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The Impact of Pediatric Brachial Plexus Injury on Families

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Abstract

Purpose—To determine the impact on families of children with brachial plexus injuries in order to best meet their clinical and social needs.

Methods—Our cross-sectional study included families with children between the ages of 1 and 18 with birth or non-neonatal brachial plexus injuries (BPI). 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 0-100, 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—One hundred two 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

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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.

Conclusion—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.

Level of Evidence—II Prognostic

Keywords

Brachial Plexus; Families; Impact on Family Scale

Introduction

In neonatal brachial plexus injuries (BPI), shoulder dystocia is the most common mechanism of injury. [1, 2] In non-neonatal cases, trauma forces (e.g., impact caused by a highspeed motor vehicle accident) are the most common causes. [3] Approximately 60% of neonatal injuries are mild and spontaneously resolve. [4] More severe injuries often have long-term, varying degrees of restricted function through the shoulder, arm, and/or hand. [2, 5, 6]

Having a child with varying disabilities can impact a family in multiple ways, including social, financial, relational, and/or emotional realms. [7-11] The impact of a child's disability on his or her family is frequently unrecognized and underestimated. [7] 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 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, and the children with the BPI were between 1 and 18 years of age. Both children with birth and non-neonatal BPI 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 USA.

Data collection

Patients scheduled to be seen in the Brachial Plexus Center were screened for inclusion eligibility over a 7-month period. For a birth BPI, a clinician documented the severity using the Narakas classification during the newborn period.[12] 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). [13, 14] 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 [13, 14]. 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). [13, 14]

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. [13, 14]

Statistical Analysis

In the original sample used for the development of the IFS [14], 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 sub-populations (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 to those obtained by Stein, et al. [13, 14] 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. ANOVA 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 (97/102) 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 (76/102) identified their child with BPI as the only household member with substantial health issues. Ninety-three percent (93/100) 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 mean comparisons showed that impact for those traveling regionally (a few hours' drive, but no overnight stay required) was significantly higher ($n = 57$, $P = .003$) compared to locally treated patients (within an hour's drive, $n = 29$). Those traveling nationally (considerable distance/an overnight stay required) ($n = 16$, $P = .002$) had an even higher impact compared to those traveling locally.

Patient Demographics

Of the 102 patients, 97 were neonatal birth injuries and 5 were non-neonatal injuries occurring after birth. (Table 2) The majority of the patients had functional deficits requiring clinical intervention. (Table 2) We did not observe a significant effect of age on family impact scores ($P = .66$ by linear regression). The Narakas classification was documented in the medical record of 57 patients. Severity of injury (least severe Narakas level 1 versus most severe level 4) was only marginally significant ($P = .054$) to the impact on the family. [12]

One question on the survey asked the caretaker and patient to each rate the BPI as severe, moderate, or mild from his or her own perspective. If the parent felt their child could not assess, they answered the question as "Child unable to rate". Thirty-nine participants had both a caregiver and child assessment of injury severity. In 27 (69%) of those instances, the caregiver and child both rated the injury the same. There was substantial parent-child agreement about the severity of the illness with a weighted kappa of .65 (.47, .82). There were discrepant ratings between the caregiver and patient in 12 cases. In 75% (9/12) of the discrepant instances, the caretaker rated the child's injury more severe than did the child.

Impact on Family Scale

Overall, families of children with BPI had a total family impact score of 43 (SD 10). Strain, by a small margin, was reliably ranked as most correlated to the family impact total ($R = .89$). The next most correlated area was the family/social dimension ($R = .87$) followed by the financial dimension ($R = .73$). Mastery (the family's ability to cope through mutual support) was weakly correlated ($R = .20$) and was ranked last. Like the original paper describing the IFS, the mastery items in our study also had very low correlations to the total thus forming an almost completely independent factor. [14]

The individual questions most strongly correlated in the financial, strain, and family/social realm were all relatively high while mastery was weak, similar to the total score results. The 2 strongest item-total correlations were "I am cutting down hours I work to care for my child" ($R = .71$) and "The illness is causing financial problems for the family" ($R = .68$). Both

were from the financial dimension of the IFS. The third strongest correlation was “Sometimes I feel like I am on a roller coaster and then OK” ($R=.66$) from the strain realm. The family/social realm's highest item-total correlation was “Our family gives up things because of my child's illness” ($R=.65$). The highest within the mastery realm “We try to treat my child as though he is normal” ($R=.27$).

Seventy-five percent (76/102) of families answered the additional questions relevant to siblings of the patients. None of the items correlated with an impact on their families. Families overwhelmingly disagreed with the statement that the BPI was causing siblings to fight (-0.69), that their non-affected children were frightened by the BPI (-0.67), and that the siblings experienced more illnesses (-0.61) or suffered lower grades (-0.68).

Discussion

Caretakers of children with BPI perceived impact on their families predominantly in the form of personal strain (psychological burden), family/social factors (disruption of social interactions), and in the financial realm (economic burden). To a much lesser extent, mastery (the family's coping ability through mutual support) was identified. The clinical care team should consider the aggregate effect of these IFS dimensions during the course of BPI treatment.

The degree of severity marginally correlated with perception of impact, similar to related research. Firat et al. found that mothers of children with neonatal BPI perceived disability regardless of severity, contrasting with health care provider's observations.[15] In another study, no statistical significance was found between the mothers' depression, anxiety, emotional exhaustion, or depersonalization and the BPI severity of their infants. [16] BPI severity may not be the strongest factor at play in affecting perception of family impact. Caring for a child with a BPI, regardless of positive prognostic indications, may be enough to create an impact for some families.

Both income and education level correlated negatively with family impact. However, the number of caregivers involved in the child's life was not significantly associated with family impact. When families were classified into equal groups where 2 parents (whether biological, adoptive, or step) were compared to those having one caregiver, there were still no significant differences. Perhaps the ability to detect significance for this variable is outside the scope of the measure, as the IFS was designed to examine the family as a whole, not individual family members.

Among the demographics, the most notable increase in impact by a rather large margin were families traveling regionally and nationally to seek care for their child. This may be explained by the numerous areas of impact involved (costs of travel, family and social strain of time away from home requiring missed work, school, etc.). This finding highlights the extensive impact that a child with BPI can have on the family. Simply arranging or obtaining care for the child can be an ordeal that affects many aspects of the family life. A robust multidisciplinary team that is capable of coordinating care and testing may be able to ease the impact greatly. A team that provides access to social services among other

resources may also minimize family impact. Easing burden through use of video conferencing, telemedicine, and online communication tools (such as MyChart) may also be options. A multidisciplinary model is key to high quality care in various health conditions. [17-19]

The majority of caregivers and children both rated the injury severity the same. In 9 of 12 discrepant cases, the caretaker rated their child's injury more severe than did the child. Caregiver ratings being more severe than the child's have similarly been reported in other conditions.[20-23] The burden of caretaker compared to a child may create this difference in perception. While we cannot explain the reasons for this discrepancy, we feel it is congruent with our finding that care of the family is warranted beyond the focus of the injured child.

Several studies have looked at quality of life (QOL) pertaining to BPI [24-26]. Mothers of children with BPI were found to have a lower QOL than healthy controls; the professional's importance in helping parents cope was cited. [24] Akel et al reported poorer QOL scores in neonatal BPI than for their healthy peers. [25] Alyanak et al, found that children with neonatal BPI and their mothers are at increased risk for a variety of psychological stressors. [27]

Parental distress and dissatisfaction with communication surrounding the diagnosis and accompanying information in both mild and severe cases of neonatal BPI have been reported, and the need for a multidisciplinary team to address the clinical care, appropriate education, and resources for these families was cited. [26] Providing education may prove an effective first step in helping families establish appropriate expectations and attainable goals. As Squitieri et al. found in adolescents who experienced neonatal BPI, such understanding is essential for patient care. Solely relying on physical examination may not be sufficient care for the patient and their family. [28] Clinician-led family programs focusing on education, care, and coping have been effective in building empowerment to ease stress and enhance well-being of parents of children with chronic and rare conditions. [29, 30] Events for families with children with BPI that provide education, support groups, and recreational/social activities provide an opportunity to meet with others sharing common experiences, gain invaluable support, and learn more about the injury. [31]

The IFS has been widely used to provide a measure of impact on the family. Firat et al. studied Turkish mothers and found them to be moderately affected by their child's BPI with an IFS total score of 57 and noted a need for inclusiveness of social workers.[15] A total IFS score of 31 was reported in children with cerebral palsy. [32] Families of children receiving congenital diaphragmatic hernia repair reported a 38 IFS score. [33] Almesned et al. reported a total IFS score of 51 for children with minor heart disease and 62 for those with more complex congenital heart disease. [34] Evidence from these studies indicate the need for resources and family support as a justified and integral component of thorough care for many health conditions. The findings heed caution of a narrow approach where attention is given solely to the ill or injured child.

This study is limited by several factors. The participants were comprised of a convenience sample, and therefore a sampling bias is inevitable. Those families feeling a high level of

impact from BPI may have been more willing to participate creating a skewed cohort. As a cross-sectional study, the data are limited in capturing change experienced over time. Although we were able to identify impact on families, data were unable to capture different impact levels for individual family members or establish if the participant was experiencing the highest impact among the family.

Ninety-three percent of the participants reported having support resources they could turn to for help and comfort, primarily in the form of family members and friends; yet they still reported feeling a moderate impact on their families. Ultimately, having a child with a BPI requiring long-term care will cause impact on the family. Therefore, the entire family should be taken into account. We find that multidisciplinary team approach robust in hospital and community-based resources, complete with access to social services during all appointments, is crucial to provide a high level of care to these families. Peer-to-peer or family-to-family support may create an opportunity for families to share coping strategies and find common ground that may provide a sense of comfort or even camaraderie in knowing they are not alone. In addition to the clinical assessment, the familial/social realm, strain, mastery, and financial impacts of the family should be identified and addressed accordingly to provide optimal care for children with BPI.

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Table 1**Demographic Data (n=102)**

| Sex of children with BPI | |
|---|------------------------|
| Male | 50 (49%) |
| Female | 52 (51%) |
| Mean age | 6.4 (range 1-18 years) |
| Race | |
| Caucasian | 53 (52%) |
| African American | 31 (30%) |
| Hispanic American | 4 (4%) |
| Asian American | 2 (2%) |
| Other | 12 (12%) |
| Insurance coverage (some with multiple coverage) | |
| Private Insurance | 61 (60%) |
| Medicaid | 36 (35%) |
| Uninsured | 1 (1%) |
| Other | 12 (12%) |
| Caregiver completing questionnaires | |
| Biological mother | 84 (82%) |
| Biological father | 10 (10%) |
| Step parent or grandparent | 8 (8%) |

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Table 2
Brachial Plexus Injury data (n=102)

| | |
|---|----|
| Narakas classification | |
| I (C5-6 injury) | 15 |
| II (C5-C7 injury) | 21 |
| III (C5-T1 injury) | 11 |
| IV (C5-T1 injury & flail arm with possible Horner's syndrome) | 10 |
| Non-neonatal | 40 |
| Unknown level of injury | 5 |
| Prior treatment | |
| Botulinum toxin A injections | 35 |
| Previous surgical intervention | |
| Primary nerve surgery | 39 |
| Muscle/tendon transfers | 40 |
| Osteotomy | 7 |
| Other | 2 |

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