Journal of Pediatric Nursing (2014) **29**, 606–613

ELSEVIER

Parents' Perceptions of Adaptation and Family Life After Burn Injuries in Children

Caisa Öster RN, PhD[a,*], Ida Hensing RN[a], Therese Löjdström RN[a], Folke Sjöberg MD, PhD[b,c], Mimmie Willebrand PhD[a,d]

[a]*Department of Neuroscience Psychiatry, Uppsala University, Uppsala, Sweden*
[b]*Department of Clinical and Experimental Medicine, Linköping University, Linköping, Sweden*
[c]*The Burn Intensive Care Unit, Departments of Hand and Plastic Surgery and Intensive Care, Linköping University Hospital, Linköping, Sweden*
[d]*Uppsala University Hospital Burn Centre, Uppsala, Sweden*

Received 16 November 2013; revised 10 June 2014; accepted 20 June 2014

Key words:
Parents' perceptions;
Pediatric burns;
Children;
Rehabilitation;
Adaptation;
Qualitative content analysis

The aim of this study was to explore parents' experiences after their child's burn injury, focusing on how the burn had influenced family life and child adjustment. Six semi-structured interviews with parents of children treated at burn centers 2 to 7 years previously revealed the theme, "Feeling quite alone in striving to regain family wellbeing". Identification of difficulties perceived by the parents during rehabilitation and up until the present is useful when developing pediatric burn care and support for parents of children with burns.

Background

IN EUROPE, 50% of all in-hospital admissions for burn care involve children younger than 16 years (Brusselaers, Monstrey, Vogelaers, Hoste, & Blot, 2010), and in Sweden about 40% of all burns are in children (Akerlund, Huss, & Sjoberg, 2007). A burn injury requiring hospitalization can be a serious trauma for a child, and rehabilitation is often challenging and is sometimes ongoing for many years (Herndon, 2012). The child has to adjust to physical changes (Kidd, Nguyen, Lyons, & Dickson, 2012), psychological challenges (Landolt, Buehlmann, Maag, & Schiestl, 2009; Meyer et al., 2007; Nelson & Gold, 2012), and must sometimes learn to live with an altered appearance (Stubbs et al., 2011).

A pediatric burn injury affects all members of the family during the acute phase in the intensive care burn unit (Thompson, Boyle, Teel, Wambach, & Cramer, 1999). For the parents this can be one of their most stressful experiences, and parents often appear to suffer as much as the child in response to their child's exposure to pain, skin graft surgery (Thompson et al., 1999) and painful wound dressings (Smith, Murray, McBride, & McBride-Henry, 2011). Symptoms of acute stress are highly prevalent in both parents during the first months after the injury (Bakker, Van Loey, Van der Heijden, & Van Son, 2012; Hall et al., 2006). After hospitalization, the care continues at home and the parents become providers of care. The ultimate goals for rehabilitation after a pediatric burn are to regain functional capacity, return to school, and be able to join in leisure time activities (Herndon, 2012). Parents report psychosocial distress up to 2 years after their child was burn injured (Phillips & Rumsey, 2008), and in mothers, symptoms of posttraumatic stress have been identified up to 10 years after the burn (Bakker, Van Loey, Van Son, & Van der Heijden, 2010).

The burn also significantly impacts the siblings of the injured child (Mancuso, Bishop, Blakeney, Robert, & Gaa, 2003; Phillips, Fussell, & Rumsey, 2007), although some studies suggest that the non-injured child may become stronger in the process of normalization of everyday life and adjustment to new life circumstances (Lehna, 2010).

* Corresponding author: Caisa Öster, RN, PhD.
E-mail address: caisa.oster@neuro.uu.se.

http://dx.doi.org/10.1016/j.pedn.2014.06.010
0882-5963/

A supportive family is of enormous benefit to severely injured children. Sheridan et al. (2000) have concluded that families are an essential part of acute management and are naturally of even more significance during aftercare when the child is back in the home environment. Associations between family relationships, family environment and the adjustment of children with burns are well documented (Blakeney, Portman, & Rutan, 1990; Hall et al., 2006; Landolt, Grubenmann, & Meuli, 2002; LeDoux, Meyer, Blakeney, & Herndon, 1998; Liber, List, Van Loey, & Kef, 2006; Meyer, Blakeney, LeDoux, & Herndon, 1995; Meyer et al., 1994; Rosenberg et al., 2007; Sheridan et al., 2000). In a recent prospective study, the impact of family dynamics, the ways in which family members relate to one another, were identified as associated with either improved or impaired physical and emotional recovery of children with burns (Sheridan et al., 2012). Family cohesion and values have previously been reported as important for long-term psychological adjustment (Blakeney et al., 1990), and in parents' reports of their child's psychological problems 1 to 9 years after injury, parents' psychological symptoms and other family variables were more influential than injury-related variables (Willebrand et al., 2011).

Recent interview studies concerning parents of children with burns indicate that they undergo difficult experiences during rehabilitation. For instance, parents reported how they suffered a loss of self-confidence and became overprotective and controlling of their child's activities, which negatively influenced the child's reintegration in school (Horridge, Cohen, & Gaskell, 2010). Another interview study focused on the experiences of blame. Mothers and fathers not only blamed themselves but also encountered blame from others, and then suffered the double trauma of their child's burn. Enduring the blame was essential to their ability to continue parenting (Ravindran, Rempel, & Ogilvie, 2012). Bakker et al. (2010) have shown that feelings of self-blame and guilt can persist for many years and are associated with mothers' symptoms of posttraumatic stress.

The importance of a supportive family in the recovery of the child, and the simultaneous burden on the family, are seemingly incompatible factors. Family life is complex, and so far only a few descriptive studies have been published. Thus, the aim of the present study was to expand the knowledge regarding parents' experiences after hospitalization by exploring parents' perceptions of rehabilitation, adaptation and the influence of the burn on family relationships after their child's burn injury.

Methods

Participants and Procedure

Families were selected from a register encompassing the two national Burn Centers in Sweden (Linköping and Uppsala), each admitting a total of approximately 100–120 patients yearly, with a near complete catchment of all severe burns in Sweden. Inclusion criteria were as follows: (1) a family with a child admitted for treatment of a burn between 2000 and 2008, (2) the child's age was <18 years at the time of injury as well as at the interview, and (3) participants were able to speak and understand Swedish.

For the interviews, a purposeful sampling of families was employed in order to get variations in experiences. Families from different living environments, socioeconomic as well as geographic, with children of different ages, both boys and girls, and with diverse causes of injury were contacted. A letter with information about the study was sent to 10 families who were then contacted by telephone, and one of the parents was invited to participate in the interview study. Parents were defined as "a caregiver living close to the child", and could include stepparents and other adults if the family wanted that person to participate in the study. Of the 10 families contacted, two declined participation and another two families were prevented from participating because family members were afflicted with gastroenteritis and influenza at the time of the interviews. Alternative interview times could not be arranged. All participants were employed outside the home. The families comprised one to four children, including the injured child. Demographics and burn characteristics are presented in Table 1.

Data Collection

The interviews were performed in a place chosen by the participants, which was mainly in the participants' homes; one interview took place at a café.

The semi-structured interview included an interview guide covering areas of interest regarding the research question, *What was it like after discharge from the hospital?* The areas of interest were: *Family life during rehabilitation and today; the physical and mental health of the child during rehabilitation and today; and the school and leisure time of the child during rehabilitation and today*. The areas of exploration were chosen from previous reports of subjects that had an impact on adaptation after a child burn. In addition to the focus on the few denoted areas regarding the parents' experiences, they were asked during the interview to narrate their own story, and prompting questions were used to explore more in depth the parents' perceptions of rehabilitation and adaptation. The interview sessions were tape-recorded, lasted for 30–60 minutes, and were later transcribed verbatim. Data were handled using Open Code 3.4 software (ICT, 2009). The study was performed in accordance with the principles of research ethics and was approved by the Regional Ethical Review Board in Uppsala.

Data Analysis

The interviews were analyzed using qualitative content analysis, a process of identifying, coding and categorizing the primary pattern in the data (Krippendorf, 2012). The analysis, inspired by Graneheim and Lundman (2004), was carried out in several steps using an inductive process of constant comparison of data from one participant to another.