Long-term Outcome of Children Surviving Massive Burns

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The successful treatment of massive burn injuries is one of the major advances in trauma care of the last 20 years. Before the 1970s, a burn involving more than one third of the body surface was almost always fatal; the few patients who did not die from burn shock during the first few postinjury days died from wound sepsis in the subsequent weeks. Improved fluid and electrolyte management and critical care combined with early wound excision and closure have had a profound impact on the natural history of such injuries. Although it has become possible to save the lives of massively burned children, the wisdom of doing so has become a health policy and ethical question.

Although almost 1 million American children are burned annually, only approximately 3% have massive injuries, defined as involving more than 70% of the body surface. Approximately 75% of those with massive injuries are managed in specialized multidisciplinary burn centers and the remainder are cared for in critical care units in pediatric general hospitals. Optimal management of severely burned persons is enormously expensive and, even after survival is ensured, may require protracted surgical, medical, psychological, and rehabilitation interventions for many years. It has been argued that the results are so dismal that these children should be allowed to “die with dignity.” The impact of comprehensive burn center management on long-term outcomes is unknown.

The existent data on children surviving massive burns are compromised by short-term follow-up, small sample size, selection bias, lack of standardized outcome measures, high dropout or nonparticipation rates, and lack of injury severity adjustments. Only 1 long-term outcome study of children with massive burns has been published. In that 4-year follow-up study

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of 12 children, the global quality of life was believed to be acceptable but was not objectively defined. Although it is commonly believed that injury size is the principal determinant of outcome quality,14,15 social and emotional factors are also thought to have a major influence.16-18 In this study, we evaluate the long-term outcome of all children managed at a single dedicated burn center who survived massive burn injuries.

METHODS

All surviving patients whose initial treatment was at the Shriners Burn Hospital for Children in Boston, Mass, for thermal injuries involving 70% or more of the body surface who were admitted between January 1, 1969, and December 31, 1992, were identified by the hospital registry. Inclusion criteria included age younger than 18 years at the time of admission, fluency in English, and residence within North America. All acute burn care was provided at the Shriners Burns Hospital in Boston, a 30-bed facility certified as a burn center by the American College of Surgeons and American Burn Association that provides comprehensive free care to children with burn injury of all degrees of severity. All care is provided at no cost to families or insurance carriers.

Surviving children are also offered continued participation in a program of multidisciplinary aftercare until age 21 years. This program, managed in the burn clinic and also offered at no cost, consists of coordinated family services, reconstructive surgery, and rehabilitation therapy. The Shriners organization is generally able to provide funds for children to travel back and forth from home to the burn center as needed to undergo evaluation and surgery. Routine postoperative physical therapy is provided by therapists near the patient’s home under supervision of burn center–based therapists. The study was approved by the Subcommittee for Human Studies at Massachusetts General Hospital, Boston, and by the Shriners Hospitals for Children.

There were 147 children who met study criteria. Eighty (54%) of these children were discharged alive. The following information was obtained from each patient’s hospital and outpatient records: patient demographics, date of injury, date of hospital admission, date of hospital discharge, presence of inhalation injury, extent of burn injury, family income, employment status of the parent(s) or guardian, enrollment in public assistance programs at the time of admission, an estimate of family functional status at the time of injury, the child’s early reintegration with preschool (school or preschool) activities after discharge, and the consistency of follow-up in the multidisciplinary burn clinic after discharge. A family was defined as functional if there was stable housing (not a shelter or transient housing), support of extended family, no parental substance abuse, no family involvement in state child protective services programs and the child was in school if of appropriate age. Children were deemed to have undergone successful early reintegration with preburn activities if they had returned to school or preschool and the family unit remained stable 4 months after discharge. This time point was chosen because it was consistently available. Children were considered to have had consistent clinic visits if they were seen at least 4 times per year for at least 2 years after discharge in the multidisciplinary burn clinic.

Between September 1995 and June 1997, patients or their families were contacted and 2 structured telephone interviews were conducted by 1 trained interviewer. The goal of the first interview was to establish contact, elicit the patient’s general circumstances, and obtain informed consent for participation in the study. During the second interview, the Short Form 36 (SF-36) was administered. No widely used and validated quality-of-life instrument exists for burn patients,19 but the SF-36 is a validated instrument that meets the requirements of our study. The SF-36 is a multidimensional, health-related quality-of-life measurement tool of proven reliability and validity in a number of chronic disease and injury disorders, and has norms for the US population.20-23 It has also been widely translated and validated in several non–North American cultures.24-27 It fulfills the requirement of measuring global reintegration and socialization28,29 as characterized by 8 domains: general health, physical functioning, social functioning, physical role, emotional role, mental health, energy/vitality, and bodily pain. The general health domain provides a measure of self-perceived overall wellness. Physical functioning items examine specific aspects of function, such as kneeling, bending, and walking. The social functioning domain asks about social activities and the impact of physical or emotional health on relationships. Physical role questions examine how physical disabilities limit usual activities such as work. Emotional role questions examine how emotional disabilities limit usual activities. Mental health items examine anxiety, depression, and psychological well-being. Energy/vitality items measure energy level and fatigue. Bodily pain items look at the intensity and extent of chronic discomfort.

At the initial interview, data were collected on age, education, work, living situation, significant others, children, and overall adjustment to life since injury. The SF-36 was administered to all patients aged 14 years and older at the second telephone interview, after the return of a signed informed consent form. Eight patients were younger than 14 years, and these subjects’ parents participated in the interview. Domain scores for these 8 patients were compared with scores for those aged at least 14 years using the t test for normally distributed outcomes and the Mann-Whitney U test for outcomes that were not normally distributed. Eight patients chose not to complete the SF-36, and demographic information was compared between this group and those who did complete the study using the t test for continuous variables and χ² analysis for categorical variables. Three mentally handicapped subjects were interviewed directly, in the company of family members. The mean (SD) follow-up period (date of initial dis-
charge to date of evaluation) for the 68 patients who completed the SF-36 was 14.7 (6.0) years (range, 4-26 years). Standardized SF-36 scores were calculated based on the general US population. The standardized score (or z score) is a measure of how many SD units above or below the US population mean a value falls, given that patient’s sex and age group. Age- and sex-specific norms were available for the age groups of 18 to 24 years, 25 to 34 years, and 35 to 44 years. For this analysis, the 60 study patients aged at least 14 years were analyzed. Those aged 14 to 17 years were standardized with norms for the 18- to 24-year age group. The 8 children younger than 14 years were excluded from this analysis. Since the standardized scores for the test domains were not normally distributed, the analysis was done using the Wilcoxon signed rank test.

A statistical analysis was done to assess the impact of important variables on SF-36 scores. These variables included age at interview, age at burn, sex, burn size, length of hospital stay, time since injury, need for public assistance, income level above or below the poverty level (defined by the US Census Bureau median income for a 4-person family, specific to the state and year of injury), family functional status at the time of injury, the child’s reintegration with preburn activities, and consistency of the child’s follow-up in the multidisciplinary burn clinic. The t test was used for the dichotomous variables and the Mann-Whitney U test for cases in which the scores were not normally distributed. Pearson correlation coefficients were calculated for continuous variables and Spearman correlation coefficients for non-normally distributed outcomes. The statistical package SPSS Version 7.0 (SPSS Inc, Chicago, Ill) was used for all analyses.

RESULTS

Of the 80 surviving children, 4 (5%) have died. One patient died 7 years after discharge from a potential suicide, 1 died 14 years after discharge from a drive-by shooting, 1 died 12 years after discharge from anoxic brain injury occurring at the time of the acute burn injury, and 1 patient died 2 years after discharge from congenital cardiomyopathy. The cause of the suicide is not known, but it is possible that it was caused by depression related to the burn.

Descriptive statistics are presented in Table 1. The complexity and severity of the injuries are reflected in the average (SD) length of stay of 150 (76) days. Length of stay was strongly influenced by the presence of inhalation injury, with the average (SD) length of stay of the 59 children with inhalation injuries equal to 170 (76) days vs 95 (41) days for 21 children without inhalation injuries (P < .001).

Social and family statistics are also presented in Table 1. Although income information could not be obtained for 6 children, 22 (28%) of the remaining families were receiving public assistance at the time of the injury, 32 (43%) had an annual family income below the poverty level, 37 (50%) had income between the poverty level and the median, and only 5 (7%) had income at or above the national median for the year of their injury and state of residence. There was at least 1 working parent in 76% of the families.

At the time of the follow-up interview, 27 (36%) of the patients were currently full-time students; 27 (36%) were gainfully employed; 1 (1%) was in prison; and 6 (8%) were full-time homemakers. Three patients (4%) were mentally handicapped and living at home assisted by their family but were able to perform activities of daily living. The etiology of the handicaps was probably secondary to retardation that preceded the injury in 1 child and secondary to anoxia occurring at the time of burn in the remaining 2. Twelve patients (16%) were unemployed and receiving public assistance but living independently or at home. Of these 12 patients, 8 reported problems with chemical or alcohol dependence. Of those 33 patients aged 25 years or older, 22 (67%) had spouses or significant others and 40% had been or

![Table 1. Descriptive Characteristics for the Study Population*](https://example.com/table1)

*Ellipses indicate data could not be collected (eg, length of follow-up for deceased persons). 
†The family unit (married, single, or divorced) was described as functional if it had stable housing, extended family support, the child in school, no alcohol or drug abuse, and no child protective services involvement. This was determined at admission and coded as yes or no.
‡Clinic notes reported the child was progressing and had returned to school and/or preburn activities. This was determined 4 months after discharge and coded as yes or no.
§The child was seen at least 4 times per year for at least 2 years after discharge in the multidisciplinary burn clinic. This was coded as yes or no.

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were currently married. From the entire group, 33 children had been born.

To assess potential response bias, the 8 patients who chose not to complete the SF-36 were compared with those who completed the study. There was no difference in patient or family demographics. The 8 patients younger than 14 years were compared with those aged at least 14 years using the Mann-Whitney U test and were different in 3 areas: higher energy scores (median score, 82.5 vs 65.0; \( P = .048 \)), lower physical functioning (median score, 52.5 vs 92.5; \( P = .001 \)), and lower physical role (median, 75.0 vs 100.0; \( P = .03 \)). The difference in energy scores is probably related to the younger age of the group aged less than 14 years, and the lower physical function scores may be due to the shorter elapsed time since injury that they had not completed reconstruction programs.

A standardized SF-36 score (z score) of 0 indicates that the individual’s score does not differ from the US population norm for their age and sex group. The standardized SF-36 domain scores of the burn patients were not different than the normal population using the Wilcoxon signed rank test, which would be sensitive to shifts near the center of the distribution, except for a slightly better score in the mental health domain \( (P = .02) \), which we could not explain (TABLE 2). However, 15% and 20% of the burn patients had scores in the physical functioning and physical role domains, respectively, more than 2 SDs below the relevant norm, indicating that a few patients had continuing serious physical disability.

The impact of important variables on SF-36 scores is presented in TABLE 3. Increasing burn size correlated with poorer physical functioning \( (P = .04) \). Increased time since injury predicted better scores in emotional role \( (P = .003) \). Female subjects scored higher than male subjects in general health \( (P = .02) \), physical functioning \( (P = .02) \), and physical role \( (P = .01) \). Male subjects scored higher on emotional role \( (P = .04) \). Younger patients scored better on energy \( (P = .009) \) and worse on emotional role \( (P = .001) \).

Three variables that might be influenced by a coordinated burn aftercare program had a significant correlation with domain scores: family functional status, early reintegration, and consistent clinic visits. The functional status of the family predicted a higher score in physical role \( (P = .04) \). The child’s return to preburn activities 4 months after discharge predicted higher scores in general health \( (P = .03) \), physical functioning \( (P = .003) \), and physical role \( (P = .01) \). Those children who were followed up consistently in the multidisciplinary burn clinic for 2 years had higher physical functioning \( (P = .04) \). Length of hospital stay and age at injury were not statistically significant factors.

### COMMENT

This is the first description, to our knowledge, of long-term outcomes in survivors of massive pediatric burns. It is a unique and nearly complete cohort from 1 unit describing long-term outcome using a well-validated quality-of-life measure. These data show that most

<table>
<thead>
<tr>
<th>Table 2. Short Form 36 Standardized Scores for Subjects Aged 14 Years or Older (n = 60)*</th>
</tr>
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<tbody>
<tr>
<td>Domain</td>
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<tr>
<td></td>
</tr>
<tr>
<td>General health</td>
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<tr>
<td>Physical functioning</td>
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<td>Social functioning</td>
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<tr>
<td>Physical role</td>
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<td>Emotional role</td>
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<tr>
<td>Mental health</td>
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<tr>
<td>Energy/vitality</td>
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<td>Bodily pain</td>
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</tbody>
</table>

*Data were calculated using the Wilcoxon signed rank test for nonparametric data.†Norms were obtained from the SF-36 Health Survey Manual and Interpretation Guide.

### Table 3. Impact of Important Variables on Standardized Short Form 36 Scores*

<table>
<thead>
<tr>
<th>Domain</th>
<th>Age at Injury</th>
<th>Female Sex</th>
<th>Burn Size</th>
<th>Public Assistance</th>
<th>Years Since Injury</th>
<th>Functional Family†</th>
<th>Early Reintegration‡</th>
<th>Consistent Clinic Visits§</th>
</tr>
</thead>
<tbody>
<tr>
<td>General health</td>
<td>( r = 0.25 (P = .06) )</td>
<td>( P = .02 )</td>
<td>( r = -0.27 (P = .04) )</td>
<td>( r = -0.22 (P = .09) )</td>
<td>( P = .03 )</td>
<td>( P = .04 )</td>
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<td></td>
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<tr>
<td>Physical functioning</td>
<td>( r = -0.27 (P = .04) )</td>
<td>( P = .04 )</td>
<td>( P = .06 )</td>
<td>( P = .37 (P = .003) )</td>
<td>( P = .01 )</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Social functioning</td>
<td>( r = -0.33 (P = .009) )</td>
<td>( P = .04 )</td>
<td>( P = .04 )</td>
<td>( P = .27 (P = .04) )</td>
<td>( P = .04 )</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Emotional role</td>
<td>( r = 0.42 (P = .001) )</td>
<td>( P = .04 )</td>
<td>( P = .04 )</td>
<td>( P = .24 (P = .08) )</td>
<td>( P = .04 )</td>
<td>( P = .04 )</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Energy/vitality</td>
<td>( r = 0.33 (P = .009) )</td>
<td>( P = .04 )</td>
<td>( P = .04 )</td>
<td>( P = .04 )</td>
<td>( P = .04 )</td>
<td>( P = .04 )</td>
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</tbody>
</table>

*Ellipses indicate \( P > .10 \).†The family unit (married, single, or divorced) was described as functional, if it had stable housing, extended family support, the child in school, no alcohol or drug abuse, and no child protective services involvement. This was determined at admission and coded as yes or no.‡Clinic notes reported the child was progressing and had returned to school and/or preburn activities. This was determined 4 months after discharge and coded as yes or no.§The child was seen at least 4 times per year for at least 2 years after discharge in the multidisciplinary burn clinic. This was coded as yes or no.¶For these non-normally distributed variables, the Mann-Whitney U test was used in place of the t test, and the Spearman \( \rho \) was used for correlations. There were no significant findings for the mental health subscale. Other variables tested that did not reach significance included length of hospital stay and income below poverty level.
such children have a quality of life comparable with the age-matched general population. Other important findings were the favorable impact of a functional family, early reintegration with preburn activities, and consistent follow-up in a multidisciplinary burn clinic.

Our data support the strong clinical impression that a supportive family is of enormous benefit to severely injured children. Burns injure families, not just individuals.3,11 Because a child’s outcome is so significantly affected by the degree of family function, it is important that family services be an integral part of acute management and aftercare.

Although early return to preburn activities was a powerful predictor of a favorable outcome, those who were successful in this area may have been those with less devastating injuries. However, this finding seems to support the benefit of directed efforts to reintegrate children with school and other age-appropriate activities as soon as possible after discharge.

Consistent follow-up in the multidisciplinary burn clinic was a predictor of better long-term results, although it appeared to select those with more serious injuries. We interpret this as demonstrating the importance of experienced multidisciplinary aftercare with coordinated physical and occupational therapy, scar management, reconstructive surgery, and family services on the end result. Participation in such a program also provides support through the relationships that develop among families dealing with similar problems as they meet and interact during visits to the burn center.

Some potential limitations of this study require comment. The SF-36 is a generic test that does not have disease-specific questions; particularly, it does not directly measure quality of life associated with physical appearance. Thus, we were not able to compare burn patients with unaffected individuals in this important area. However, to the degree that appearance affects psychological state, these effects are captured by the instruments’ mood questions. Second, although we found that increasing burn size was associated with worse physical function scores, we were not able to demonstrate a specific impact of facial or hand burns because virtually all children had injury to these areas. Third, although the sample is nearly complete, the small numbers of subjects in certain subsets and the wide range of ages represented may preclude firm conclusions. Fourth, our measures of a functional family and early reintegration with preburn activities are imprecise and should be refined in future studies. Finally, the study involves patients from only 1 center—the population was mostly white and low income. The generalizability to other samples remains to be demonstrated.

Children who survive massive burns will have major cosmetic and functional impairments that can never be completely corrected. However, these data show that treatment of massively burned children is not routinely followed by poor quality of life. Although massively burned children cannot be returned to their preinjury appearance and function, high-quality acute care combined with skillful multidisciplinary aftercare and family support can produce satisfying long-term outcomes for children with massive burns.

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**REFERENCES**


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