Measuring the Burden of Pediatric Burn Injury for Parents and Caregivers: Informed Burn Center Staff Can Help to Lighten the Load

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This study sought to identify which commonly experienced burn-related issues parents/caregivers of burn-injured youth deemed most stressful, difficult, and disruptive, during their child’s initial acute burn care hospitalization, and following the child’s discharge. Participants completed an 11-item survey, asking parents to rate the difficulty of items regarding their child’s burn injury. The scale was created by burn doctors, nurses, and psychologists with an average of 10.5 (SD ± 4.8) years of experience. Items selected were among common parental problems reported in the burn literature. Respondents included 69 parents/caregivers of previously hospitalized, burn-injured youth. The majority were mothers, n = 51 (74%), and n = 34 (49%) were Caucasian. The most represented age group was 37 to 45 years, n = 31 (45%). Children were on average, 6.04 years out from their initial injury. All parents reported *their child’s pain* as the most difficult part of the injury, n = 69 (100%). The second most common issue was *the child’s first hospital stay*. The other two items found to be “very hard” or “pretty hard” were *the time spent away from their other children*, and *feelings of hopelessness in being unable to fix everything for their child*. In this study, key parental problems occurred during the child’s initial hospitalization. Burn staff cannot alleviate all problems, however, staff education regarding distressing problems faced by parents, as well as possible solutions, can be made available. (J Burn Care Res 2014;XXX:00–00)
outcome, parents/caregivers must also deal with the sequelae of their own emotional impact and its effect on the rest of the family.14

A number of investigators have reported that the pediatric burn injury experience is challenging and distressing for parents. Parents of burn-injured youth experience high rates of psychological trauma including depression, posttraumatic stress disorder, and significant guilt.12,15–17

Mothers are reported to be especially susceptible to experiencing high levels of psychological trauma.12,18

In one study of parents whose children experienced burn injury, as many as 69% of participants tested positive for clinically significant anxiety levels during the child’s inpatient hospitalization, and 22 to 44% reported clinically significant depression afterwards, as they were dealing with their child’s outpatient issues.19 Additionally, long-term outcomes have shown that psychological issues can persist in a sizeable subgroup of parents.5,12

Many problems faced by families of injured or chronically ill children have been identified and include a myriad of stressors, including financial difficulties, role pressures (mother becomes the child’s nurse), need for adjustment to continuing medical care needs, disruption of routine, lack of understanding of impending health care needs, and doubt about the child’s future.20,21 Pediatric burn injury has been associated with parental difficulties, among them are the heightened levels of stress and disruption of the family.12 An increased rate of divorce after the event has also been documented.4,22 Meyer et al found that mothers of burn-injured children reported higher levels of stress than the normative group. The mothers acknowledged that many of their own issues such as depression, role change, feelings of incompetence, marital strain, and social isolation had contributed to their increased stress levels after their child’s injury.23 However, studies assessing the particular demands and difficulties that parents/caregivers experience as a result of their child’s burn injury and issues following hospital discharge are limited.14 Most studies evaluating the impact of injury or illness on caregivers have focused on adult patients. Such studies have discovered that relatively high levels of burden are placed on the caregiver, including both objective challenges (eg, transporting the individual to medical appointments, and assisting with activities of daily living, therapy, financial costs, etc) and subjective burden (distress, anger, fear, depression, and caregiver burn-out).24–26 This study sought to identify which of the frequently experienced burn-related issues parents/caregivers of burn-injured youth deemed most stressful, difficult and disruptive, not only during their child’s initial acute burn care hospitalization, but following the child’s discharge as well.

Methods

Parents of burn-injured children from the Southwestern and Midwestern United States were asked to complete a family information sheet, and an 11-item Likert scale survey regarding difficulties and challenges experienced by parents of previously hospitalized, burn-injured children. The scale was developed after a literature review of related studies, which outlined a number of problems reported by parents of such children.5 A group of burn doctors, nurses, psychologists, and therapists, working at a large burn center, with an average of 10.5 (SD ± 4.8) years of experience in caring for pediatric burn patients, selected the final 11 survey items. The survey was then administered to parents by a psychologist. Instructions read as follows: “Below are some things that parents find hard about their child’s burn injury. Please circle the answer that best describes how hard each item was for you. Then please circle the ONE item which was the hardest of all for you. The Likert scale used was scaled as follows: 1 (Not at all), 2 (Just a little), 3 (Pretty Hard), 4 (Very Hard), and 5 (N/A-Didn’t Happen).” Items included in the survey addressed the child’s physical pain, teasing by others, the scarring and disfigurement of the child, time away from their other children, parents’ inability to fix things for their child, employment problems, the need for reconstructive surgeries, getting to doctor/therapy visits, financial burden, and parents being blamed for the burn injury.

Summary statistics are provided as mean (standard deviation) or count (percentage), as appropriate. Significance was calculated using t-tests for continuous variables and χ² tests for count variables. SPSS, ver 21 (IBM, Armonk, NY) was used to analyze the data. All tests were two-tailed, and P < .05 was used as the criterion for statistical significance.

Results

The survey was completed by 76 parents/caregivers of burn-injured youth. Seven respondents reported that they were not involved with the child’s initial hospitalization due to their status as guardian or adoptive parent. Therefore, we chose to include only the responses of the 69 who were present at the time of the injury, as the majority of the survey statements pertained to the initial injury event and hospitalization. The gender of children included 32 boys (46%) and 37 girls (54%). The mean age of children was
12.04 (SD ± 3.87) years, and mean age at time of burn injury was 6.0 (SD ± 3.7) years. Forty-two parents reported that their child (61%) had visible burn scars, while 27 (39%) had children with hidden burns. More girls (65%) had visible scars than boys (56%). The cause of the child’s burn was identified as Scal 38 (55%), Flame 29 (42%), Road Rash 1 (1%), and Chemical 1 (1%), and all of these children had been hospitalized for their burns with total body surface area burns ranging from 10 to 90%. Parents reported that 48% of the children/youth who had visible scars had received some type of psychological therapy after being discharged from the hospital, while only 21% of their parents had. Additionally, 26% of children with hidden burn scars engaged in some type of psychological care, while 22% of this parent group participated. A larger percentage of boys received psychological therapy, 14 (44%), than girls, 13 (35%). For the entire group, 27 (39%) said their children had engaged in therapy and 42 (61%) said their child had not received counseling after their burn injury.

Table 1 outlines the demographic characteristics of the parent/caregiver participants. When asked if they had engaged in any psychological therapy after their child’s burn, 54 (78%) of parents/caregivers said they had not undergone therapy while 15 (22%) reported that they had engaged in some type of psychological counseling.

Table 2 provides the mean response scores for the 11 items and the percentage of NA/Didn’t Happen answers from parents/caregivers. The responses to items in the table are sorted in descending (from highest to lowest) mean score. The highest mean score was 3.9 (.39) for the item, “The physical pain my child experienced” and 100% of participants acknowledged this as the most difficult thing about their child’s burn injury (90% “very hard” and 10% “petty hard”). The item, “Other adults/family members blaming me for the injury” had the lowest mean score of 1.5 (SD ± 0.75).

Parents of children with visible scars reported significantly greater difficulty with teasing and staring. Those parents whose children had hidden scars reported a mean score of 1.4 (SD ± 1.15), while parents of youth with visible scars reported a mean of 2.4 (SD ± 1.29), P = .001. Parents of children with visible scars had a higher mean score 2.5 (SD ± 1.06) for the item, “The scars or disfigurement of my child are difficult for me,” as compared to parents of children with hidden scars, mean of 2.0 (SD ± 1.06), which trended towards significance P = .06.

Parents of girls reported a higher mean score of 2.4 (SD ± 1.25), than parents of boys, mean = 1.6.
(SD ± 1.32) on the item, “Others teasing or staring at my child,” with a significant difference of \( P = .02 \). Although parents of girls also had a higher mean score 2.4 (SD ± 1.07) on the question “The scars or disfigurement of my child are difficult for me,” compared to parents of boys 2.3 (SD ± 1.11), the difference was not significant.

When comparing responses between participants whose children had a burn injury up to 3 years before the survey was completed vs those whose children had a burn injury 4 or more years before, no significant differences were found. The only item that trended towards significance, “The burn injury resulted in a financial burden,” had a \( P \)-value of .07, with the 3 years or less since the burn injury group, 22 (32%), reporting a higher mean score of 2.4 (SD ± 1.14) vs the 4 years or more since the burn injury group, 47 (68%), reporting a mean of 1.8 (SD ± 1.26). The range of time since the child’s burn injury and hospitalization ranged from 8 months to 14 years.

**Limitations**

There were several limitations in this study. First we did not have information regarding the size of the burn injury or the number of surgeries the children underwent during or after their initial hospitalization. The surveys were completed mostly by mothers and nearly half of them were Caucasian; therefore, the results may not be generalizable to other parents/caregivers. Additionally, though a number of children and a minority of parents received some type of psychological counseling, the specific type and duration of care was not identified.

**Discussion**

The top four parental responses in this study, in terms of the difficulty of challenges related to the child’s burn care experience, occurred during the child’s initial hospitalization. These issues included the child’s physical pain, the initial hospitalization itself, the parental time spent away from their other children, and parent/caregiver’s feelings of hopelessness in not being able to fix everything for their child. While burn care staff cannot alleviate all of these problems, especially parental time away from their other children, education of staff regarding the most common and distressing problems faced by parents, as well as possible solutions and remedies for these problems, can be made available. The item parents/caregivers recalled as most difficult, on average 6 years after the child’s injury, was the physical pain their child experienced. Uncontrolled pain was also found to be a major stressor for parents in a previous study by Watts et al. Pain control, even with improved protocols and adjuncts such as distraction and music therapy, continues to be a problem for many pediatric burn patients.27–29

#### Table 2. Parent/caregivers’ survey items in ranked order

<table>
<thead>
<tr>
<th>Perceived Parental Difficulty Regarding Their Child’s Burn Injury</th>
<th>Item Mean Scores</th>
<th>Pretty Hard and Very Hard Responses n (%)</th>
<th>Not Applicable/Didn’t Happen Responses n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The physical pain my child experienced</td>
<td>3.9 ± 0.39</td>
<td>69 (100)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>2. My child’s first hospital stay when he/she got burned</td>
<td>3.4 ± 0.91</td>
<td>60 (87)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>3. Time I had to spend away from my other children</td>
<td>3.3 ± 1.00</td>
<td>48 (70)</td>
<td>10 (14)</td>
</tr>
<tr>
<td>4. My feeling of hopelessness of being unable to fix everything for my child</td>
<td>3.0 ± 1.09</td>
<td>40 (58)</td>
<td>9 (13)</td>
</tr>
<tr>
<td>5. The scars or disfigurement of my child*</td>
<td>2.4 ± 0.98</td>
<td>31 (45)</td>
<td>3 (4)</td>
</tr>
<tr>
<td>6. People/Children teasing or staring at my child*</td>
<td>2.4 ± 1.07</td>
<td>27 (39)</td>
<td>11 (16)</td>
</tr>
<tr>
<td>7. The burn injury resulted in a financial burden</td>
<td>2.3 ± 1.06</td>
<td>26 (38)</td>
<td>9 (13)</td>
</tr>
<tr>
<td>8. The need for ongoing reconstructive surgeries for my child</td>
<td>2.3 ± 1.11</td>
<td>18 (26)</td>
<td>18 (26)</td>
</tr>
<tr>
<td>9. The loss of employment of a parent</td>
<td>2.3 ± 1.21</td>
<td>17 (25)</td>
<td>27 (39)</td>
</tr>
<tr>
<td>10. Getting to the doctor and therapy appointments</td>
<td>1.9 ± 0.89</td>
<td>14 (20)</td>
<td>7 (10)</td>
</tr>
<tr>
<td>11. Other adults/family members blaming me for the injury</td>
<td>1.5 ± 0.75</td>
<td>6 (9)</td>
<td>32 (46)</td>
</tr>
</tbody>
</table>

* Sixty-one percent of children had visible burn scars vs 39% with hidden scars.
† The NA answers are not figured into the mean scores.

\( n \), number of respondents for each item.
can have a direct impact on children’s pain experiences, including their manner of expressing pain. \cite{30,51}

Staff can encourage parents to be involved in the child/youth’s pain management regimen by inviting parents/caregivers to notify them when the child is experiencing discomfort. They can also ask parents to share feedback concerning their child’s previous experiences and ability to deal with pain. Parents/caregivers can be a good source of information regarding the ways in which their child typically responds, both physically and emotionally, to pain and discomfort. This can help to empower parents in feeling like they are helping their child, assisting the nurse and/or therapist in better meeting pain control needs, and set up the expectation that the child’s pain will be well-managed.

One study found that allowing parental participation during burn dressing changes had a significant impact on reducing the children’s pain experience. \cite{32}

Their results mirror those of other studies measuring improvement in pediatric pain control during invasive procedures, when parents were permitted to participate. \cite{33,34} Parents can be asked to supply the child’s favorite music, and encouraged to help their child by using relaxation techniques. Effective pain management of pediatric patients is important for both their short and long-term well-being, as unresolved pain has been associated with adverse psychological and physiological outcomes. \cite{35,36} Effective pain control is also likely to help patients and parents to feel less hopeless, distressed, and depressed. \cite{37}

The item which parents ranked as the second most difficult was the child’s initial burn hospitalization experience. The acute burn care setting is a stressful environment and one for which the average parent/caregiver is unprepared. Therefore, parent education regarding a variety of aspects of the burn-injured child’s inpatient needs, such as daily dressing changes, debridement and skin grafting surgeries, the need for increased nutritional support, the necessity for and importance of physical and occupational therapy, splinting, etc. may help to reduce the distress of parents/caregivers. One educational tool is the book entitled Brayden Bear Visits the Burn Center. It is written in both Spanish and English and available, free of charge, from Baxter Pharmaceutical. The book provides a simplified explanation of many facets of the acute pediatric burn care experience. The story explains the course of acute burn care through the eyes of a bear cub who sustained a serious scald burn. It can also be provided to siblings, in order for them to better understand their brother’s or sister’s condition, and to help to mitigate some of the confusion regarding their parent(s) need to be at the hospital so often. Another option is the “The Remember Me” program, created by the Shriner’s Hospital in Cincinnati. This program is designed to maintain communication between the burn-injured child and his or her peers when patients require a long hospital stay. Parents also can assist staff in the planning and implementation of a program about pediatric burn injury at their child’s school. \cite{15}

Additionally, staff can discuss some common parents/caregiver problems such as anxiety, sleep deprivation, and feelings of uncertainty and hopelessness, which are often experienced by caregivers. Discussing these issues can help parents anticipate and adjust to potential stressors and problems. Staff can recommend psychological care to help address anxiety, depression, and feelings of guilt expressed by parents. The burn center psychologist or social worker can assist in addressing other psychological stressors, such as loss of employment and financial burden. These interventions can help parents/caregivers feel that they are not alone in their child’s burn recovery journey, help to normalize their experience, and provide them with increased knowledge of community resources that may be available.

Parents of children with visible burn scars reported more problems in dealing with their children’s disfigurement and also reported experiencing significantly more concern about others teasing or staring at their child. These issues should be emphasized and discussed, especially with parents of visibly disfigured children. A study regarding burn injured/youth and bullying found that children with visible burns indeed had more issues than those with hidden burns. \cite{38} Therefore, the potential for bullying is also an important conversation for burn care staff to initiate with these parents.

Finally, parents/caregivers play a critical role in the support of the burn-injured-child/youth, so it is important for them to function in a positive manner. Providing them with interventions they can use, such as allocating their time more efficiently, scheduling time with their other children, and asking for help from other relatives or family friends in managing the needs of their other children, and communication regarding the burn patients’ status may be helpful. Staff can alert parents/caregivers to potential problems that their other children may experience as a result of their child’s burn injury. These include increased levels of resentment and depressive symptoms. These problems have been found to occur more frequently in girls and older children, possibly because they are relied upon to take on more of the parental duties in the home than boys or younger children. \cite{39} Child Life can assist by sending
“kid-friendly” updates regarding the patient’s status to help siblings and schoolmates better understand the child/youth’s need for the hospital care being provided for their sibling or schoolmate. This can help to diminish fear and anxiety on the part of siblings.

Conclusions
As ever greater numbers of children and youth survive serious burn injuries, more focus will be placed on the parents and siblings of survivors. Providing care is a normal expectation of parents. However, the role of the pediatric burn patient’s parent/caregiver, and at times siblings, is often expanded to include unfamiliar nursing and physical and occupational therapy duties. Parents often take on the responsibilities of providing wound care, changing dressings, performing scar massage/hydration, and ensuring that their child engages in a home exercise program; all responsibilities outside the normal and expected realm of parenting. As previously noted, the level of reported anxiety, depression, and posttraumatic stress disorder for parents of burn-injured children is often elevated. 12, 15–17

It is important for burn care professionals to consider this and to be empathetic to the stresses of the parents/caregivers of children in their care.

Burn centers caring for pediatric patients should educate staff to be aware of and able to address some of the more commonly experienced problems of their patients’ parents/caregivers and other family members. Directed education can assist the pediatric burn care team members in feeling more comfortable in initiating conversation regarding potential parent/family burn-related stresses and problems. Conversations with and education of parents should occur not only in the acute care phase, but also when youth and parents/caregivers return for follow-up care and/or reconstruction surgeries. These measures will help to ensure that the most critical support system for the child, their family, will be more successful in managing their personal stress. It will also help to ensure a better outcome for their child, the pediatric burn patient.

REFERENCES
8. Delgado Pardo G, García IM, Gómez-Cía T. Psychological effects observed in child burn patients during the acute phase of hospitalization and comparison with pediatric patients awaiting surgery. J Burn Care Res 2010;31:569–78.