

# The Impact of Pediatric Brachial Plexus Injury on Families

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**Purpose** To determine the impact of brachial plexus injuries on families to best meet their clinical and social needs.

**Methods** Our cross-sectional study included families with children between the ages of 1 and 18 years with birth or non-neonatal brachial plexus injuries (BPIs). The consenting parent or guardian completed a demographic questionnaire and the validated Impact on Family Scale during a single assessment. Total scores can range from 0 to 100, with the higher the score indicating a higher impact on the family. Factor analysis and item-total correlations were used to examine structure, individual items, and dimensions of family impact.

**Results** A total of 102 caregivers participated. Overall, families perceived various dimensions of impact on having a child with a BPI. Total family impact was 43. The 2 individual items correlating most strongly with the overall total score were from the financial dimension of the Impact on Family Scale. The strongest demographic relationship was traveling nationally for care and treatment of the BPI. Severity of injury was marginally correlated with impact on the family. Parent–child agreement about the severity of the illness was relatively high.

**Conclusions** Caretakers of children with a BPI perceived impact on their families in the form of personal strain, family/social factors, financial stress, and mastery. A multidisciplinary clinical care team should address the various realms of impact on family throughout the course of treatment. (*J Hand Surg Am.* 2015;40(6):1190–1195. Copyright © 2015 by the American Society for Surgery of the Hand. All rights reserved.)

**Type of study/level of evidence** Prognostic II.

**Key words** Brachial plexus, families, Impact on Family Scale.

**I**N NEONATAL BRACHIAL PLEXUS INJURIES (BPIs), shoulder dystocia is the most common mechanism of injury.<sup>1,2</sup> In non-neonatal cases, trauma forces (eg, impact caused by a high-speed motor vehicle accident)

are the most common causes of BPI.<sup>3</sup> Approximately 60% of neonatal injuries are mild and spontaneously resolve.<sup>4</sup> More severe injuries often have long-term, varying degrees of restricted function through the shoulder, arm, or hand.<sup>2,5,6</sup>

Having a child with varying disabilities can impact a family in multiple ways, including social, financial, relational, and/or emotional realms.<sup>7–11</sup> The impact of a child's disability on their family is frequently unrecognized and underestimated.<sup>7</sup> Care is often solely focused on treating the injured child, with little attention given to the entire family. This study evaluated parental perceptions of the BPI's impact on family life. Identification of these perceived impacts may help determine the best ways

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to meet the clinical and social service needs of the entire family.

## MATERIALS AND METHODS

### Study population

Institutional review board approval was obtained prior to the study. Caregivers (parents or guardians) were required to be at least 18 years old, and the children with the BPI were between 1 and 18 years of age. Both children with neonatal and non-neonatal BPIs were eligible to participate if it had been one year since injury, ensuring that families had ample time to provide an adequate assessment of the injury impact. Previous surgical intervention was not an exclusionary criterion for eligibility. All participants were first-language English-speaking with primary residence in the United States.

### Data collection

Patients scheduled to be seen in the Brachial Plexus Center were screened for inclusion eligibility over a 7-month period. For a neonatal BPI, a clinician documented the severity using the Narakas classification during the newborn period.<sup>12</sup> For those families opting to participate, the consenting caregiver completed a brief questionnaire during a single assessment while waiting for their child's multidisciplinary Brachial Plexus Center clinic visit.

### Questionnaire measure

Questionnaires were composed of 3 sections: demographics of the child with BPI, broader family demographics (family caregiver's marital status, education, income, etc), and the validated Impact on Family Scale (IFS).<sup>13,14</sup> The IFS measures a parent's perception of their child's health condition on family life. The IFS is a widely accepted self-administered scale appropriate for caregivers of children with chronic illnesses.<sup>13,14</sup> It was developed to assess the effect of a child's illness on the family. Within the scale, 4 dimensions of impact are captured: financial (economic burden); familial/social (extent interaction within and outside of the family has been disrupted); personal strain (primary caretaker's challenges, such as psychological burden, fatigue, and/or uncertainty); and mastery (the family's ability to cope with the stress through mutual support).<sup>13,14</sup>

The IFS consists of 27 questions and an additional 6 questions for children with siblings. It is formatted as a 4-point (*strongly agree* to *strongly disagree*) Likert-type scale. The scale's high reliability allows for its use at any point during the child's duration of

illness. Strong face validity and psychometric data, including construct validity, are favorable to capture a caregiver's perception of the impact of the child's chronic illness on the family. The 4 dimensions of the scale are not completely independent. Scores for each of the 4 dimensions are calculated using inverse proportion computing. The sum of the 4 dimension scores equals the total impact score. A high total score is indicative of a high impact on the family.<sup>13,14</sup>

### Statistical analysis

In the original sample used for the development of the IFS,<sup>14</sup> the standard deviation of the total score was 9.5. This was used to estimate our sample-size calculations. For a potential predictor of family impact in this population, we considered the mean difference of the total score of at least 5 points between the demographic subpopulations (marital status, sex, etc) to be of clinical interest. Factor analysis was used to examine the structure of the IFS in our sample. We estimated a 4-factor model (with promax rotation) and compared the pattern of factor loadings with those obtained by Stein et al<sup>13,14</sup> as a comparable model. We also computed item-total correlations to assess which individual items and dimensions of impact were most closely related to the total IFS score. Analysis of variance was used to determine significance among demographics. Associations of other variables with the total score were assessed using linear correlation and *t* tests. To determine a relationship as significant, the type I error rate was set at  $\alpha = .05$ , two-sided.

## RESULTS

### Family demographics

A total of 166 families met inclusion criteria of the 256 unique patients seen during the 7-month enrollment period. A total of 102 caregivers of children with BPI participated (Table 1). Ninety-five percent (97 of 102) of caregivers resided in the same household as the child with BPI. The number of household providers was not significantly associated with impact ( $P = .38$ ,  $r = -.09$ ). The caregiver income and level of education both correlated negatively with family impact ( $P = .01$ ,  $r = -.25$ ) and ( $P = .04$ ,  $r = -.24$ ), respectively. Seventy-five percent (76 of 102) identified their child with BPI as the only household member with substantial health issues. Ninety-three percent (93 of 100) identified having support resources they could turn to for help and comfort, primarily in the form of family or friends.

The strongest demographic relationship was distance traveled for BPI treatment services. Post hoc

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