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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.

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

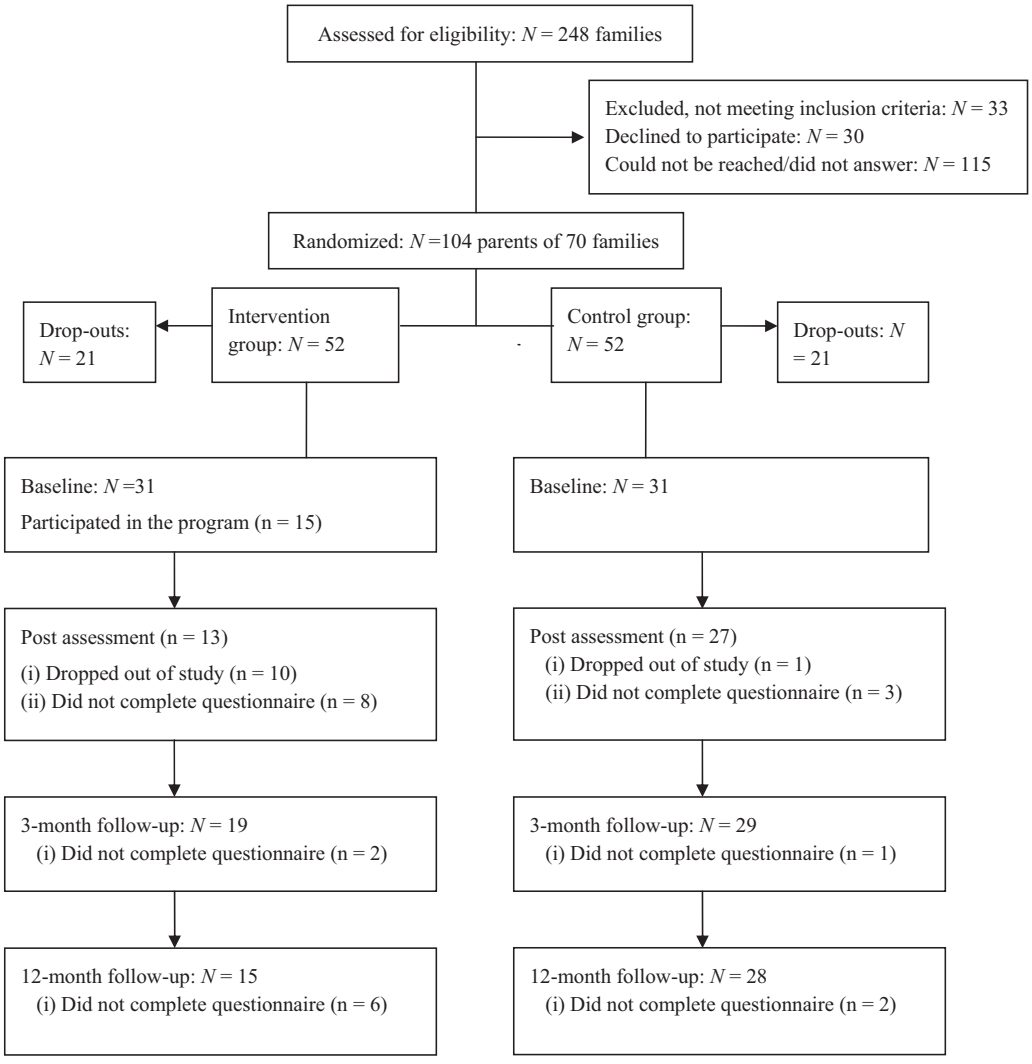

Fig. 1 – Participant flow diagram and passage of events during the study.

such as validation, visualization, mindfulness, metaphor and acceptance strategies, exposure training, and progressive relaxation. The participants also received a homework assignment each week based on these techniques. After each module, participants received written feedback on the assignments from a therapist (i.e., a psychologist or psychotherapist) via the platform. For a more detailed overview of the content, see the published study protocol [16].

2.3. *Outcome measures*

2.3.1. *Primary outcome (stress)*

The Impact of Event Scale-Revised (IES-R) [17] was used to measure posttraumatic stress. It contains 22 items divided into three subscales: Intrusion, Avoidance and Hyperarousal. The items are rated on a 4-point Likert-type scale as in the original IES: 0, 1, 3, and 5, where 0 equals no symptom and 5 equals a high frequency of the symptom; total scores range from 0 to 110. The Swedish version has shown excellent psychometric properties in previous studies after burns [18,19] and performs well as a screening measure for PTSD. The recommended cut-off score of 40 or above indicates clinical levels of PTSD symptoms (discriminant ability=0.89) [18]. In the present study, internal consistency was good to excellent (range over time Cronbach's alpha=0.84–0.94).

The short form Parenting Stress Index (PSI-SF) contains 30 items from the Parenting Stress Index [20]. The PSI-SF was used to assess child and parent stress; the items are rated on a 5-point Likert-type scale (1=strongly disagree, 5=strongly agree). Internal consistency in the present study was excellent (range over time Cronbach's alpha=0.91–0.96).

The Perceived Stress Scale (PSS) [21] was used to assess general perceived stress among the parents. The PSS includes 14 items rated on a 5-point Likert-type scale (0=never, 4=very often; half of the questions have reversed scoring) and the total score ranges from 0 to 56. In the present study, internal consistency was good to excellent (range over time Cronbach's alpha=0.84–0.90).

2.3.2. *Secondary measures*

2.3.2.1. Sociodemographic and burn-related variables. Data regarding the in-hospital treatment, injury, gender and age of the child were obtained from medical records.

Table 1 – Overview of the intervention's content, reproduced from Sveen et al. [16].

	Module 1	Module 2	Module 3	Module 4	Module 5	Module 6
Content	Burn, burn care and rehabilitation Parents' role in rehabilitation Demonstration of distraction techniques to use during painful procedures	Trauma and stress reactions in children and adults Learning theory and exposure techniques	Coping with the consequences of burn, overprotection, worries, guilt, and rumination Cognitive restructuring and decentering	Daily stress Avoidant behavior Sleep and sleep hygiene	Changes for the family, siblings and partners after the burn Communication skills including active listening	Summary of the five modules
Weekly skills	Validation skills Demonstrations of validation	Mindfulness and its use during exposure	Identifying thought patterns Acceptance Metaphor-exercises	Relaxation and progressive muscle relaxation	Parts of motivational interviewing (MI) as motivation tool and approach Demonstrations of MI	Motivation with the help of life values Introduction to the life compass
Weekly assignments	Describe the burn accident and the thoughts, feelings and emotions during the event Practice validation and report progress in diary	Practice mindfulness and report progress in diary Talk with the child (if old enough) about the burn	Identifying and reflecting on: being overprotective, having guilt feelings, and thinking traps Practice mindfulness and report progress in diary	Practice progressive muscle relaxation and report progress in diary.	Practice MI-skills and report progress in diary Reminded to practice previously taught skills	Life compass exercise

2.3.2.2. *Parent's health*. The Montgomery-Åsberg Depression Rating Scale (MADRS) [22] was used to measure symptoms of depression and includes 9 items. Scores of 12 or below indicate no depression or low symptoms of depression. Injury-related fear-avoidance was assessed with 4 items, with higher scores indicating a higher degree of fear-avoidance [23,24], and parental guilt and embitterment was assessed with 4 questions developed by the authors (JS, MW) and inspired by Guilt Scale [25], Structured Clinical Interview for DSM-IV Axis I Disorders [26] and previous burn literature. The short form Family Environment Scale (FES-SF) contains eight items from the Family Environment Scale [27]. It was used to measure family function with a focus on family conflict, with higher scores indicating more family conflicts.

2.3.2.3. *Child's health as perceived by the parent*. Psychological health was assessed with the Strengths and Difficulties Questionnaire (SDQ) [28], containing 25 items including emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems and prosocial behavior. The total difficulties score was used in the present study and a score of 14 and above indicates caseness. The short form Child Stress Reaction Checklist (CSRC-SF) [29], 9 items, measures PTS reactions.

2.3.2.4. *Research participation*. To assess parents' view of research participation, the Reaction to Research Participation Questionnaire-Parent version (RRPQ-P) [30] was used at the 12-month follow-up (T3). It contains 12 items divided into four subscales: positive appraisal of participating, negative appraisal, assessment of informed consent and trust in the research team, and the right of participants. The responses 'agree' and 'strongly agree' were considered affirmative responses to the items and were merged for the analysis rendering a dichotomous, ordinal scale (0, 1).

The selected items from the original PSI, FES and CSRC included in the present study (PSI-SF, FES-SF, CSRC-SF) constitute the *Short-form psychosocial questionnaire* developed by Murphy et al. [31] to evaluate psychosocial functioning in children following burns.

2.3.3. *Feasibility of the program (intervention group)*

2.3.3.1. *Participant evaluation*. The intervention group received an evaluation form after each module and one form for the entire program after the six weeks, as well as a brief evaluation at the 3 and 12-month follow-ups. The form assessed whether the participant found the modules/program: informative, upsetting, meaningful, neutral, understandable, boring, and supportive; and whether participation made the situation better or worse. The items were rated on a scale of 0=No, not at all to 4=Yes, to a high degree.

2.3.3.2. *Participant adherence*. The number of homework assignments was logged, and participants were asked at post-intervention how many hours a week they spent working with the text and the homework assignments.

2.3.4. *Statistical analysis*

Data analysis was performed using the SPSS version 21.0. Demographic, burn-related and baseline data were compared in t-tests and Chi-square tests, and significance was accepted at $p<0.05$. Fisher's exact test was used when the expected count of one or more cells was less than five. All primary outcome analyses were done on an intent-to-treat basis, i.e., including treatment dropouts. As few individuals completed

the intervention program, completer analysis was not possible. To examine the program effects on the primary outcome variables Generalized Estimating Equations (GEE) were used. With the PSS as the outcome variable, GEE with linear scale response and autoregressive (first order) correlation matrix were used, and with the IES-R and PSI as outcome variables, which were not normally distributed, GEE using negative binomial with log link counts and autoregressive (first order) correlation matrix were conducted. Intervention group, measurement time point and the interaction of group and measurement time point were chosen as factors/covariates. GEE uses all available observations instead of using only participants with complete data for all time points. To examine the program effects on the secondary outcomes, between-group differences were analyzed with t-test and significance accepted at $p<0.05$. No adjustment for multiple comparisons were made.

3. Results

Participants included in the study were 62 parents (42 mothers and 20 fathers, 13 of whom were parents of the same child). Demographic variables of the parents and children as well as burn characteristics of the children are presented in Table 2. In general, the majority of parents were married/cohabitating, working/studying, and almost half had a university degree. In the majority of children, the cause of burn was scalding. There were no differences between the intervention and the control group on demographic and burn-related variables.

Descriptive data for the primary and secondary outcomes for each measurement time point are shown in Tables 3 and 4. There were no baseline differences between the intervention group and the control group. Parents reported low symptom levels on posttraumatic stress (IES-R) and depression (MADRS), and they had low fear avoidance. Children's mental health problems (SDQ) and posttraumatic stress (CSRC-SF) as reported by the parents were low.

3.1. *The effect of the program on primary outcomes*

Group comparisons over time regarding IES-R revealed a significant interaction effect (Fig. 2a). The intervention group had lower scores at T2 compared to the control group, $\beta=-11.5$ (SE=3.88), $p=0.003$, and at T3, $\beta=-7.89$ (SE=3.38), $p=0.020$, but there was no significant difference at baseline or at T4. There were no significant effects regarding PSS (Fig. 2b) or PSI-SF (Fig. 2c).

3.2. *Secondary outcomes*

There were no effects of the program on any of the secondary outcome variables: MADRS, fear-avoidance, guilt, SDQ, or FES.

3.3. *Feasibility of the program*

Of the participants who filled in the evaluation form at the end of the program (n=11), all answered that it was informative (n=11/11) and comprehensible (n=11/11). The majority

Table 2 – Characteristics of the parents and children.

	Intervention (n)	Control (n)
Parent characteristics	n=31 parents	n=31 parents
No. of mothers/fathers	22/9	20/11
Age in years, mean (SD)	36.4 (6.6)	38.3 (5.5)
Level of education		
Elementary school	2	1
High school	12	17
University	16	13
Married or partner	30	27
Employment or student	28	30
Parental leave	1	1
Unemployed	2	–
Children characteristics	n=26 children	n=23 children
No. of girls/boys	13/13	9/14
Age in years, mean (SD)	5.30 (3.5)	6.36 (3.8)
Age at injury, mean (SD)	2.43 (2.9)	3.53 (3.8)
Time since injury, mean (SD)	2.87 (1.4)	2.84 (1.4)
Cause of injury		
Scalds	19	18
Fire	1	1
Contact burns	6	1
Other (electrical, chemical)	–	3
TBSA mean (SD)	8.54 (7.0)	9.88 (7.0)
TBSA-FT mean (SD)	1.81 (4.4)	2.47 (4.3)
Length of stay in hospital, days	7.0 (8.3)	7.5 (6.7)

Note: TBSA: Percentage Total Body surface area burned; TBSA-FT: Percentage Total Body surface area full-thickness burned. There were no significant differences between the intervention and control group on any variables displayed in the table.

Table 3 – Mean scores and standard deviations (SD) for primary outcomes at the four time-points.

	Intervention		Control	
	Mean	SD	Mean	SD
IES-R				
Pre-assessment	13.7	11.8	15.5	17.1
Post-assessment	10.6	9.4	20.0	19.4
3-month follow-up	9.6	9.3	16.3	18.1
12-month follow-up	12.3	11.7	12.2	15.6
PSS				
Pre-assessment	18.9	7.4	22.0	7.9
Post-assessment	23.3	7.3	22.9	9.0
3-month follow-up	18.2	6.9	19.3	9.0
12-month follow-up	20.5	8.3	19.7	10.0
PSI-SF				
Pre-assessment	47.5	12.9	52.9	14.9
Post-assessment	50.7	10.6	51.1	20.6
3-month follow-up	49.1	20.8	48.7	17.8
12-month follow-up	44.9	11.0	48.9	20.5

Note: IES-R: Impact of Event Scale-Revised; PSS: Perceived Stress Scale; PSI-SF: Parenting Stress Index short form.

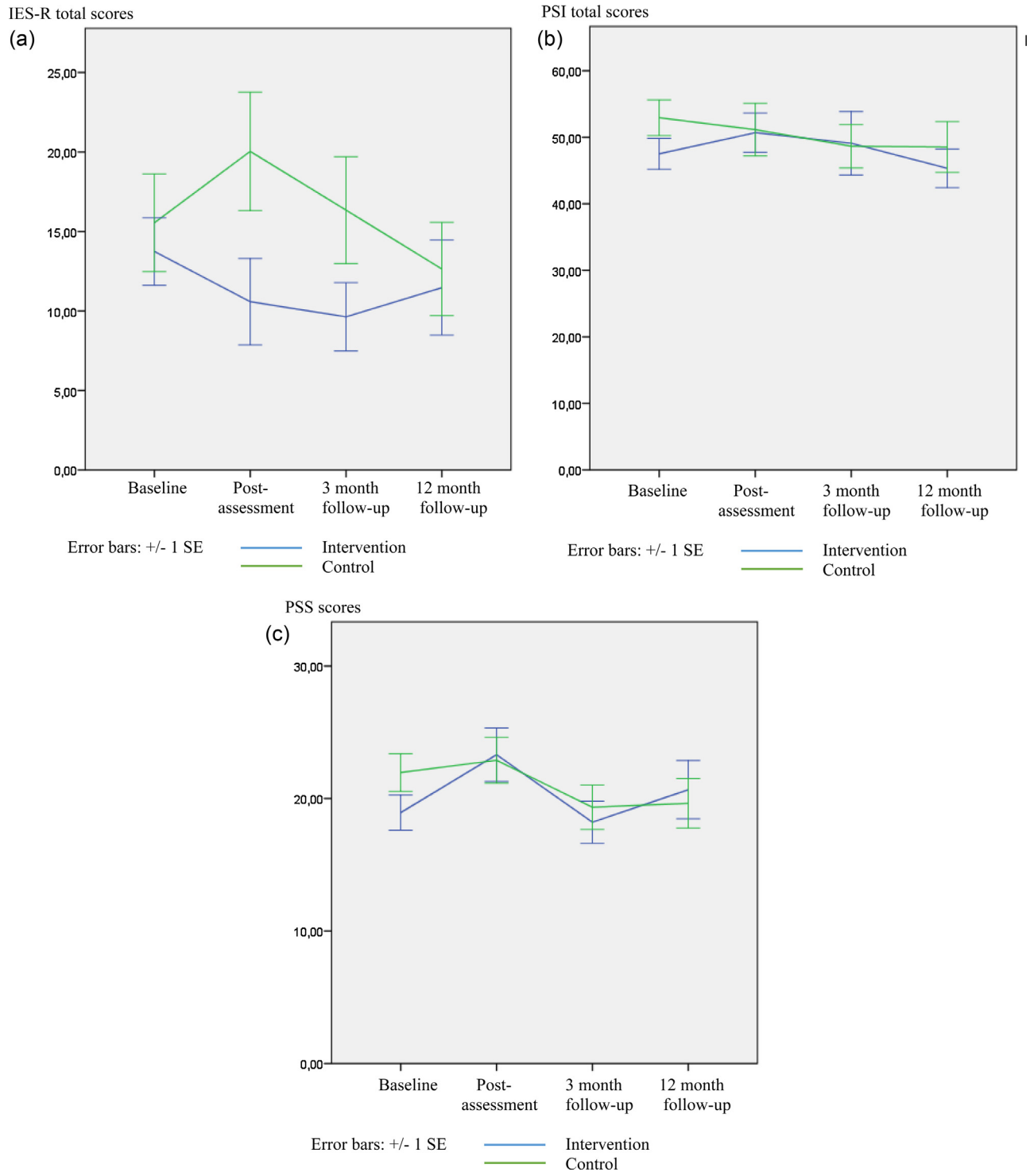

Fig. 2 – (a) Changes in IES-R scores between groups. IES-R: Impact of Event Scale-Revised. (b) Changes in PSI scores between groups. PSI: Parenting Stress Index. (c) Changes in PSS scores between groups. PSS: Perceived Stress Scale.

thought it was meaningful (n=9/11) and supportive (n=8/11). Few participants reported that the program was upsetting (n=2/11) or boring (n=3/11). No one answered that participating in the program had made the situation worse, while four parents answered that the program had made the situation better. Six individuals reported that the program had helped them with their problems.

The most positive aspects of the program, according to the parents, were to process and talk about the burn incident again, and to learn skills for doing so with the other parent and/or the child. They thought validation, mindfulness, and relaxation were useful techniques and appreciated the tips on how to handle everyday life as well as obstacles in life. Negative aspects were that the program was time-consuming

Table 4 – Mean scores and standard deviations (SD) for secondary outcomes at baseline and follow-ups.

	Intervention		Control	
	Mean	SD	Mean	SD
MADRS				
Pre-assessment	4.4	5.3	4.9	5.5
3-month follow-up	4.6	6.3	6.0	6.9
12-month follow-up	6.9	6.7	5.3	7.1
Fear-avoidance				
Pre-assessment	0.67	0.55	0.74	0.64
3-month follow-up	0.66	0.43	0.81	0.66
12-month follow-up	0.45	0.52	0.59	0.51
Guilt				
Pre-assessment	2.8	0.9	2.8	0.9
3-month follow-up	3.2	0.6	3.0	1.0
12-month follow-up	3.3	0.7	3.2	0.7
SDQ total				
Pre-assessment	6.0	3.4	7.2	4.7
3-month follow-up	5.4	3.3	6.7	4.6
12-month follow-up	6.1	4.3	5.8	5.2
CSRC-SF				
Pre-assessment	0.36	0.53	0.49	0.71
3-month follow-up	0.25	0.43	0.28	0.68
12-month follow-up	0.15	0.40	0.22	0.58
FES-SF				
Pre-assessment	0.11	0.15	0.19	0.22
3-month follow-up	0.22	0.15	0.16	0.20
12-month follow-up	0.19	0.14	0.17	0.22

Note: MADRS: Montgomery-Åsberg Depression Rating Scale; SDQ: Strengths and Difficulties Questionnaire; CSRC-SF: Child Stress Reaction Checklist Short Form; FES-SF: Family Environment Scale Short Form.

There were no statistically significant differences between the intervention group and the control group.

and that some felt they had insufficient time. Most participants thought it was positive to access the program via the internet. Time spent working with the text varied greatly, from about 20 min per module up to 2 h per module, and time spent on homework assignments varied from 20 min to 3 h per module.

3.4. *Reaction to research participation*

The results of the RRPQ did not differ between the intervention and control group and are thus reported together. The majority of parents reported positive appraisals of research participation: 79% answered they were glad they were in the study, 88% felt good about helping others by being in the study and 61% felt good about themselves participating. There were few negative appraisals: 9% of parents found the study boring, 2% were upset or sad, and no one answered that they were sorry about participating in the study. Regarding informed consent and trust in the research team: 93% felt that it was their choice to participate, 67% felt that the things they said stayed private and 74% felt they were told the truth about the study. Regarding the rights as a participant: 72% of parents knew they could stop participating at any time.

4. Discussion

The results indicate a potential role for a psychoeducational support program to reduce symptoms of posttraumatic stress in parents after a child is burned. The present program had a beneficial effect on posttraumatic stress symptoms in the short term, but did not affect general stress or parental stress. The parents perceived the program as informative and meaningful; however, it was reported by some of the parents to be time-consuming. The most valued skills, as reported by the parents, were validation in communicating with the child and others, and mindfulness. Most parents were positive about research participation, and this did not differ between the intervention and the control group.

The program is broad in scope. Much of the text is psychoeducational, with both preventive and consulting aims regarding common problems after a child is burned, for instance how to handle the burn and rehabilitation, daily stress and sleep, communication, acceptance of changes, and how to assist the child in social encounters. One module was directed toward symptoms of PTSD and the homework assignments carried some elements of exposure treatment; for instance, participants were encouraged to think and write about the burn event and to talk about it with their child (if possible). Therapist contact was minimal, and included weekly written feedback on the assignments and prompts to continue participation (if needed). It is possible that a more directed program or more elaborate therapist support would have resulted in a stronger effect on symptoms of PTSD.

A recent meta-analysis [32] concluded that there is support for the efficacy of using internet-based Cognitive Behavior Therapy (iCBT) in treating PTSD. Moreover, iCBT with therapist support has a better effect than iCBT without support [33–35]. However, there are no iCBT studies on parents of children with burns or other physical injuries.

A strength of this study is the nationwide inclusion of children with burns, comprising the two main Swedish burn centers with national responsibility for treating patients with severe burns and including children of all ages between 0 and 18 years. The rationale for this approach is the low yearly incidence rate of burns in Sweden, and the geographical spread of the affected families. The low incidence of burns also justified the cross-sectional design of the study, with a wide range of time since injury. However, as symptoms of PTS have been seen to persist for many years, this was not considered a problem for the study. Nevertheless, the wide inclusion criteria is also a potential limitation of this study, as most parents and children did not present with psychological symptoms according to the self-reported data. Thus, it might have been beneficial for the study if there had been an initial screening for parents and children who had elevated psychological symptoms. In addition, the parents reported a low amount of family conflicts, indicating good family functioning, and the majority of parents were married/cohabitating and working/studying, indicating stable social and economic circumstances. It is possible that the program might be even

more effective for parents and children with more psychological difficulties.

Other limitations include the relatively small sample and the high attrition rate. The majority of children had minor to moderate burns and short hospital stays. Thus the sample may not be representative of families of children with burns in general or children with larger burns involving lengthy hospital stays. Further evaluation is needed, for instance as prevention of symptoms in parents of children with more recent burns, more extensive burns, or in parents with clinically significant psychological symptoms.

In conclusion, the present program had a beneficial effect on parents' posttraumatic stress symptoms; it was perceived by the parents as informative and meaningful and they valued the skills included in the program. Thus the current psycho-educational support program has a potential role in reducing distress in parents of children with burns.

Conflict of interest

None.

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