SCIENTIFIC ARTICLE

Understanding Quality of Life and Patient Expectations Among Adolescents With Neonatal Brachial Plexus Palsy: A Qualitative and Quantitative Pilot Study

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Purpose To explore the quality of life (QOL) and patient expectations among adolescents with neonatal brachial plexus palsy (NBPP) and their parents using qualitative and quantitative approaches.

Methods A total of 18 adolescents (10–17 y) with residual NBPP impairment and their parents underwent separate 1-hour tape-recorded semistructured interviews. We also collected quantitative physical examination measures and patient-rated outcome scores, specifically the Pediatric Outcomes Data Collection Instrument and the Child Health Questionnaire, to quantify the severity of each adolescent's functional deficit and increase our understanding of QOL and patient expectations.

Results Through qualitative analysis, we identified several patient- and system-dependent factors contributing to QOL, such as social impact and peer acceptance, emotional adjustment, aesthetic concerns and body image, functional limitations, physical and occupational therapy, finances, pain, and family dynamics. Despite residual impairment, most adolescents and their parents reported a good overall QOL according to quantitative outcome measures. Our study results showed that functional and aesthetic factors were responsible for most observed differences in QOL among NBPP adolescents. We also found that the Pediatric Outcomes Data Collection Instrument might be more sensitive than the Child Health Questionnaire in assessing patient expectations and QOL among this patient population.

Conclusions Understanding patient expectations and QOL in NBPP adolescents is essential for medical decision making and advancing care. Physical examination measurements alone may not be sufficient for measuring outcome, and knowledge regarding environmental factors and family dynamics is important for clinicians to consider when counseling families of children with NBPP and improving overall outcome. *(J Hand Surg Am. 2013;38(12):2387–2397. Copyright © 2013 by the American Society for Surgery of the Hand. All rights reserved.)*

Type of study/level of evidence Prognostic IV.

Key words Brachial plexus palsy, patient expectations, qualitative.

Additional material is available online.

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NEONATAL BRACHIAL PLEXUS PALSY (NBPP) affects approximately 0.1 to 5.1 per 1,000 live births.[1–4] Although most infants (66% to 96%) experience full recovery without intervention, those with residual deficits experience varying degrees of muscle imbalance, soft tissue contractures, and osseous deformities leading to functional impairment and aesthetic consequences.[4–12] Thus, children and adolescents with NBPP encompass a wide range of clinical presentations and neurologic deficiencies that require unique and tailored treatment algorithms.[1,5,11,12] Over the past several decades, advances in microsurgical nerve repair and reconstruction have changed the landscape of long-term surgical management and treatment outcomes among adolescents with NBPP.[1,10,12] However, little information exists regarding patient-rated outcome measures for NBPP and the long-term psychosocial impact of NBPP on children and their families.

Traditionally, functional health status and surgical outcomes for NBPP have been measured using a variety of validated physician-derived scores based primarily on physical examination findings, such as the modified Mallet Classification, Toronto Test Score, and Active Movement Scale.[13,14] However, across all disciplines of medicine, physicians, payers, and policy makers have increasingly recognized the importance of incorporating patient opinions and expectations when evaluating health outcomes.[15–17] For reconstructive procedures aimed solely at improving quality of life (QOL) rather than increasing life expectancy, it is imperative to identify the best method of assessing patient expectations and global health-related QOL to develop valid outcome measures to guide surgical treatment, economic analyses, and health policy.[13–18]

To date, several quantitative studies have been published evaluating different patient-rated QOL outcome measures in children with upper extremity deficits.[19–23] However, much of this work has focused on children with other chronic conditions such as cerebral palsy, whereas NBPP has remained relatively understudied.[19–23] Among published NBPP studies, most fail to use reliable comprehensive assessment tools including both motor and psychosocial outcomes. Furthermore, there is little research including adolescents.[14,20,24–26] Unlike quantitative studies, which are limited by statistical power and the a priori perspective of study investigators, qualitative research uses open-ended interviews and focus groups to gain insight into various theories relating to a specific health care condition or patient group.[18,27–31] Qualitative methods are best used for generating additional contextual information about complex health care topics for which research is not well established or when conventional quantitative theories seem premature or inadequate.[18,27–31]

Understanding the contribution of psychosocial factors to overall health status and patient expectations in the adolescent population is most important because of rapidly changing emotional needs, increasing desire for independence, and greater emphasis on peer acceptance during this period. There is a paucity of information in the literature regarding the coping mechanisms of children with congenital upper extremity impairments and the importance of family dynamics on overall child well-being and QOL. The purpose of this pilot study was to explore the global QOL and patient expectations among adolescents with NBPP and their families using qualitative and quantitative research methods. We aimed to identify factors that influence patient- and parent-rated outcomes and treatment desires to assist clinicians in evaluating and counseling adolescents with NBPP and their families.

METHODS

Study sample

Because the objective of qualitative studies is to generate themes of interest rather than to statistically quantify measured health outcomes, validity is judged on the basis of sample selection and depth or scope of interview content rather than sample size as in quantitative studies.[18,27–31] We chose to purposively sample adolescents diagnosed with NBPP who had some degree of residual impairment beyond infancy and received a combination of surgery, botulinum A injections, and/or continued therapy and follow-up. To explore divergences in experience between maturing adolescents and their health care proxies, we also chose to interview the parents of NBPP patients. An informational flyer was mailed to all eligible patients identified in an institutional review board–approved data repository containing information for all patients seen at a single institution from 2010 to 2012. We also mailed the same informational flyer to all physical and occupational therapists known to treat infants with NBPP throughout Michigan. From our database of 280 patients with NBPP, flyers were sent to 27 eligible subject pairs and to 50 physical and occupational therapists. Nineteen eligible patient–parent pairs elected to participate in our