heijden, & Van Son, 2012; Bakker, Van Loey, Van Son, & Van der Heijden, 2010; Bakker, Van Son, Van der Heijden, & Van Loey, 2013). Parents, at least parents of preschool-aged children, seem to be more affected by the burn event than children themselves. Significant worries in parents concerning the child's potential future problems (Bakker, van der Heijden, et al., 2013) may add to the burden of the acute burn event for parents. Although reactions shortly after the trauma may be considered normal and perhaps adaptive in the face of an adverse stressor, research has also shown that acute stress symptoms may increase the risk for long-term

problems (Kassam-Adams, Fleisher, & Winston, 2009). Psychosocial support during hospitalization is available for children and their families, but psychosocial support in the after-care phase is predominantly centered around the child's physical recovery. Our findings showed that couples of more severely injured children, who are more likely to be in prolonged outpatient aftercare, experienced more stress symptoms. However, burn severity was not the single or most important predictor for parental problems. Subjective parental experiences such as early appraisal of the life threatening character of the child's burn and parents' feelings of anger and guilt about the burn event dominated objective characteristics such as the severity of the child's burn injury. Systematic monitoring of parental stress symptoms may facilitate early detection of parents at risk and contribute to optimization of pediatric burn aftercare. Recently developed innovative web-based systems (Haverman, Engelen, van Rossum, Heymans, & Grootenhuis, 2011) may be useful to implement in a broader family-centered aftercare program following pediatric burns. Our results suggest that monitoring is at least indicated for parents who have high in-hospital stress scores, who feared for the child's life, or who experience feelings of anger or guilt related to the burn event.

In trauma literature and in pediatric medical traumatic stress studies, posttraumatic stress disorder (PTSD) is more often diagnosed in women than in men. Variables that may contribute to this risk include differences regarding the type of trauma experienced, perceived threat and loss of control, and acute responses to trauma (Olff, Langeland, Draijer, & Gersons, 2007). Parents in our studies were faced with the same type of stressor, that is, a serious burn injury in their child. We found that mothers demonstrated generally higher stress scores than fathers and more mothers than fathers had stress scores in the clinical range (Bakker et al., 2012; Bakker, Van Son, et al., 2013). Findings on variables associated with parental stress seem to support the notion that gender differences concerning the appraisal of the event contribute to gender differences in PTSD (Olff et al., 2007). For instance, more mothers than fathers perceived their child's life to be in danger and mothers generally reported more guilt feelings than fathers. Moreover, we found that the effect of threat appraisal and guilt feelings more strongly affected avoidant stress responses in mothers than in fathers. Future (qualitative) studies may gain more insight into mechanisms behind stress symptoms in parents and unravel whether differences regarding proximity at time of the burn event, during hospitalization or wound care procedures, acute psychobiological reactions, or coping styles may contribute to the differences between mother's and father's level of stress symptoms.

Despite the different level of stress symptoms in mothers and in fathers, we may conclude that a significant group of mothers and fathers is at risk for long-term traumatic stress symptoms and that feelings of guilt may play a central role. The results from Chapter

6 furthermore suggest a link between the permanent character of the scars, guilt feelings, and the persistence of parental stress symptoms, such that scars may function as painful reminders of the burns in mothers who experienced guilt feelings about what happened (Bakker et al., 2010). Guilt feelings are well present in this group of parents and deserve our clinical attention. We believe it is important to recognize and acknowledge parental guilt feelings and educate parents about a range of normative parental reactions after a burn event. Moreover, parent support groups may be helpful preventive interventions to help parents share and normalize their feelings (Frenkel, 2008). In case of severe or persistent guilt feelings, therapy may be indicated. It is hoped that results from this dissertation raise the awareness about the profound and long-term impact of parental guilt feelings and encourage timely preventive interventions.

The Importance of Family Subsystems in the Aftermath of a Pediatric Burn Event

From a bio-ecological perspective, interactions between the individual child and its environments are crucial to understand the child's postburn adjustment. An important aim of this dissertation was to gain more knowledge on the importance of the family context and its subsystems in the aftermath of a pediatric burn event. The importance of the family emerged from the consistent relationship between child postburn adjustment on the one hand and family functioning and maternal reactions on the other hand (Bakker, Maertens, et al., 2013). This concurs with pediatric psychology literature (e.g., Kazak, 1997; Kazak et al., 2006; Landolt, Ystrom, Sennhauser, Gnehm, & Vollrath, 2012; Le Brocque, Hendrikz, & Kenardy, 2010) and broader child trauma literature (e.g., Alisic, Jongmans, et al., 2011; Scheeringa & Zeanah, 2001).

As the (bidirectional) association between the child and the family seems established, a next research step may involve unraveling the family's subsystems. Results from this dissertation may add to the literature on family posttrauma functioning by shedding light on two types of family subsystems. First, we looked at the parent-child dyad. In a prospective study on the relationship between parental acute stress symptoms and child behavioral problems at 3 and 12 months postburn, we found that the mother's and the father's stress symptoms were equally associated with the child's behavioral problems (Bakker, van der Heijden, et al., 2013). Although parental stress was assessed prior to child behavior problems, causality cannot not be claimed and it should be kept in mind that parents were informants of their own and their child's symptoms. Still, the findings point at the significance of both the mother-child dyad and the father-child dyad in the aftermath of a pediatric burn event and suggest that the perspective of both parents should be incorporated in clinical practice and in future studies in this field.

Couples were a second subsystem of interest in our studies. The participation of both parents enabled us to study the occurrence of traumatic stress reactions in couples and provided interesting findings concerning couples' avoidance of stimuli regarding their child's burn event. That is, although parents in couples were not likely to both display traumatic stress reactions in the clinical range, parents within couples responded more alike than parents of different couples in terms of avoidance symptoms (Bakker et al., 2012; Bakker, Van Son, et al., 2013). We may speculate that persistent avoidance behaviors within couples may eventually translate to the larger family system and consequently restrict the openness within the family to discuss issues related to the (impact of) the burn event. In child trauma literature (Pynoos, Steinberg, & Piacentini, 1999) and pediatric medical literature (Cabizuca, Marques-Portella, Mendlowicz, Coutinho, & Figueira, 2009), the concept of a 'conspiracy of silence' has been described as an extreme of parental practices that negatively contributes to the child's future appraisal of a traumatic event. Although this pattern and underlying mechanisms should be subjected to further study, our results could hint at the origin of an avoidant behavioral pattern within families.

Future research in the field of child (medical) trauma should consider to include multiple family members to study family functioning and interactions in the aftermath of trauma. The impact of for instance couple's traumatic stress reactions on subsequent child adjustment remains to be elucidated. Moreover, the impact on and interactions with siblings may as well provide important information. Despite a broader view on important family subsystems after child medical trauma provided in this dissertation, questions remain about the mechanisms behind these posttrauma family interactions. Knowledge about what children and their parents do and communicate within the family context may give insight how families cope with and may be best supported after such a stressful event. In addition, investigating family interactions may also be essential to increase our understanding of how perceptions about appearance visible differences may be transferred within the family from parents to the child (Rumsey & Harcourt, 2007), a phenomenon that has not been investigated so far among families of children with burns.

A Bio-Ecological Perspective on Supporting Child Postburn Recovery

Like we aimed to understand child adjustment from a broader point of view, we may as well propose the usefulness of a bio-ecological perspective on supporting child postburn recovery or resilience. A bio-ecological view on resilience recognizes the interplay between the child and the different contexts over time. In this line of reasoning, resilience refers to the capability of a person to adapt to severe stressors but may as well encompass the capability of the environment to adapt to the child's needs. This implies that individuals, as part of complex systems, are not always the most important locus for change (Ungar,

Ghazinour, & Richter, 2013). Importantly, we do not want to disregard the strength of individual children and the importance of individual characteristics and experiences, but we chose to focus here on the possibilities to embed elements of postburn support in potentially important environments for the child.

We propose that promoting recovery in children with burns will be most powerful if the child's different contexts are involved in a comprehensive support program. Starting most closely to the child, parents may play a key role in child postburn adjustment. Our research clearly demonstrated the severe impact on parents of children with burns (Bakker et al., 2012; Bakker et al., 2010; Bakker, Van Son, et al., 2013), and we found a direct relationship between parent acute stress symptoms and child behavioral problems (Bakker, Van der Heijden et al., 2013). In other young trauma populations, emotionally burdened parents have been suggested to be less capable to address the emotional needs of their child (Scheeringa & Zeanah, 2001), to be less able to perceive their child's reactions (Kassam-Adams, Garcia-Espana, Miller, & Winston, 2006), to transfer traumatic stress reactions through parenting practices or social learning (De Young, Kenardy, & Cobham, 2011; Gewirtz, Forgatch, & Wieling, 2008; Langeland & Olff, 2008), and to transfer beliefs about the child's appearance to the child (Rumsey & Harcourt, 2007). From a more positive point of view, family characteristics such as cohesion and expressiveness have been found positively related to positive child postburn adjustment (Bakker, Maertens, et al., 2013). Family resilience research has described two overall important family characteristics in the aftermath of trauma, with family *cohesion* referring to the emotional connection between family members and closeness within the family and family *adaptability* referring to the family's capability to be flexible at times of stress (Walsh, 2003). As was stated by Rolland & Walsh (2006) concerning a child's adaptation to a medical condition: "The functioning of the family as a collaborative team can make all the difference" (p. 528). Postburn psychosocial support from this understanding should be aiming at helping parents and reduce their stress, supporting the family's existing problem-solving capabilities, and maximizing the family's strength in terms of cohesion and flexibility. The support of the burn team was found highly valuable to provide information, guidance, and reassurance to parents (Thompson, Boyle, Teel, Wambach, & Cramer, 1999). Other aspects of parent support after a pediatric burn event may involve informing parents about potential reactions in children to help parents recognize their child's symptoms. Educating materials and a web-based intervention are available to assist health care professionals, parents, and children who have experienced a medical event (Marsac, Kassam-Adams, Hildenbrand, Kohser, & Winston, 2011; Dutch version at www.nahetziekenhuis.nl). Notably, web-based information may be useful to reach many parents, not only from children that have been treated in a burn center but as well at other hospitals.

When children grow older, their immediate environment expands beyond the family, and social contacts with peers become increasingly important. It has been suggested that children with a visible difference may develop difficulties at this stage in terms of negative self-perceptions or psychosocial problems (Rumsey & Harcourt, 2007). Promoting child postburn adjustment on this level may for instance include social support from friends, school-based interventions, and burn camps. Social support from friends has received little attention so far in research on children with burns and other children who have experienced a traumatic event, but may be highly valuable for children (Alisic, Boeijs, Jongmans, & Kleber, 2011). Return-to school projects may be an example of a school-based intervention that has been deemed valuable by children, parents, and teachers (Blakeney et al., 1995). These projects, in the Netherlands supported by the Dutch Burns Foundation and carried out by burn center professionals, are tailor-made and may range from information provision to teachers to aftercare nurses assisting the child with burns in a lecture for their classmates about burns and their hospital stay. Other school initiatives to discuss appearance-related issues, such as classroom discussions about societal attitudes regarding appearance and school services to assist teachers with promoting social inclusion, have also shown promising results (Rumsey & Harcourt, 2007). Notably, communication and cooperation between different caregivers of the child on a meso-level (i.e., interactions between microsystems such as burn center and parents, parent and school [Horridge, Cohen, & Gaskell, 2010], school and burn center) are hypothesized to contribute to child postburn recovery as well.

The potential beneficial effects of burn camps, in the Netherlands organized by volunteers from the Foundation Child & Burn, were investigated in Chapter 7. Satisfaction with and self-reported benefits from the burn camp experience were very positive (Bakker et al., 2011), which has been confirmed in research across Europe (Gaskell et al., 2009). Our study furthermore suggested that appearance-related satisfaction was enhanced shortly after burn camp in comparison to a group of children that did not attend burn camp during the study period. Research on burn camps suggests that meeting other young burn survivors is one of the most powerful ingredients of burn camp. We propose that the strength of this companionship may be extended, for instance through group interventions aiming to increase burn-related coping skills and overall adjustment. Results from a group-based cognitive behavioral intervention to support resilience and prevent psychosocial problems in children with a chronic illness has for instance shown positive effects on overall adjustment and disease-related coping skills (Scholten et al., 2013). Such examples from group-based interventions are promising and may inform future development of interventions for children with burns.

GENERAL CONCLUSION

In this dissertation, we focused on the psychological consequences of pediatric burns on children and parents, relationships within the family (parent-child, mother-father subsystems), and potential benefits from burn camp participation. Results of a literature review study showed that many children displayed at least some symptoms of traumatic stress or disturbed behavior during hospitalization. The synthesized long-term results suggested that most children seemed to adapt well to their situation. However, the predominant use of cross-sectional study designs and generic child outcomes limits our understanding of potential difficulties and challenges that children with burns may be faced with in the course of their lives. Suggested important topics for future longitudinal research involve appearance-related matters and children's experiences in social life.

Findings from our family studies demonstrated that a significant proportion of parents experienced posttraumatic stress symptoms as a result of their child burn event, with mothers generally reporting more symptoms than fathers. At 18 months after the injury, at least one parent in every 5 families was at risk for clinically significant stress symptoms. Parental appraisal of the life threatening character of the injuries and feelings of guilt and anger linked to the burn event, mostly more strongly present in mothers than in fathers, may be helpful for early detection of parents at risk for high levels of traumatic stress in the longer run. Moreover, scarring in the child was found to accelerate the influence of guilt feelings on persistent maternal stress symptoms after many years. The interrelatedness within couples in terms of avoidance symptoms and the interrelatedness between parent- and child symptoms stresses the need for a broad family focus in pediatric burn care.

Finally, a bio-ecological perspective on child postburn adjustment, that acknowledges the importance of the child's different ecologies, was presented as a useful framework to arrange interventions to support child postburn recovery. Supporting parents, with particular attention for the interplay between mothers and fathers and between parents and children, and strengthening the existent skills and resources of families are recommended as essential components of postburn support. In addition, the reported gains from meeting and learning from other children with burns seems promising and may for instance be translated to group-based interventions for young burn survivors. Although it is recognized that many psychosocial topics in the field of pediatric burns are still in need of thorough investigation and this dissertation has raised suggestions for future research as well, it is hoped that the results from this dissertation may contribute to further development of a comprehensive pediatric burn aftercare program.

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Samenvatting (Summary in Dutch)

INTRODUCTIE

Dit proefschrift richt zich op psychische gevolgen van een brandwondenongeval op kinderen en hun ouders. We voerden meerdere studies uit om inzicht te krijgen in de omvang van psychische problemen bij kinderen en hun gezin; in posttraumatische stress symptomen bij ouders korte en geruime tijd na het brandwondenongeval, in onderlinge relaties binnen het gezin met het oog op uitkomsten na het trauma en in mogelijke positieve effecten van vakantieweken voor kinderen (8-17 jaar) met brandwonden. We vatten eerst de belangrijkste resultaten van dit proefschrift samen, bespreken vervolgens enkele overkoepelende thema's rondom de impact van een brandwondenongeval bij een kind en sluiten het proefschrift af met een conclusie.

SAMENVATTING VAN HOOFDBEVINDINGEN

Om de klinische praktijk te informeren over de omvang van psychische, gedrags-, en sociale gevolgen van brandwondenongevallen bij kinderen en het gezin en over factoren die samenhangen met negatieve uitkomsten, begonnen we dit proefschrift met een overzicht van empirische studies gepubliceerd tussen 1991 en 2011 (**Hoofdstuk 2**). In totaal werden 75 artikelen doorgenomen op de belangrijkste bevindingen en voorspellers van kind- en gezinsuitkomsten en beoordeeld op methodologische kwaliteit. Een synthese van de studies liet zien dat de meerderheid van de kinderen zich goed aanpaste na het brandwondenongeval. Toch laten problemen rondom depressie, angst en sociaal functioneren in een subgroep van de kinderen zien dat klinische aandacht nodig is. Recente prospectieve studies vonden acute traumatische stress reacties in een derde van de kinderen opgenomen in het brandwondencentrum (zowel in de voorschoolse- als in de schoolgaande leeftijd). Factoren gemeten kort na het ongeval, zoals angst om van de ouder gescheiden te worden en pijn, waren gerelateerd aan de ontwikkeling van posttraumatische stress symptomen bij kinderen. De grootte van de brandwond was meestal niet direct geassocieerd met meer problemen. Maar recentere studies suggereren dat de grootte van de brandwond indirect psychische uitkomsten zou kunnen beïnvloeden, bijvoorbeeld via symptomen van de ouder of via pijn. Gezinsstudies vonden dat moeders ernstig waren getroffen door het brandwondenongeval van hun kind; velen ervoeren angst, schuldgevoelens, depressie en zorgen over hun kind. Het algemene gezinsfunctioneren leek niet negatief te zijn beïnvloed door het brandwondenongeval. Gezinsfactoren, zoals posttraumatische reacties van moeders en kenmerken van het gezin werden herhaaldelijk in verband gebracht met het herstel van het kind. Alhoewel de kwaliteit van studies gepubliceerd in de afgelopen twee decennia zeker vooruit was gegaan, liet de synthese van

methodologische tekortkomingen allereerst duidelijk de behoefte zien aan prospectieve studies van voldoende steekproefgrootte om het beloop van problemen en vroege voorspellers van latere uitkomsten in kaart te kunnen brengen. Ten tweede kwamen onderwerpen voor toekomstig onderzoek naar voren, zoals concepten rondom het uiterlijk en het sociaal functioneren. Ten derde bleek een behoefte aan kennis op het gebied van de impact van een brandwondenongeval op het hele gezin, naast de meer bestudeerde impact op moeders.

In **Hoofdstuk 3** beschreven we de eerste resultaten van een grote prospectieve studie naar jonge kinderen (0-4 jaar) met acute brandwonden en hun ouders. Dit eerste gedeelte van de studie keek naar acute stress symptomen in ouderparen. Binnen de eerste weken na het brandwondenongeval van het kind rapporteerden 182 moeders en 154 vaders van 193 jonge kinderen over traumatische stress symptomen en emoties na het brandwondenongeval. We vonden dat de helft van de moeders en een kwart van de vaders traumatische stress symptomen in de klinische range had. Binnen ouderparen, vonden we dat in 15% van de koppels beide ouders hoge traumatische stress scores hadden. In 55% van de ouderparen had ten minste één ouder klinisch significante symptomen en dit was niet in alle gevallen de moeder.

Door de reacties van ouders in een familie-model te bestuderen kwam naar voren dat symptomen van herbeleving, zoals opdringende herinneringen aan de gebeurtenis, hoofdzakelijk individuele ervaringen waren voor moeders en vaders. De gedachte dat het kind het ongeval niet zou overleven en bepaalde emoties over het ongeval (schuldgevoel en boosheid) waren geassocieerd met deze individueel beleefde symptomen. Met andere woorden, ouders die dachten dat hun kind het ongeval niet zou overleven en die zich schuldig en boos voelden hadden meer traumatische stress symptomen. Het was een interessante bevinding dat symptomen van vermijding, zoals het uit de weg gaan van gesprekken of dingen die doen herinneren aan het brandwondenongeval, voor een deel overlaptten in ouderparen. De antwoorden van twee ouders van eenzelfde ouderpaar leken meer op elkaar dan de antwoorden van twee willekeurige ouders. Een gedeelte van deze overlap hield verband met kenmerken die ouders deelden; zo rapporteerden ouderparen van ernstiger gewonde kinderen en ouderparen waarbij het brandwondenongeval thuis was gebeurd meer vermijdingsreacties.

Met deze kennis over de grote impact van een brandwondenongeval op de ouders en het veronderstelde belang van het gezinssysteem bij het bestuderen van de aanpassing van het kind, onderzochten we in **Hoofdstuk 4** hoe acute stress symptomen van ouders van invloed waren op internaliserend en externaliserend probleemgedrag van het kind in het

eerste jaar na het brandwondenongeval. Eerdere studies hadden laten zien dat internaliserende problemen en traumatische stress symptomen behoorlijk vaak voorkomen bij jonge kinderen met brandwonden en dat de aanpassing van het kind aan het ongeval vaak samengaat met posttraumatische stress symptomen van de moeder. De bestaande studies waren echter beperkt tot een follow-up van maximaal 6 maanden en moeders waren in nagenoeg alle studies de deelnemende ouder. Hierdoor ontbreekt een langer termijn inzicht, het perspectief van vaders op problemen van het kind en de mogelijke samenhang tussen de symptomen van het kind en de vader.

In dit gedeelte van het onderzoeksproject rapporteerden 150 moeders en 125 vaders van 155 jonge kinderen over gedragsproblemen en hun zorgen over het kind op 3 en 12 maanden na het brandwondenongeval. We onderzochten de relatie tussen gedragsproblemen van het kind volgens de moeder- en vader rapportage en de relatie met acute stress symptomen van moeders en vaders. Moeders en vaders hadden een vrij overeenstemmend beeld van gedragsproblemen van het kind. Kinderen in deze studie hadden over het algemeen minder gedragsproblemen in vergelijking met gepubliceerde multinationale normgegevens. Studiecriteriën en kenmerken van de onderzoeksgroep hebben mogelijk bijgedragen aan dit positieve resultaat. Op een open vraag over de zorgen van ouders over het kind, beschreven ouders zowel algemene zorgen over het gedrag en de ontwikkeling van het kind (bijvoorbeeld eet of spraak/taal problemen), maar ook over fysieke en emotionele aspecten van de brandwonden van hun kind, zoals hoe de littekens er uiteindelijk uit komen te zien, de psychische impact van het ongeval en mogelijke sociale problematiek in de toekomst. Ouders met veel acute stress symptomen rapporteerden meer gedragsproblemen bij het kind en meer aan brandwonden gerelateerde zorgen, maar niet meer 'algemene' zorgen over het kind. Deze relatie werd niet alleen tussen moeder en kind gevonden, maar ook tussen vader en kind, wat het belang benadrukt van het betrekken van beide ouders in onderzoek en in klinische follow-up.

In **Hoofdstuk 5** volgden we de ouders van jonge kinderen op tot 18 maanden na het brandwondenongeval. In andere studies naar ouders van kinderen die een ongeluk meemaakten werd een afname van symptomen gevonden in de eerste maanden na het ongeval. Omdat de meeste studies zich tot nu toe richtten op moeders, is het beloop van symptomen van vaders nog niet goed bekend. Ook is er weinig onderzoek naar symptomen van ouders na het eerste jaar na een ongeval.

Intrusie en vermijdingssymptomen van moeders en vaders werden middels zelfrapportage onderzocht binnen de eerste maand (Hoofdstuk 3) en vervolgens op 3, 12 en 18 maanden na het brandwondenongeval. We keken naar verschillen tussen moeders en vaders, maar besteedden ook aandacht aan overlap of overeenkomsten binnen

ouderparen. De resultaten bevestigden de algehele afname van symptomen in het eerste jaar na het brandwondenongeval, maar deze afname leek daarna te stagneren. Achttien maanden na het brandwondenongeval had nog altijd 18% van de moeders en 6% van de vaders een verhoogd niveau van posttraumatische stress symptomen. De afname van symptomen was niet voor alle ouders even groot. Zo namen intrusie symptomen bijvoorbeeld sterker af in moeders dan in vaders. Moeders bleven wel op alle meetmomenten meer klachten houden dan vaders. Het beloop van vermijdingssymptomen was stabiel in beide ouders en een parallel patroon werd gevonden binnen ouderparen. Net als in de directe fase na het ongeval, bleek dat de gedachte bij de ouder dat het kind het brandwondenongeval niet zou overleven en emoties bij de ouder over het brandwondenongeval van invloed waren op intrusie symptomen. Het was een interessante bevinding dat de invloed van boosheid afnam in de loop van de tijd. Dus ouders die boos waren over het brandwondenongeval hadden initieel bijvoorbeeld meer intrusieve herinneringen of nachtmerries over het ongeval, maar dit was op latere tijdstippen niet langer het geval. Vrees voor het leven van het kind en emoties over het brandwondenongeval hadden een blijvende invloed op vermijdingssymptomen tijdens de hele studieperiode. De invloed van schuldgevoelens en gedachten dat het kind het ongeval niet zou overleven was sterker in moeders dan in vaders. Naast deze verschillende relaties tussen emoties en vermijding in moeders en vaders, wezen de longitudinale resultaten wederom op een gedeelde component van vermijdingssymptomen binnen ouderparen die deels verklaard kon worden door kenmerken van het kind en de brandwonden. Daarnaast werden potentiële gezinsdynamieken besproken die dit gedeelde patroon in ouderparen wellicht ook kunnen hebben beïnvloed.

Hoofdstuk 6 presenteert de resultaten van een follow-up studie ongeveer 11 jaar na het brandwondenongeval waarin de rol van blijvende littekens en schuldgevoelens op persisterende posttraumatische stress symptomen van moeders werd onderzocht. Ouders, waarvan het kind in 1994-1995 in een brandwondencentrum of een algemeen ziekenhuis was behandeld voor brandwonden, werd een jaar later naar hun posttraumatische stress symptomen gevraagd. Daarna, ongeveer 2 jaar na het ongeval werden diepte interviews met ouders gehouden, waarin onder andere naar schuldgevoelens over het brandwondenongeval werd gevraagd. Elf jaar na het brandwondenongeval werden ouders opnieuw uitgenodigd om mee te werken en vulden zij een vragenlijst in over posttraumatische stress symptomen. In totaal namen 48 moeders deel aan alle drie de meetmomenten. Twee jaar na het brandwondenongeval gaf 27% van de moeders aan schuldgevoelens te ervaren over het brandwondenongeval van hun kind. Deze moeders hadden ongeveer 10 jaar later significant hogere posttraumatische stress scores. Vervolgens

onderzochten we de invloed van schuldgevoelens op het beloop van traumatische stress symptomen tussen I en II jaar na het brandwondenongeval. Het bleek dat de uitgebreidheid van het restletsel de relatie tussen schuldgevoelens en traumatische stress symptomen modereerde, dat wil zeggen dat schuldgevoel het beloop van stress symptomen significant beïnvloedde bij moeders van wie het kind uitgebreid restletsel had, maar niet bij moeders van wie het kind minder uitgebreid restletsel had. Schuldgevoelens werden in dit onderzoek 2 jaar na het brandwondenongeval gemeten en moeten daarom beschouwd worden als chronische schuldgevoelens. Maar de resultaten lieten duidelijk zien dat schuldgevoelens belangrijk zijn om te monitoren bij ouders en dat de littekens van het kind de impact van schuldgevoelens op posttraumatische stress reacties op lange termijn kunnen beïnvloeden.

In **Hoofdstuk 7** beschrijven we de evaluatie van Nederlandse vakantieweken voor kinderen (8-17 jaar) met brandwonden. Wereldwijd worden vakantieweken voor kinderen met brandwonden georganiseerd om kinderen met brandwonden te ondersteunen en hen in contact te brengen met andere kinderen met brandwonden. De inhoud van de programma's en de samenstelling van de leiding kunnen verschillen, maar er wordt verondersteld dat het gevoel van eigenwaarde van de deelnemers verbetert door deelname en dat deelnemers beter leren omgaan met brandwonden gerelateerde problemen. Eerder onderzoek naar de effecten van vakantieweken voor kinderen met brandwonden liet een hoge mate van tevredenheid van deelnemers zien, maar vond geen effecten op het gevoel van eigenwaarde. Wij voerden een studie uit met een voor- en nameting, met een vergelijkingsgroep, om mogelijke effecten van de vakantieweken te onderzoeken op het gevoel van eigenwaarde en de sociale impact en tevredenheid over het uiterlijk. Deelnemers van de vakantieweken in 2008 ($n = 83$) vulden voorafgaand, twee weken na en vier maanden na de vakantieweek vragenlijsten in. De vergelijkingsgroep bestond uit 90 kinderen die niet meegingen op een vakantieweek in 2008. Verder vulden deelnemers aan de vakantieweken en hun ouders een evaluatieformulier in over de sterke punten van de vakantieweken en wat zij hadden geleerd door mee te gaan op de vakantieweek.

Kinderen die mee waren geweest op een vakantieweek waren kort na de vakantieweek meer tevreden over hun uiterlijk; in de vergelijkingsgroep trad geen verandering op. Op lange termijn verschilde de tevredenheid over het uiterlijk niet significant van de tevredenheid over het uiterlijk voorafgaand aan de vakantieweek. Het gevoel van eigenwaarde en de sociale impact van de brandwonden veranderden niet gedurende de studieperiode; niet in de vakantiewekengroep en ook niet in de vergelijkingsgroep. Kwalitatieve gegevens lieten een hoge mate van tevredenheid over de

vakantieweken zien en deelnemers beschreven meerdere positieve aspecten van hun deelname. Veel kinderen, en hun ouders, waardeerden de vakantieweken om het feit dat ze er andere kinderen met brandwonden konden ontmoeten. Hierdoor konden zij van andere kinderen leren hoe zij met hun brandwonden omgaan en het maakte hen ervan bewust dat ze niet de enige zijn met brandwonden. Kinderen in de vergelijkingsgroep die nog nooit op een vakantieweek waren mee geweest gaven aan geen of slechts één ander kind met brandwonden te kennen. Een ander thema dat uit de kwalitatieve gegevens naar voren kwam, betrof het toegenomen vertrouwen in henzelf en in hun uiterlijk. Hoewel het effect dat uit de kwantitatieve gegevens naar voren kwam kleiner leek in vergelijking met de kwalitatieve gegevens, was dit een van de eerste studies die de vaak gerapporteerde positieve effecten van de vakantieweken kon kwantificeren. De resultaten suggereren dat lichaamsbeeld en vertrouwen in het uiterlijk geschikte uitkomstmaten kunnen zijn om de potentieel positieve effecten van vakantiewekendeelname te vangen.

DISCUSSIE

In de discussie werden vier centrale thema's besproken, met de klinische implicaties en aanwijzingen voor vervolgonderzoek, die uit dit proefschrift naar voren kwamen: de uitdaging om aanpassing na brandwonden op korte en lange termijn goed te onderzoeken, de grote impact van brandwondenongevallen op ouders, het belang van subsystemen binnen het gezin na een brandwondenongeval en een bio-ecologisch perspectief op het ondersteunen van kinderen na een brandwondenongeval.

In het eerste thema gaan we in op het belang van geschikte onderzoeksinstrumenten en onderzoeksdesigns om het psychisch herstel na een brandwondenongeval goed in kaart te brengen. Brandwondenongevallen vertonen in eerste instantie overeenkomsten met andere niet opzettelijke verwondingen, zoals het plotseling ontstaan van het ongeluk, de pijn en de acute opname in het ziekenhuis. Als we kijken naar psychische symptomen kort na het ongeval, met name acute en posttraumatische stress symptomen, lijken die inderdaad op symptomen die werden gevonden bij andere acute pediatrie populaties. Een zorgteam dat zich bewust is van de psychische impact van medisch traumatische gebeurtenissen, het ondersteunen van de draagkracht van gezinnen, het monitoren van behoeften en een adequaat pijnbeleid zijn belangrijk om het kind en gezin in deze fase goed te ondersteunen. Na deze eerste fase van het ongeval en de opname krijgen brandwonden door permanent fysiek letsel ook een meer chronisch karakter. Kinderen moeten bijvoorbeeld meerdere malen worden geopereerd en het leven met littekens kan ook de nodige aanpassingen vragen, bijvoorbeeld op het gebied van sociale interacties en op het gebied van zelfbeeld.

Onderzoek op de lange termijn laat zien dat kinderen met brandwonden zich over het algemeen goed aanpassen aan hun situatie. Voordat we concluderen dat brandwonden geen lange-termijn impact op kinderen hebben, is het belangrijk te benadrukken dat er nagenoeg geen studies zijn die kinderen over een langere termijn hebben gevolgd en dat de meeste onderzoeken gebruik maakten van vrij generieke concepten om ‘aanpassing na een brandwondenongeval’ te onderzoeken. Wij bevelen daarom aan om meer longitudinale studies op te zetten die meer specifieke, aan brandwonden gerelateerde, concepten in kaart brengen. Systematische monitoring van kinderen zou enerzijds kunnen bijdragen aan het vroegtijdig signaleren van problemen en anderzijds zeer waardevolle informatie op kunnen leveren over de ontwikkeling na het brandwondenongeval. Thema's die belangrijk zijn voor andere kinderen met uiterlijke afwijkingen kunnen inzicht geven en ook een aantal recente studies onder kinderen met brandwonden laat zien dat concepten rondom het uiterlijk en sociale interacties mogelijk beter aansluiten bij de specifieke uitdagingen waar kinderen met brandwonden mee te maken kunnen krijgen. Daarnaast suggereren de over het algemeen positieve lange-termijn uitkomsten dat veerkracht van kinderen na een brandwondenongeval een onderwerp is dat beter in kaart gebracht moet worden.

Ten tweede komt uit dit proefschrift duidelijk de grote impact van een brandwondenongeval op de ouders naar voren. Korte en langere tijd na het ongeval vertonen veel ouders posttraumatische stress symptomen. Bovenop de initiële impact kunnen zorgen over mogelijk toekomstige problemen van het kind een extra belasting vormen voor ouders. We zagen dat moeders over het algemeen meer posttraumatische stress symptomen hadden dan vaders, wat mogelijk zou kunnen komen door de verschillende betekenis die ouders toekennen aan het trauma. Zo waren schuldgevoelens, boosheid en de angst dat het kind het ongeval niet zou overleven – allemaal sterker aanwezig bij moeders – van invloed op posttraumatische stress symptomen bij ouders. Schuldgevoelens bleken op lange termijn met name van invloed op posttraumatische stress symptomen bij moeders als het kind uitgebreid restletsel overhield aan de brandwonden. Vervolgonderzoek zou verder in kunnen gaan op factoren die bijdragen aan de verschillen tussen ouders binnen de gezinscontext. In de klinische praktijk is psychosociale zorg beschikbaar voor kinderen en het gezin tijdens de opnameperiode. In de nazorgfase is deze zorg met name ingericht rondom de fysieke follow-up van de kinderen. Hoewel ouders van ernstiger verwonde kinderen, die waarschijnlijk vaker voor medische follow-up terugkomen, in onze studie meer psychische klachten rapporteerden, was dit niet de enige of meest belangrijke factor voor problemen van ouders. Op basis van onze resultaten strekt het tot de aanbeveling om ouders die kort na het ongeval veel stress reacties vertonen, sterke emoties over het brandwondenongeval hebben, of voor het leven van hun kind hebben gevreesd, systematisch te volgen. Recente internettoepassingen, ontwikkeld

voor diverse kinderziekenhuis populaties, zouden kunnen bijdragen aan het vormgeven van een breed nazorgprogramma voor kinderen met brandwonden en hun gezin. Tot slot verdienen schuldgevoelens van ouders bijzondere aandacht. Het erkennen en normaliseren van schuldgevoelens, mogelijk in oudergroepen, kunnen onderdeel zijn van preventieve interventies. We hopen dat de resultaten van dit proefschrift bijdragen aan bewustzijn over de ernst en impact van schuldgevoelens bij ouders en aanmoedigen om tijdig interventies in te zetten.

Een derde overkoepelend thema betrof het belang van verschillende subsystemen van het gezin na een brandwondenongeval. Vanuit een bio-ecologisch perspectief op de aanpassing na een brandwondenongeval zijn interacties tussen het kind en zijn omgeving van groot belang. Eerder onderzoek bij kinderen met brandwonden toonde consistent een relatie aan tussen de aanpassing van het kind enerzijds en gezinskenmerken en het welbevinden van de moeder anderzijds. In dit proefschrift gingen we nader in op twee verschillende subsystemen binnen het gezin, namelijk het ouder-kind en het moeder-vader subsysteem. Uit het prospectieve onderzoek naar gedragsproblemen van jonge kinderen bleken acute stress symptomen van zowel de moeder als van de vader van invloed op gedragsproblemen van het kind in het eerste jaar na het brandwondenongeval. Dit toont aan dat het belangrijk is om beide ouders te betrekken in de klinische praktijk en in vervolgstudies. Binnen ouderkoppels vonden we dat vermijdingssymptomen deels overlaptten tussen moeders en vaders. We kunnen speculeren dat deze dynamiek binnen ouderparen uiteindelijk ook zijn weerslag vindt op het bredere gezinssysteem. We betogen dat vervolgstudies in dit veld meerdere gezinsleden bij het onderzoek moeten betrekken, waaronder beide ouders, maar bijvoorbeeld ook broertjes en zusjes. Hoewel dit proefschrift liet zien dat er samenhang is binnen diverse subsystemen, blijft een belangrijke vraag welke mechanismen aan deze samenhang ten grondslag liggen. Meer kennis over wat zich precies binnen de gezinscontext afspeelt op het gebied van posttraumatische reacties, maar ook op het gebied van het belang van het uiterlijk, kan bijdragen aan meer inzicht in hoe gezinnen met zulke ingrijpende gebeurtenissen omgaan en hoe zij het best kunnen worden ondersteund na een brandwondenongeval.

Tot slot bespraken we een bio-ecologisch perspectief op het ondersteunen van kinderen na een brandwondenongeval. Dit perspectief hecht veel belang aan de omgeving van het kind. Het suggereert dat veerkracht niet alleen inhoudt dat het kind zich moet aanpassen aan moeilijke gebeurtenissen, maar ook dat een omgeving zich moet aanpassen aan de (nieuwe) behoeften van het kind. Hoewel we niet voorbij willen gaan aan de kracht van het unieke kind, richten we ons hier met name op de omgeving van het kind. Allereerst is het van belang om het gezin, de meest directe omgeving voor jonge opgroeiende kinderen, te ondersteunen. Ouders zijn ernstig getroffen na een brandwondenongeval van

hun kind en ons onderzoek liet onder andere zien dat acute stress symptomen van de ouder van invloed waren op gedragsproblemen bij het kind. Uit ander traumaonderzoek is bekend dat ouders die psychisch belast zijn bijvoorbeeld verminderd emotioneel beschikbaar zijn voor het kind en minder goed in staat zijn de symptomen van hun kind te herkennen. Andersom draagt bijvoorbeeld cohesie binnen het gezin bij aan een betere aanpassing na het brandwondenongeval. Belangrijke aspecten van zorg voor gezinnen na een brandwondenongeval zijn onder andere het reduceren van stressklachten van de ouder, het informeren van ouders over mogelijke reacties van kinderen na ingrijpende gebeurtenissen, het ondersteunen van het bestaande probleem-oplossende vermogen van gezinnen en het bevorderen van de kracht van het gezin op het gebied van cohesie en aanpassingsvermogen. Naarmate kinderen ouder worden, wordt hun leefomgeving groter en nemen leeftijdgenoten een steeds belangrijkere rol in. Ook op dit omgevingsniveau van het kind zijn meerdere interventiemogelijkheden. De sociale steun van vrienden of klasgenoten is nog niet uitgebreid onderzocht, maar blijkt uit breder traumaonderzoek erg waardevol te kunnen zijn voor kinderen. Daarnaast worden in Nederland terug-naar-school projecten georganiseerd, waarvan in de internationale literatuur ook positieve effecten worden vermeld. Een bijzondere vorm van sociale steun van leeftijdgenoten betreft de speciale vakantieweken voor kinderen met brandwonden. Wereldwijd en ook in Nederland worden deze vakantieweken en het kunnen ontmoeten van andere kinderen met brandwonden zeer gewaardeerd. Wij denken dat de kracht van het lotgenotencontact ook breder ingezet zou kunnen worden, bijvoorbeeld in groepscursussen over het omgaan met gevolgen van het hebben van brandwonden.

CONCLUSIE

In dit proefschrift onderzochten we psychische gevolgen van brandwondenongevallen bij kinderen en ouders, samenhangen binnen het gezin (ouder-kind en moeder-vader subsysteem) en de mogelijke effecten van het meegaan op een vakantieweek. Ons literatuuronderzoek liet zien dat veel kinderen last hebben van acute stress symptomen of verstoord gedrag tijdens de opname in het brandwondencentrum. Op de lange termijn suggereert het beschikbare onderzoek dat de meeste kinderen zich goed aan hun situatie aanpassen. Doordat deze studies vaak cross-sectioneel van aard waren en generieke onderzoeksinstrumenten gebruikten, is de kennis over mogelijke problemen en uitdagingen die kinderen in de loop van hun leven tegenkomen beperkt. Mogelijk belangrijke onderwerpen om mee te nemen in toekomstig longitudinaal onderzoek zijn de beleving van het uiterlijk en ervaringen van kinderen in het sociale domein.

In onze prospectieve onderzoeken vonden we dat een aanzienlijk gedeelte van de ouders posttraumatische stress reacties vertoonde na het brandwondenongeval van hun kind, waarbij moeders over het algemeen meer symptomen rapporteerden dan vaders. Anderhalf jaar na het ongeval had in één op de vijf gezinnen nog altijd minimaal één ouder last van klinisch significante symptomen. De gedachte dat het kind het ongeval niet zou overleven en schuldgevoelens en boosheid over het brandwondenongeval, alleen meestal sterker aanwezig bij moeders dan bij vaders, kunnen belangrijke factoren zijn om ouders die risico lopen op lange termijn stressklachten vroegtijdig te signaleren. Daarbij bleek de mate van littekens van invloed te zijn op de relatie tussen schuldgevoelens en stressklachten van de moeder vele jaren later. De samenhang in vermijdingssymptomen binnen ouderparen en de samenhang tussen symptomen van ouders en het kind benadrukken het belang van een brede gezinsfocus in de brandwondenzorg.

Tot slot presenteren we een bio-ecologisch perspectief op het ondersteunen van kinderen na een brandwondenongeval. Het ondersteunen van ouders, waarbij speciaal gelet moet worden op de wisselwerking tussen ouders, en het versterken van bestaande vaardigheden en bronnen van gezinnen worden aanbevolen als essentiële onderdelen van ondersteuning na brandwonden. Daarnaast lijken de effecten van lotgenotencontact veelbelovend. Dit zou bijvoorbeeld vertaald kunnen worden naar groepsinterventies voor kinderen met brandwonden. Hoewel vele psychosociale onderwerpen in dit veld nog onderzoek behoeven en dit proefschrift ook vragen voor vervolgonderzoek oproept, hopen we dat dit proefschrift ook bij kan dragen om een veelomvattend nazorgprogramma voor kinderen met brandwonden en hun gezin verder te ontwikkelen.

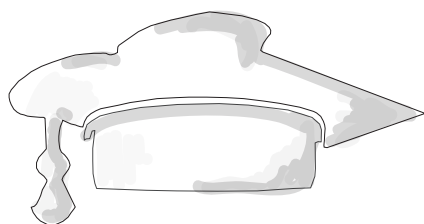
Dankwoord (Acknowledgements)

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Curriculum Vitae



Anne was born on May 10th 1981 in Muiderberg, The Netherlands, where she grew up with her parents and two brothers. After graduation (VWO) at Goois Lyceum in 1999, Anne studied Educational Sciences at the University of Amsterdam and graduated in 2005. After her studies, Anne worked as a research assistant at the psychosocial department of the Emma's Children Hospital (Academic Medical Center Amsterdam) on a research project on patient reported outcomes in pediatric oncology practice, supervised by doctors Engelen, Detmar, Koopman, and professor Grootenhuis. In 2007, Anne started as a PhD student at the Association of Dutch Burn Centres/ Utrecht University under supervision of doctor van Loey, professor van Son, and professor van der Heijden. The results of this research on the psychological consequences of pediatric burns on children and parents are presented in this thesis. Anne presented the study results successfully at various national and international congresses and meetings. In the fall of 2011, Anne visited and collaborated with the Center for Injury Research and Prevention at the Children's Hospital of Philadelphia, USA under supervision of doctor Marsac and professor Kassam-Adams. Since May 2013, she works as a post-doctoral researcher at the psychotrauma group of professor Olff (AMC, psychiatry department) on resilience and effectiveness of online selfhelp and prevention after trauma. In 2012, Anne and her husband Tom became parents of daughter Maren Annelies, making me not only a proud father, but also a proud grandfather.

Anne werd op 10 mei 1981 geboren in Muiderberg, waar zij opgroeide met haar ouders en twee broers. Na het eindexamen VWO op het Goois Lyceum te Bussum, studeerde Anne Pedagogische Wetenschappen aan de Universiteit van Amsterdam en behaalde in 2005 haar bul. Na haar studie werkte Anne als onderzoeksassistent op de psychosociale afdeling van het Emma Kinderziekenhuis (Academisch Medisch Centrum Amsterdam) op een onderzoeksproject over 'patient reported outcomes' in de kinderoncologische praktijk, onder supervisie van doctors Engelen, Detmar, Koopman en professor Grootenhuis. In 2007 begon Anne aan haar promotieproject bij de Vereniging Samenwerkende Brandwonden-centra Nederland/ Universiteit van Utrecht, onder supervisie van doctor van Loey, professor van Son en professor van der Heijden. De resultaten van dit onderzoek naar de psychische gevolgen van brandwondenongevallen bij kinderen en ouders staan in dit proefschrift. Anne presenteerde met succes de resultaten van het onderzoek op diverse nationale en internationale congressen en bijeenkomsten. In de herfst van 2011 bezocht Anne 'the Center for Injury Research and Prevention' van the Children's Hospital of Philadelphia, USA (doctor Marsac en professor Kassam-Adams). Sinds mei 2013 werkt Anne als postdoc bij de psychotrauma groep van professor Olff (AMC, psychiatrie) op een onderzoeksproject naar veerkracht en effectiviteit van zelfhulp en preventie na trauma. In 2012 werden Anne en haar man Tom de ouders van dochter Maren Annelies. Dat maakt mij niet alleen een trotse vader, maar ook een trotse opa.

Jan Bakker

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AWARDS AND NOMINATIONS

Nominated for Best Abstract at the 2011 European Burns Association Congress for the abstract Bakker, van Son, van der Heijden, & van Loey. Child traumatic stress reactions in the acute aftermath of a pediatric burn event: preliminary findings on agreement between child, mother, and father report.

Nominated for Kreisprijs (2011; annual award for burn research in the Netherlands) for the poster presentation held at the 2011 International Society for Traumatic Stress Studies in Baltimore, USA: Bakker, van Loey, van der Heijden, & van Son, Multilevel regression analysis on (in)dependence in intrusion and avoidance symptoms within parent-couples after a burn event of their child.

Research Award for Best New Published study in Camp Setting 2011 by the Association of Camp Nurses for the article Bakker, van der Heijden, van Son, van de Schoot, & van Loey, (2011). Impact of pediatric burn camps on participants' self esteem and body image: an empirical study.

Presentation Award Professionals Allied to Medicine at the 2009 European Burns Association Congress for the presentation Bakker, van Son, van der Heijden, & van Loey. Mothers' long-term posttraumatic stress symptoms following a burn accident of their child.

Presentation Award at the 2009 Dutch Meeting for Pediatric Psychology for the presentation Bakker, van Son, van der Heijden, & van Loey, Mothers' long-term posttraumatic stress symptoms following a burn accident of their child.

