



Perceived support in parents of children with burns



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ABSTRACT

Objective: Children sustaining burns that require treatment in a burn center have a need for multiprofessional aftercare services over a prolonged time. So far, there is little research into satisfaction with care and support after pediatric burns. The aim was to investigate parents' perception of support after pediatric burn and associations with parent, child and injury characteristics.

Method: Parents ($n=101$) of children aged 0.4–17.8 years completed questionnaires on support, parent's psychological symptoms and health of the child. Time since injury was 0.1–9.0 years.

Results: Perceived lack of psychosocial, medical, societal or family support was reported by 21% of the parents. Lack of support was not associated with injury or sociodemographic characteristics, but it was significantly associated with parents' symptoms of general anxiety, depression and injury-related fear avoidance, as well as parents' ratings of their child's general health and heat sensitivity.

Conclusion: Perceived support did not differ on account of burn severity or sociodemographic status. However, care providers should be more attentive to and supportive of parents signaling poorer general health in their child and cognitive beliefs that the child is at risk for harm when active and parents who themselves show signs of psychological symptoms.

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1. Introduction

A pediatric burn can be a traumatic event for the entire family. Parents of children with burns go through a range of difficult situations such as witnessing the accident and painful medical procedures, early hospital discharge and having difficulties caring for the burn at home, dealing with social consequences, affected family relations and alterations in everyday life [1,2]. Parents also experience a range of psychological difficulties. Already in 1973, it was discussed that families of burn victims experience three common responses to the stress: indecisiveness, intensification of preexisting conflicts and guilt [3]. Since then, studies have found many parents of children with burns to have an acute stress reaction, as well as later psychological symptoms of general stress, anxiety, depression and guilt [4–8].

In studies of posttraumatic stress disorder (PTSD), 72% of the parents have some symptoms in the acute stage [9], 47% have symptoms at 3 months postburn [10] and 14–42% have symptoms of PTSD up to 5 years after the burn [11]. Between 9% and 19% of parents fulfill diagnostic criteria for PTSD during the first months after injury [11] and about 16% of the parents still have PTSD up to 7 years later [9].

Symptoms of depression occur in 19–44% of the parents during the first months and 31–54% have symptoms of depression up to 5 years after the burn, while 0–36% fulfill diagnostic criteria for depression

0–5 years postburn [11]. Altogether, a burn is a taxing event for the whole family and a sizable proportion of the parents describe having psychological symptoms of PTSD, anxiety and depression for an extended time period after the burn.

Rehabilitation after pediatric burns is a prolonged process that begins in specialist care and continues in rehabilitation centers, local general hospitals, primary care facilities and in the patients' homes. It is multiprofessional and usually requires the services of plastic or burn surgeons, specialists in intensive care and anesthesia, occupational therapists, physiotherapists, nurses and social workers. In addition, there may be need for specialists in pain management, infection and psychiatry, as well as psychologists, dietitians, play or music therapists and/or psychotherapists. The present study took place in Sweden where the incidence of burns is comparatively low [12]. Due to long distances, most patients have to travel far to get to the Burn Center, and therefore, local general hospitals and care facilities are mostly responsible for the rehabilitation and psychosocial services. Also, parents are encouraged to take an active part in the care at the Burn Center, as well as during rehabilitation in order to manage the daily treatment in the home after discharge. Evaluation of burn rehabilitation in Sweden is challenging as there are many actors involved, as well as many individual and local solutions for aftercare support. A first step to evaluation of burn care and rehabilitation is therefore to investigate whether parents perceive any lack of support during their child's recovery.

Recent qualitative studies indicate that parents perceive a need for support [1,2]; however, little is known regarding what type of support to provide or the factors that indicate which and how many parents perceive

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a need for support. The aims of this cross-sectional study were therefore to investigate the rate and type of perceived lack of support after discharge from in-hospital care and to explore associations with burn severity, sociodemographic factors and parents' ratings of the children's health, injury-related fear avoidance and their own psychological symptoms.

2. Material and methods

2.1. Participants and procedure

The Uppsala Burn Center and the Linköping Burn Center are the two main Swedish burn centers with nationwide responsibility for treating patients with severe burns. Admission criteria are based on the recommendations of the American Burn Association. At the time of the study, the catchment area for the two centers included approximately 6.3 million inhabitants (approximately 70% of the Swedish population). The sample for this study comprised consecutively admitted patients at the two Burn Centers between January 2000 and December 2008. Inclusion criteria were (1) age of the burn injured child <18 years at the time of the investigation and (2) sufficient ability to understand Swedish. A total of 220 children fulfilled the criteria, of which 206 families had an obtainable address. The families received study information, a questionnaire booklet and a prepaid response envelope by regular mail. The questionnaire covered the child's postburn health that has been reported earlier [13,14], as well psychological symptoms of the parents and perceived lack of support. Nonresponders received reminders after 3 weeks. Responders received a lottery ticket worth 2.5 Euros. The study was approved by the Regional Ethics Review Board in Uppsala.

2.2. Measures

2.2.1. Perceived lack of support

Lack of support was measured with one question: did you or your child perceive a lack of support of any kind? If yes, please specify.

2.2.2. Parents' psychological symptoms, life events and beliefs

The *Impact of Event Scale-Revised* (IES-R) [15] was used to assess symptoms of PTSD among the parents. The Swedish version of the IES-R covers three symptom domains (Intrusion, Avoidance and Hyperarousal) and has shown excellent psychometric properties in studies after burns [16]. A total score of 40 and above indicates clinical levels of symptoms [17]. *Hospital Anxiety and Depression Scale* (HADS) [18] was used to assess symptoms of general anxiety and depression among the parents. The HADS consists of two subscales, Anxiety and Depression, and the recommended cutoff for possible caseness is ≥ 8 points for each subscale [18,19]. The *List of Threatening Experiences-Questionnaire* (LTE-Q) was administered to assess the number of stressful experiences during the parents' lifetime. The LTE-Q covers illnesses, accidents, losses, interpersonal problems, unemployment, financial crises and legal problems [20]. *Injury-specific fear avoidance* was assessed by four items: (1) the burn injury has put my child's body at risk for the rest of his/her life, (2) my child can't do the same things other people do since there is too great a risk that he/she will get burned again, (3) I'm afraid my child might get hurt again if he/she puts him- or herself in risky situations and (4) it is really not safe for my child to be physically active. Development and use of this scale has been described earlier [13,21].

2.2.3. Children's health and comorbidity

The Swedish adaptations of the *Burn Outcomes Questionnaire* (BOQ) 0–4 [22] and 5–18 [13,23] were used to assess parent-rated general health of the child, current itching, pain, concerns about appearance and comorbidity. Comorbidity assessment included a range of specified preexisting medical, developmental and psychological problems that parents rated as 1=present and 0=not present. Responses were subsequently categorized as any comorbidity, including all conditions, and the more specific psychological comorbidity. *Heat sensitivity* was

assessed with the corresponding subscale from the *Burn Specific Health Scale-Brief* (BSHS-B) consisting of five items measuring difficulties being outside in hot or sunny weather and skin sensitivity [24]. The Swedish version of the *Strengths and Difficulties Questionnaire* (SDQ) was used to assess the parents' perception of psychological health in their children [25]. The total difficulties score represents the sum of four subscales: Emotional symptoms, Conduct problems, Hyperactivity/inattention and Peer relationship problems. Higher scores on the BOQ and the BSHS-B indicate a better perceived health, whereas higher scores on the SDQ indicate more perceived problems.

2.2.4. Injury characteristics

Data regarding length of stay (LOS) as inpatients at the burn center, total body surface area burned (TBSA burned) and TBSA with full-thickness burns (TBSA-FT) were obtained from medical records. Parents were asked to report the presence of scars and visible scars (on hands, face or neck) at the time of the investigation (1=present and 0=not present).

2.2.5. Sociodemographic data

Age and gender of the child were obtained from medical records. The following parent characteristics were obtained in the questionnaire: gender; marital status (0=single/widowed, 1=married/cohabiting); education level divided into low (9 years compulsory school), medium (high school degree/upper secondary school) and high (university degree); and working status (0=unemployed, on sick-leave, 1=working or studying).

2.3. Statistical analyses

All analyses were performed with the statistical package IBM SPSS statistical package version 21. Values for TBSA, TBSA-FT and LOS were transformed (Log10) before analyses due to skewed distributions. The chi-square test, Fisher's Exact Test, Student's *t* test and logistic regression (enter model) were used in analyses.

3. Results

3.1. Sample characteristics

Response rate was 51% as 106 parents responded to the questionnaire. The responders did not differ from the nonresponders regarding the available background data, i.e. children's gender, age at injury, time since injury, TBSA burned, TBSA-FT or LOS.

On a total of 94 questionnaires, the responders had indicated their relationship with the child; 69 were mothers, and 20 were fathers (one mother and one father were stepparents). Another 5 couples had filled in the questionnaire jointly and were not included in gender-based analyses. As all responders had a parental role toward the children, the responders will be referred to as "parents". Of the respondents, 87% were married or cohabiting, 41% had a university education and 89% were working or studying.

3.2. Child and injury characteristics

A total of 66 children were boys and 40 were girls. A total of 71 injuries were scalds, 13 were flame burns, 8 were contact burns, 3 were due to electricity, 1 was an explosion and the remaining 10 had no registered cause. A total of 48 children had full-thickness burns according to medical records, and 57 children had some current scarring according to the parents' reports. For further child- and injury-specific data, see Table 1.

3.3. Psychological symptoms

Overall, the parents had low to moderate symptoms of PTSD, general anxiety and depression (Table 1). However, 20% of the parents exceeded the cutoff score for symptoms of PTSD, 25% exceeded the

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