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# Internet-based information and support program for parents of children with burns: A randomized controlled trial

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## ABSTRACT

**Background:** The aim of the study was to evaluate the feasibility and effects of an internet-based information and self-help program with therapist contact for parents of children and adolescents with burns. The program aimed to reduce parents' symptoms of general and posttraumatic stress.

**Methods:** Participants were parents of children treated for burns between 2009–2013 at either of the two specialized Swedish Burn centers. Sixty-two parents were included in a two-armed, randomized controlled trial with a six-week intervention group and a wait-list control group, including a pre and post-assessment, as well as a 3 and 12-month follow-up. The intervention contained psychoeducation, exercises and homework assignments, and the intervention group received weekly written feedback from a therapist. The main outcome was stress (post-traumatic stress, general stress and parental stress).

**Results:** The program had a beneficial effect on posttraumatic stress in the short term, but did not affect general stress or parental stress. The parents rated the program as being informative and meaningful, but some of them thought it was time-consuming.

**Conclusion:** The program has the potential to support parents of children with burns. The intervention is easily accessible, cost-effective and could be implemented in burn care rehabilitation.

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## 1. Introduction

In Europe, half of all in-hospital admissions for burn are children under the age of 16 [1]. In Sweden, young children up

to four years of age constitute almost 30% of all burn victims and the most common cause is scalds [2]. A burn is one of the most painful and traumatic injuries a child can experience and it is also a very distressing event for the parents. A child's burn can have a major impact on the whole family, such as

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alterations in everyday life and affected family relationships. Parents also worry about the child's remaining physical problems and changes in appearance [3,4].

Posttraumatic stress disorder (PTSD) is characterized by recurrent re-experiencing of the traumatic event, persistent avoidance of trauma-related stimuli, negative changes in cognitions and emotions, and persistent symptoms of hyperarousal. Posttraumatic stress (PTS) is a common reaction in injured children and their parents [5,6]. Previous studies have shown that 10-20% of children and between 14 and 42% of parents have symptoms of posttraumatic stress [6]. One study found that 16% of the parents fulfilled the criteria for (PTSD) up to 7 years post-burn [7]. Symptoms of depression are also common in parents after a child is burned and 31-54% have symptoms of depression up to five years after the burn [6].

There is growing evidence that the parents' mental health is important for the child's health [8,9]. One study found that PTSD symptoms in mothers were linked to stress reactions in children after a burn, and that parenting stress and family functioning were associated with the child's adjustment, whereas burn severity was not [6]. Moreover, poor family functioning has been shown to affect the child's health negatively [10,11]. Hence, after a pediatric burn, it is important to support the parents as well as the children.

A recent study has shown that up to 20% of parents of children with burns perceive a lack of psychological, medical, social or other support during the acute phase and during rehabilitation [12]. Perceived support might be improved by providing information and educative self-help recommendations about both the psychological and physiological aspects of burns. One study evaluating an internet-based psychoeducational program targeting posttraumatic stress for parents of children with a physical injury found that the program increased knowledge; however, it did not reduce PTS symptoms [13]. To date, no internet-based psychoeducational or support program has been evaluated for parents of children with burns.

It has been recommended that self-help interventions should be based on Cognitive Behavior Therapy (CBT) principles rather than being purely educational [14]. Hence, the program in this study is based on CBT as well as Acceptance and Commitment Therapy principles [15].

The aim of this study was to evaluate the feasibility and the effects of an online information and self-help program with minimal therapist contact for parents of children and adolescents who had been hospitalized for burn. A hypothesis was that parents in the intervention group would report decreased levels of stress, particularly symptoms of posttraumatic stress.

## 2. Methods

This study was undertaken as a randomized controlled trial comparing an intervention group and a wait-list control group (controls were inactive during the intervention and offered the program after the first follow-up at three months). The study was conducted on a secure internet platform at Uppsala University Hospital and was approved by the Regional Ethics

Review Board in Uppsala (Dnr: 2013/148). The study protocol has been published [16].

### 2.1. Participants and procedures

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. The sample for this cross-sectional study comprised all consecutively admitted children at the two burn centers between January 2009 and December 2013. The wide time range of inclusion is reasonable, as parents may suffer from symptoms of PTS several years after a burn [6]. Inclusion criteria for the parents were: (1) age of their child <18 years at time of study; (2) not being treated for burn at the same time as the child; (3) the burn of the child was not intentional and there was no indication of abuse or neglect of the child as a cause of burn, and (4) ability to understand and respond in Swedish. Parents of 215 children fulfilled the inclusion criteria.

The families first received an information letter describing the study, a consent form and a prepaid envelope. After about one week, the families were contacted by telephone and asked for consent by one of the investigators (JS), unless they had already returned the form. Of the 215 eligible families, 30 families declined and 115 could not be contacted by telephone (unknown telephone number or no answer); thus, in total, 70 families including 104 parents (1 step-parent) consented to participate in the study.

The parents were randomized to either the intervention group or the control group by one of the researchers, using a computer-generated list. The parents were stratified by the child's total body surface area full-thickness burns (TBSA-FT) and time since injury, as parents of children with more severe burns and/or more recent burns may have more symptoms of stress, which may in turn affect the results. In cases where both parents of a child were participating, they were assigned to the same group. Fig. 1 provides information on participants' flow. One hundred and four parents were randomized to either the intervention or control group. Of these, 31 (60%) in each group completed the baseline assessment; thus, 62 parents total were included in the trial.

Assessments were conducted via a secure website for both groups at pre-assessment/baseline (T0), post-assessment (i.e., six weeks after randomization, T1), and at three (T2) and 12 months (T3) after the intervention (i.e., 4.5 and 13.5 months after randomization). The primary outcomes were assessed at all four time-points. Sociodemographic and burn-related variables were assessed at baseline and the remaining secondary measures were assessed at baseline and at the 3 and 12-month follow-ups.

### 2.2. Intervention

The program consisted of six modules, one module per week, and was accessed via a secure website. Modules included information about burns and rehabilitation, common psychological reactions after trauma, general information about stress and sleep, and family communication (Table 1). The modules also included instructions for selected techniques

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