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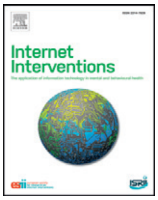

Internet-based information and self-help program for parents of children with burns: Study protocol for a randomized controlled trial

Josefin Sveen [a,*], Gerhard Andersson [b,c], Lisa Ekselius [a], Folke Sjöberg [d], Bo Buhrman [b], Mimmie Willebrand [a]

[a] Department of Neuroscience, Psychiatry, Uppsala University, Uppsala, Sweden
[b] Department of Behavioural Sciences and Learning, Linköping University, Linköping, Sweden
[c] Department of Clinical Neuroscience, Karolinska Institute, Stockholm, Sweden
[d] Department of Clinical and Experimental Medicine, Linköping University, Linköping, Sweden

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ABSTRACT

Background: A burn is one of the most traumatic and painful injuries a child can experience and it is also a very stressful experience for the parents. Given the great psychological distress and perceived lack of multiprofessional support experienced by the parents, there is a need for support during in-hospital treatment as well as during recovery. The aim of the study is to develop and evaluate an internet-based information and self-help program for parents of children who have been hospitalized for burn injury. The program aims to decrease parents' symptoms of stress.

Methods: Participants will consist of parents of children treated for burns between 2009 and 2013 at either of the two specialized Swedish Burn centers. The study is a two-armed randomized controlled trial with a six-week intervention group and an inactive control group, with a pre- and post-assessment, as well as a 3- and 12-month follow-up. The main outcome is stress (post-traumatic stress, general perceived stress and parental stress). The data will be analyzed with the intention-to-treat principle. The intervention is based on Cognitive-Behavior Therapy (CBT) and is inspired by Acceptance and Commitment Therapy (ACT). It is psychoeducational and provides basic skills training in communication and stress management.

Conclusion: We believe that this program will offer parents of children with burns information and support, decrease symptoms of stress, and that parents will perceive the program as useful. If the program is found to be beneficial, it could be implemented in burn care as it is accessible and cost-effective.

1. Introduction

Young children up to four years of age constitute almost 30% of all burn victims in Sweden, and another 10% are children aged five to 14 years (Åkerlund et al., 2007). Similar rates have been observed in other western countries (Brusselaers et al., 2010). Burns are one of the most traumatic and painful injuries a child can experience. It is also a very stressful experience for the parents with symptoms of anxiety, depression and post-traumatic stress disorder (PTSD) following the burn (Bakker et al., 2013). For example, studies have shown that almost half of the parents have symptoms of PTSD in the first months after the burn (Hall et al., 2006) and 14–42% up to 5 years post-burn (Bakker et al., 2013). There is increasing evidence that parents' psychological health is of importance for the health of the child (Cuijpers et al., 2015; Gunlicks and Weissman, 2008). In burns research it has been observed that PTSD symptoms in the mother were related to the child's stress reactions following burn, and family functioning and parenting stress were associated with the child's adjustment, while burn severity was not (Bakker et al., 2013). Thus the parent's health and functioning following a child's burn is likely to also be important for the child's health and recovery after the injury.

Considering the significant psychological distress experienced by the parents, parents need support following the burn of the child (McGarry et al., 2015). However, up to 20% of the parents of children with burns perceive a lack of psychological or other support and information during treatment and rehabilitation (Willebrand and Sveen, preliminary data). This could be improved by the health care professionals, for example, by providing educational programs and written information about both the physiological and psychological aspects of burn injuries. Previously described parent and caregiver support programs are diverse in purpose and design. For instance, a study on the health determinants of adult caregivers of children with cerebral palsy supported a biopsychosocial framework that was family-centered rather than focused exclusively on the child (Raina et al., 2005). A conclusion was that prevention of caregiver health problems might be feasible through providing parents with cognitive and behavioral strategies to manage their child's behaviors (Raina et al., 2005). A randomized controlled trial (RCT) of an educative-

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* Corresponding author at: Department of Neuroscience, Psychiatry, University Hospital, SE-751 85 Uppsala, Sweden.
E-mail address: Josefin.Sveen@neuro.uu.se (J. Sveen).

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behavioral program for parents of premature infants showed that the program decreased maternal stress, length of stay in hospital, post-discharge anxiety and depression, and increased positive parent-infant interactions (Melnyk et al., 2006). As of yet, no such program for parents of children with burns has been formally evaluated. A questionnaire with open-ended questions administered to close persons of children with burns indicated that a family support program should include the following categories: 1) provide advice and support regarding family members' acceptance of the child's altered appearance, 2) provide advice and support and information regarding scars and appearance, 3) provide support in understanding changes in the child after the burn, and in coping with altered family dynamics, and 4) to provide advice on how to deal with uncomfortable social encounters (Phillips and Rumsey, 2008). Further, in a summary of clinical experiences from an outpatient parent support group in South Africa, the following core themes were reported: blame and guilt (linked to isolation and stigma), fear that the child would die, gratitude that the child survived, concern about scarring, religion as an anchor and a way of making sense of the event, description of the child's changed behavior (more clingy, frightened), and family problems (Frenkel, 2008). Although many themes are likely to be universal, cultural adaptation of parent support programs is necessary, both in terms of themes and in terms of format. Group-based interventions with face-to-face sessions may not be feasible, beneficial or necessary for all parents, especially considering the varying degree of symptoms, the vast geographical spread of the injuries in Sweden, and the relatively low yearly incidence of burns in Sweden (Åkerlund et al., 2007).

Internet-based cognitive behavior therapy (ICBT) is an increasingly used strategy and it is reported to have several advantages over traditional CBT, such as anonymity, accessibility and being less expensive (Andersson and Titov, 2014). In addition, it can be designed with varying levels of therapist support in order to meet the specific needs of a patient group. ICBT with therapist support has better effect than ICBT without support (Andersson and Cuijpers, 2009; Saddichha et al., 2014; Spek et al., 2007). ICBT has been found to be effective in individuals with PTSD (Ivarsson et al., 2014; Spence et al., 2011). In addition, it has been advised that self-help interventions should be based on CBT principles rather than being purely educational (Gellatly et al., 2007). In keeping with this, a web-based posttraumatic stress psycho-educational program for parents of children with physical injury was found to increase early knowledge post-intervention, but it did not reduce symptoms of PTS (Marsac et al., 2013), whereas a pilot study of a web-based psychological support program for caregivers of children with cystic fibrosis was reported to improve parental mental health and quality of life (Fidika et al., 2015).

As of yet, no internet-based information and self-help program has been formally evaluated for parents of children with burns. The project aims to develop and evaluate an internet-based information and self-help program for parents of children and adolescents who have been hospitalized for burn injury. A hypothesis is that parents in the intervention group will report decreased levels of stress, in particular symptoms of post-traumatic stress.

2. Methods

2.1. Study design

This study will be a two-armed RCT design with an intervention group and an inactive control group. Online assessments will be conducted, for both groups, at pre-assessment (T0), post- assessment (six weeks after randomization, T1), and at three (T2) and 12 (T3) months (4.5 and 13.5 months after randomization).

2.2. Study population

The Linköping Burn Center and the Uppsala 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 (2015). The sample for this study will comprise consecutively admitted patients at the two burn centers between January 2009 and December 2013. The inclusion time range is justified as parents may suffer from symptoms of PTSD years after the event (Bakker et al., 2013). Inclusion criteria for the parents are as follows: (1) age of the 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 unintentional, and there is no suspicion of abuse or neglect of the child as a cause of the burn, and (4) ability to understand and respond in Swedish. The study has been approved by the Regional Ethics Review Board in Uppsala.

2.3. Procedure

The families will first receive an information letter describing the study, including a consent form and a prepaid response envelope. After one week the families will be contacted by telephone by one of the investigators (JS) and asked for their consent to participate, unless they have already returned the consent form by post.

Parents agreeing to take part in the study will access the internet platform by logging in to the e-service “My Healthcare Contacts” (Mina vårdkontakter) by using electronic identification. They are then redirected to a secure platform. After filling in the pre-assessment section, they will be informed whether they have been randomized to the intervention group or the control group. Members of the control group will be informed that they will be contacted for a follow-up after six weeks and the intervention group members will receive access to the self-help program provided on the same platform as the pre-assessment. After the three-month follow-up (T2) assessment, the participants in the control group who are interested will be offered access to the self-help program.

2.4. Randomization

The parents will be randomized, by one of the researchers, to either the control group or the intervention group. The groups will be stratified by time since injury and the child's total body surface area full-thickness burns (TBSA-FT), as parents of children with more recent burns and/or more severe burns may have more symptoms of stress which may affect the results. When both parents of a child are participating they will be assigned to the same group.

2.5. Sample size

Between January 2009 and December 2013, 215 children have been admitted for burn treatment at the Linköping University Hospital and the Uppsala University Hospital, and fulfill the inclusion criteria, thus all parents of the 215 children will be invited to participate in the study.

2.6. Intervention development

When developing the program a literature review was conducted and experts in the field were consulted (i.e. health professionals in the burn center including surgeons, nurse, occupational therapist, physiotherapist and psychologist) and interviews with parents of children with burns. The program included important topics as identified in the literature, e.g. changes in child's behavior and appearance, coping with social encounters and changes in family dynamics, as well as blame and guilt feelings among the parents. In addition, information regarding stress and posttraumatic stress in the child and in the parent will be included. The intervention has been developed by the authors (JS, MW, and BB) and provides psycho-educational information and skills training based on principles and techniques of Cognitive-Behavior Therapy (CBT) and Acceptance and Commitment Therapy (ACT) (Hayes et al., 2006; Hayes et al., 2004). The intervention contains six modules with information, assignments, interactive exercises, and audio and video clips. In some of the modules there are options to read more about certain topics.

2.7. Intervention content

The intervention will run for six weeks, and participants receive one module per week. Intervention content includes information about burns and rehabilitation, psychological reactions following trauma, feelings of guilt, stress, sleep problems, and family communication after the burn. The written material comprises 8–14 pages per week, including images and description of exercises. The six modules will include techniques such as validation, visualization, mindfulness, metaphor and acceptance strategies, exposure training, and progressive relaxation. Parents will receive brief written feedback on the assignments from a therapist (i.e. a psychologist or psychotherapist) after each weekly assignment via the platform. It is expected that the therapist will spend approximately 10–15 min per week with each participant. For more detailed overview of the content see Table 1. The number of completed modules and assignments for each parent will be recorded.

2.8. Measures

2.8.1. Primary outcome

The Impact of Event Scale-Revised (IES-R) (Weiss and Marmar, 1997) will be used to measure symptoms of posttraumatic stress among parents. 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, with a recommended cut-off of 40 for PTSD caseness (Sveen et al., 2010a). The Swedish version of the IES-R has shown excellent psychometric properties in previous studies after burns (Sveen et al., 2010a; Sveen et al., 2010b). Thirty items from the Parenting Stress Index (PSI) (Abidin, 1996) will be used to assess child and parent stress, the items are rated on a 5 point Likert-type scale (1 = strongly disagree, 5 = strongly agree). Cronbach's alpha = .82–.90 (Murphy et al., 2012).The Perceived Stress Scale (PSS) (Cohen et al., 1983) will be used to assess general perceived stress among the parents. It consists of 14 items rated on a 5-point Likert-type scale (0 = never, 4 = very often; half of the questions have reversed scoring). Total score ranges from 0 to 56.

2.8.2. Secondary measures

2.8.2.1. Sociodemographic, burn injury, and care-related variables. Data regarding the in-hospital treatment, the injury, gender and age of the child will be obtained from medical records. Satisfaction with hospital care is measured with a modified version of the Quality of Care Parent Questionnaire (QCPQ) (Ygge and Arnetz, 2001), 28 items and 5 questions (rating scores from 1 to 4) regarding the aftercare and psychological support were developed by the authors (JS, MW).

2.8.2.2. Parent's health. The Montgomery–Åsberg Depression Rating Scale (MADRS) (Montgomery and Asberg, 1979), 9 items (rating scores from 0 to 6), will be used to measure depressive symptoms and the Satisfaction With Life Scale (SWLS) (Diener et al., 1985), 5 items (rating scores from 1 to 7), to measure quality of life.

Injury-related fear-avoidance (Sgroi et al., 2005), 4 items (rating scores from 0 to 4), will be assessed and parental guilt and embitterment, 4 items (rating scores from 0 to 4), will be assessed with questions developed by the authors (JS, MW). Eight questions from the Family Environment Scale (Moos and Moos, 1986) will be used to measure family function, rated as True or False.

2.8.2.3. Child's health as perceived by the parent. Mental health will be assessed with the Strengths and Difficulties Questionnaire (SDQ) (Smedje et al., 1999), 25 items (rating scores from 0 to 2) and the Child Stress Reaction Checklist (CSRC) (Saxe et al., 2003), 9 items (rating scores from 0 to 2), while burn-related health will be assessed with questions regarding pain, itch, appearance and the child's general health from the Burn Outcome Questionnaire (BOQ) (Daltroy et al., 2000; Kazis et al., 2002), 19 items and heat-sensitivity from the Burn Specific Health Scale-Brief (BSHS-B) (Kildal et al., 2001), 5 items (rating scores from 0 to 4).

2.8.2.4. Research participation. Reactions to research participation will be assessed at the 12-month follow-up (T3) with the Reaction to Research Participation Questionnaire (RRPQ) (Kassam-Adams and Newman, 2002), 12 items (rating scores from 1 to 5).

2.8.3. Evaluation of intervention

Parents in the intervention group will receive a module evaluation form at the end of each module and will complete an evaluation form for the entire program after the six weeks as well as a brief evaluation at the 3- and 12-month follow-ups. The evaluation includes questions on whether the participant finds the module/program: informative,

Table 1
Overview of the intervention's content.

	Module 1	Module 2	Module 3	Module 4	Module 5	Module 6
Content	Burn injury, 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 injury	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

upsetting, meaningful, neutral, understandable, boring, and supportive; participation has made the situation worse, participation has made the situation better (items are rated on a scale from 1 = No, not at all, to 4 = Yes, a lot). Two open-ended questions: *Is there anything that we have missed to include which is or was important to you*? *Do you have suggestions on how to improve the content in the module/program*?

2.8.4. Data collection

All assessments will be filled in online via the internet platform by the parents.

At the pre-assessment, all measurements will be presented to all participants, except for reactions to research participation, which will be assessed at the 12-month follow-up. The primary outcomes will be re-assessed at post-assessment and at each follow-up. Secondary measurements will be re-assessed at follow-ups, except for questions on satisfaction with care, heat-sensitivity and questions from the BOQ (see Table 2). All data will be saved encrypted on a secure server at Uppsala University Hospital. Once all assessments are conducted the data will be exported to Microsoft Excel and all personal data are de-identified.

2.9. Statistical analyses

All analyses will be performed with the statistical package IBM ® SPSS ® Statistical package version 21. All data will be analyzed with the intention-to-treat principle where all randomized participants are included in the analyses assuming missing data at random (Salim et al., 2008). Mixed effects modeling analysis will be used to examine changes across assessments and the effects of the intervention. Cohen's d and a 95% confidence interval will be calculated to measure the between-group effect size at post-intervention and follow-up. We expect an effect size of Cohen's $d = 0.20$ to 0.50, which is small to medium. Burn severity, age and gender effects will be analyzed given that the sample size is adequate.

3. Discussion

In this study protocol, we describe the design of a novel randomized controlled trial evaluating an information and self-help program with weekly therapist feedback for parents of children who have been hospitalized for burn injury, based on CBT and ACT principles. We attempt to offer parents support and information via the internet as it is more accessible and cost-effective than face-to-face interventions. We expect that parents of children with burns will perceive this program as useful. We expect that the intervention will have effect on the outcome measures on a statistical level, however as all parents regardless of symptom levels are included, we do not expect clinically significant effects on a group level. This is a possible limitation with the study. A strength of the study design is that it has the possibility of recruiting a representative sample of Swedish speaking parents as the inclusion is nationwide and spans across all ages of the children, as well as all forms of burn injuries that required in-hospital specialist burn care.

Table 2
Timing of measurements.

	Baseline	Post-intervention	3-month follow-up	12-month follow-up
Parent measures				
Posttraumatic stress symptoms	X	X	X	X
Parental stress	X	X	X	X
Perceived stress	X	X	X	X
Depression	X		X	X
Satisfaction with life	X		X	X
Fear-avoidance	X		X	X
Guilt and embitterment	X		X	X
Family environment	X		X	X
Satisfaction with burn care	X			
Parents evaluation of the intervention		X	X	X
Parents reaction to study participation				X
Child measures by parent-proxy				
Psychological health	X		X	X
Burn and physical health	X			

4. Conclusion

As of yet, no information and self-help program for parents of children with burns has been formally evaluated. If the information and self-help program is found to be beneficial, it could be implemented in burn care.

Trial status

At the time of revised manuscript submission, the participant recruitment is completed and study is ongoing.

Conflict of interest

None.

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