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Medical Decision-Making Among Adolescents with Neonatal Brachial Plexus Palsy and their Families: A Qualitative Study

Lee Squitieri, MD, MS¹ [Resident Physician], Bradley P. Larson, BS² [Research Associate], Kate W-C Chang, MA³ [Research Associate], Lynda J-S. Yang, MD, PhD⁴ [Associate Professor of Neurosurgery], and Kevin C. Chung, MD, MS⁵ [Professor of Surgery]

¹Department of Surgery, Division of Plastic and Reconstructive Surgery, The University of Southern California

²Department of Surgery, Section of Plastic Surgery, The University of Michigan

³Pediatric Brachial Plexus Program, The University of Michigan

⁴Department of Neurosurgery, The University of Michigan

⁵Department of Surgery, Section of Plastic Surgery, The University of Michigan

Abstract

Background—Elective surgical management of neonatal brachial plexus palsy is complex, variable, and often individualized. Little is known about the medical decision-making process among adolescents with NBPP and their families faced with making complex treatment decisions. The experiences of these patients and their parents were analyzed to identify key factors in the decision-making process.

Patients and Methods—Eighteen adolescents with residual NBPP deficits between the ages of 10 to 17 years along with their parents were included in the present study. A qualitative research design was employed involving the use of separate one hour, in person, semi-structured interviews, which were audio recorded and transcribed. Grounded theory was applied by two independent members of the research team to identify recurrent themes and ultimately create a codebook that was then applied to the data.

Results—Medical decision-making among adolescents with NBPP and their families is multifaceted and individualized, comprised of both patient and system dependent factors. Four codes pertaining to the medical decision-making process were identified: 1) knowledge acquisition, 2) multidisciplinary care, 3) adolescent autonomy, and 4) patient expectations and treatment desires. Overall, parental decision-making was heavily influenced by system dependent factors, while adolescents largely based their medical decision-making on individual treatment desires to improve function and/or aesthetics.

Conclusions—There are many areas for improving the delivery of information and health care organization among adolescents with NBPP and their families. We recommend the development

of educational interdisciplinary programs and decision aids containing evidence-based management guidelines targeted toward primary care providers and patients. We believe that a computer-based learning module may provide the best avenue to achieve maximum penetrance and convenience of information sharing.

Keywords

Brachial Plexus Palsy; Medical Decision-Making; Qualitative

Neonatal brachial plexus palsy (NBPP) is a distressing condition for families faced with the potential of raising a child with permanent impairment of the affected arm. Although the majority (66–96%) of infants with NBPP demonstrate spontaneous recovery within the first 3 months of life, those with persistent neurologic deficits often experience muscle imbalance and subsequent deformity.^{1–9} Over the past 30 years, advancements in microsurgical repair/reconstruction have popularized the use of primary nerve surgery and changed the landscape of long-term NBPP management.^{2,7} However, in cases of late presentation (no longer candidate for primary nerve surgery) or when primary nerve surgery yields incomplete return of function, combinations of reconstructive surgical interventions (e.g., tendon transfers, osteotomies) remain the mainstay of treatment to address residual impairment.^{2,8}

Among children and adolescents with lasting deficits, elective surgical management is variable and does not follow a prescribed algorithm. Both the timing and choice of interventions are usually individually tailored to the child's unique functional, emotional, and practical needs, as well as the time of initial presentation. To date, little is known about the decision-making process of children and adolescents with NBPP who suffer from residual impairments and require ongoing treatment, including therapy, Onabotulinumtoxin A injections (Allergan Inc., Irvine CA), and/or surgery. Previous studies have shown that the collaborative process of medical decision-making between patients and their physicians is influenced by a variety of factors, such as individual patient and family experiences, and the opinions of family, friends, or other knowledgeable parties.^{10,11} For elective reconstructive procedures aimed solely at improving quality of life (rather than increasing life expectancy), the concept of risk-benefit is often more individualized and varied according to patient specific desires and values.^{11,12} Thus, among these interventions, it is imperative to understand the motivations, preferences, and expectations that drive medical decision-making in order to maximize the likelihood of patient satisfaction and improved outcomes.

The purpose of the present study was to explore and describe the medical decision-making process among children and adolescents with NBPP from the patient and family perspective using qualitative research methods. This knowledge will allow physicians and caregivers to more effectively counsel children and adolescents with NBPP and their families.

Patients and Methods

For this study, we applied qualitative research methods to gain insight into various themes regarding medical decision-making. The inductive and interpretive nature of qualitative research yields additional contextual information about complex health care topics for which research is not well established, or when conventional quantitative theories seem premature

or inadequate.^{13–18} We used grounded theory to guide both data collection and analysis. Grounded theory is a type of qualitative methodology that uses the inductive process of identifying analytical themes or ideas as they emerge from data (developing them from the “ground-up” rather than defining them prior to study initiation).^{13,17,19,20} Data collection generally arises from knowledge obtained during open-ended or semi-structured interviews with a sample of individuals or focus groups.^{13,18–23} These data are then analyzed through a rigorous iterative coding process that allows multiple theories and data hypotheses to emerge simultaneously in an unbiased systematic fashion.^{13,18–23}

Study Sample

Unlike quantitative studies that use systematic random sampling with adequate power to prove an a-priori hypothesis, qualitative studies typically use purposive sampling of smaller subpopulations that possess specific study characteristics of interest.^{13,15,16,18,20} For this study, we included adolescents diagnosed with NBPP who suffered from some degree of residual impairment beyond infancy and required some combination of surgery, OnabotulinumtoxinA injections, and/or continued therapy and follow-up. We also interviewed the parents of each NBPP patient who participated in our study, to gain additional perspective and to explore differences between maturing adolescents and their health care proxies. Eligible adolescent-parent pairs were recruited via two methods: 1) from a University of Michigan Institutional Review Board (IRB) approved data repository for NBPP patients, and 2) through a list of physical and occupational therapists known to treat infants with NBPP throughout the state of Michigan. Eighteen consecutive patient-parent pairs with adolescents between the ages of 10–17 years participated in separate 1 hour semi-structured interviews. Both informed consent from each parent/guardian and an additional informed assent from each minor were required for participation in this study. Each subject pair received a \$100 gift card to either Target, Meijer, or Home Depot to thank them for their time. This study was approved by the University of Michigan Institutional Review Board (HUM35037).

Data Collection

Adolescents and their parents underwent separate, in-person, tape-recorded, semi-structured interviews. To maintain consistency, all interviews were conducted by the same member of the research team (K.W-C. C.) using a semi-structured interview guide focused on medical decision-making and quality of life. The latter topic was examined in an analysis separate from this one.²⁴ Adolescents and parents were interviewed separately to examine differences in opinion and ensure comprehensive coverage of interview topics. Each parent was interviewed before the adolescent to obtain general information for building rapport in case the adolescent was too shy to comment on their condition. To increase our understanding of each adolescent’s degree of functional impairment in the context of their interview, we also measured objective functional scores (Narakas, Mallet, and Raimondi). The Narakas classification is an accepted measure of the severity of NBPP based on neurological involvement and clinical exam. Scores range from one to four with one being the mildest and four being the most severe.²⁵ The Mallet classification system evaluates the global movement and functions of the upper extremity (primarily shoulder function). The scale assesses five movements (listed above) and grades each one from one to five with one being

no movement/range of motion and five being normal movement/range of motion.²⁶ The Raimondi classification is used to evaluate hand function. Scores range from zero to five with zero representing complete paralysis and five representing excellent function.²⁷

Data Analysis

All audio-recorded interviews were transcribed verbatim immediately after each interaction so that findings from early interviews could be explored and verified in greater depth with subsequent study subjects.^{13,18} Once the transcripts were finalized, two members of the research team (B.P.L. and L.S.) independently performed open coding and identification of key concepts to reduce inherent biases in the personal interpretation of interview transcripts.^{13,18} After open coding of all transcripts was completed by both reviewers, the research team convened to collaborate on their discrete findings. Through comprehensive review and discussion, a final codebook was generated that included categories, codes, and subcodes.^{13,18} The transcripts were then reread independently by the same two reviewers with application of the codebook. Upon completion of codebook application, the research team met again to resolve any discrepancies. The final coded transcripts were then analyzed to identify which codes occurred most frequently within patient groups and representative quotations were selected for inclusion in the manuscript.^{13,18}

Results

Eighteen adolescent-parent pairs including thirteen females and five males with a mean age of 11.6 years (range 10–17 years) participated in our study (Table 1). Ten patients (56%) were managed with therapy alone, four patients (22%) were treated with therapy and OnabotulinumtoxinA injections, and four patients (22%) underwent surgical intervention. Patients displayed a wide range of functional impairment, from good to poor outcomes, as measured by Narakas score (range 2–3), Mallet score (range 2–4), and Raimondi hand score (range 0–5).^{25–27}

Overall, interviews averaged 62 minutes in duration (range 55–65). Twelve codes and twenty-six subcodes emerged within two broad categories: (1) medical decision-making and (2) quality of life. This analysis will focus on medical decision-making. Based on our interviews, we found that medical decision-making among adolescents with NBPP and their parents is complex and individualized, comprised of both patient and system dependent factors. Creation and application of the codebook demonstrated contributions from the following four codes: (1) knowledge acquisition, (2) multidisciplinary care, (3) adolescent autonomy, and (4) patient expectations and treatment desires (Table 2). The frequency and relative percentages of each code are displayed in Figure 1 and representative quotes from each code are listed in Table 3. Overall, parental decision-making was heavily influenced by system dependent factors, such as knowledge obtained from physicians, the Internet, and other parents (43%) and the complex logistical coordination of multidisciplinary care (26%). Alternatively, adolescents largely based their medical decision-making on individual treatment desires to improve function and/or aesthetics (73%) with a lesser consideration of coordinating appointments/therapy sessions and postoperative care.

Knowledge Acquisition

Knowledge acquisition through use of the Internet, inter-parental communication networks, and physician interactions played a significant role in medical decision-making for most parents. In the immediate post-birth time period, several parents expressed frustration regarding a lack of knowledge sharing and patient education from health care workers in the hospital. Thus, many parents obtained their initial information regarding NBPP etiology and management from the pediatrician at the initial follow-up visit after hospital discharge and from the Internet. In addition to providing general medical information, websites also provided a message blog or discussion forum for parents to share information, management strategies, and specialty referrals.

Multidisciplinary Care

Many parents in our study commented on the confusing and rigorous nature of establishing care for NBPP due to the lack of familiarity with current management algorithms and timelines among primary care providers (pediatricians, obstetricians, therapists, etc.). Given the numerous types of specialists involved in the care of this complex condition, most parents deferred to their primary care provider or the advice of friends/other parents regarding initiation of therapy and/or interventions. In addition to coordinating opinions between various specialists, parents were also inconvenienced by the burdensome process of scheduling multiple appointments with different specialists. Several parents who received care at the University of Michigan commented on the benefits of a coordinated team approach with an established group of multispecialty physicians and therapists, such as increased convenience and facilitated information sharing between specialties.

Adolescent Autonomy

As adolescents increased in age, their ability and desire to independently communicate with the physician increased as well as their influence on the medical decision-making process. This shift was often accompanied by a transition from paternalistic medical decision-making when the children are young, to either shared decision-making by adolescent and parent or autonomous adolescent decision-making. Some parents of current adolescents reported that they would defer to the adolescent expressing a desire for change in outcome before seeking interventions such as surgery. Furthermore, parents also acknowledged how the emotional development of the adolescent influenced their readiness for surgery and anticipated compliance with rehabilitation.

Patient Expectations and Treatment Desires

Many parents and adolescents commented on their own specific treatment desires and expectations. Aesthetics and appearance of the arm were highly valued by patients and their parents, especially among females. Functional limitations (if present) were also important contributors to the medical decision-making process, especially if they were obvious to peers.

Discussion

Medical decision-making within the doctor-patient relationship may be viewed as a continuum between the extremes of the paternalistic model (doctor decides, patient complies without explanation) and the informative model (doctor provides information, patient decides).²⁸ Over the past several decades, physicians, payers, and policy-makers have increasingly recognized the importance of patient autonomy and continually advocated for the incorporation of individual patient preferences in medical decision-making.^{28,29} Studies have shown that for select conditions involving choices between outcomes with uncertain evidence or risk-benefit profiles that patients value differently, the inclusion of patient preferences in decision-making can result in improved compliance, clinical outcome, and patient satisfaction, as well as decreased decision regret.^{19,29-33} Regardless of how proactive patients elect to be in their own medical decision-making, it is essential for caregivers to comprehensively understand individual patient concerns, desires, and values so that they may best counsel their patients about treatment options and interventions.²⁹

In this study, we sought to explore the medical decision-making process among adolescents with NBPP and their families using qualitative research methods. We found that medical decision-making among this group is complex and individualized, comprised of both patient and system dependent factors. Patient dependent factors, such as adolescent autonomy and individual expectations/treatment desires, are characteristics unique to each adolescent and generally unable to be influenced by physician interactions or delivery of care. However, clinicians should be cognizant of these individual factors when counseling patients about various treatment options and when managing patient expectations.

Alternatively, system dependent factors, such as knowledge acquisition and coordination of multidisciplinary care, may be heavily influenced by individual physicians and caregivers through multispecialty collaboration, information sharing, and efficient referral algorithms. Throughout the interviews, it was evident that some parents lacked guidance when trying to obtain information about their child's condition and subsequently relied on information acquired from the Internet and from other parents of children with NBPP. Similarly, a few parents reported feeling confused and frustrated when attempting to establish/maintain care with the numerous specialists involved in NBPP care. The benefits of a coordinated team approach, such as increased patient convenience and better transfer of information, were noted by parents who received care at a single multidisciplinary center. Taken together, these findings suggest multiple areas for improvement regarding information sharing and the delivery of care for children and adolescents with NBPP and their families.

Several limitations should be recognized when interpreting the results of any qualitative research analysis.^{13,15,16,18} Although all study methods are subject to investigator bias, it is especially relevant in qualitative research, which by definition, is open ended and based on the subjective perspectives of both the researcher and the participants. Our study was also limited to a small sample size and a selection bias toward more happy and functionally competent patients able to arrange transportation and accommodate study participation. However, because the objective of qualitative studies is to generate themes of interest rather than statistically quantify measured health outcomes, validity is generally judged on the

basis of sample selection and depth/scope of interview content rather than sample size as in quantitative studies.^{13,15,16,18} During interviews, our findings were also limited by recall bias among participants and subjective biases among interviewers. Preconceived notions of potential hypotheses generated from the data may influence the way interview guides are written and the way the interviewer directs the discussion. Similarly, these same biases may affect how passages and codes are selected, interpreted, and incorporated into the final manuscript. To reduce these aforementioned limitations, the codebook was developed by team consensus and each interview guide was independently coded by two members of the study team.

Conclusions and Future Recommendations

Shared decision-making combines individual patient preferences with evidence-based medicine to foster communication between patients and their physicians.^{32,34} Through this informed and joint decision-making process, it is intended that patients and health professionals share ownership of and participate in the responsibility for health care decisions.^{32,34} For several conditions, shared decision-making has been associated with improved compliance, clinical outcomes, and patient satisfaction, and also resulted in less decision regret.^{30–32} Decision aids are evidence-based tools designed aid patients in making specific and deliberated choices between healthcare options, according to their specific preferences.³⁴ Patient decision aids supplement (rather than replace) clinician counseling and differ from general health education materials because of their detailed, specific, and personalized focus on options and outcomes.³⁴ In a recent Cochrane review, decision aids were shown to increase patient involvement in their decision and lead to increased likelihood of making informed values-based decisions.³⁴

The results of our study suggest several areas for improving the delivery of information and health care organization among adolescents with NBPP and their families. We recommend the development of educational interdisciplinary programs and decision aids containing evidence-based management guidelines targeted toward primary care providers and patients. More specifically, given our finding that many parents obtained information from the Internet, we believe that a computer-based learning module may provide the best avenue to achieve maximum penetrance and convenience of information sharing. To date there is a paucity of research regarding the utility of decision aides in the pediatric population.³⁵ However, studies have shown that parents are interested in participating in decision-making and desire information and support when evaluating options.³⁶ In addition, other research has demonstrated that communication skills training for pediatric clinicians may improve health outcomes, especially for children from minority groups.³⁷ We believe that better education regarding management options to both primary care providers and patients, in addition to facilitated counseling with the use of decision aids will ultimately help empower patients along with their providers to achieve the best outcomes.

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Adolescent Medical Decision Making

Parent Medical Decision Making

Figure 1.
Frequency and Relative Percentages of Codes

Table 1**Patient Information**

Parameter	
Age (years) [†]	11.6 (10–17)
Gender distribution	
Male	5
Female	13
Palsy Side	
Right	14
Left	4
Nerve Involvement	
Upper Trunk	9
Lower Trunk	0
Panplexopathy	9
Treatment Type	
Therapy Alone	10
Therapy + Botox	4
Therapy + Surgery	4
Narakas Score (1–4) [†] ◆	2.67 (2–4)
Mallet Score (1–5) [†] *	
Active Abduction	2.72 (2–4)
External Rotation	2.50 (2–4)
Hand to Head/Nape of Neck	3.17 (2–4)
Hand to Back	2.89 (2–4)
Hand to Mouth	3.22 (2–4)
Raimondi Score (0–5) [†]	3.61 (0–5)

[†] Data presented as: mean (range)

◆ The Narakas classification is an accepted measure of the severity of NBPP based on neurological involvement and clinical exam. Scores range from one to four with one being the mildest and four being the most severe.²⁵

* The Mallet classification system evaluates the global movement and functions of the upper extremity (primarily shoulder function). The scale assesses five movements (listed above) and grades each one from one to five with one being no movement/range of motion and five being normal movement/range of motion.²⁶

The Raimondi classification is used to evaluate hand function. Scores range from zero to five with zero representing complete paralysis and five representing excellent function.²⁷

Table 2

Categories, Codes, and Subcodes Relating to Medical Decision Making

Medical Decision Making[†]
Knowledge Acquisition [‡]
Inter-Parental Communication ^γ
Use of Internet ^γ
Physician Interactions ^γ
Multidisciplinary Care [‡]
Coordination of Referrals/Appointments ^γ
Communication ^γ
Team Approach ^γ
Adolescent Autonomy [‡]
Independent Communication ^γ
Age ^γ
Treatment Desires [‡]
Adolescent-Parent Differences ^γ
Improvement of Aesthetics ^γ
Improvement of Function ^γ

[†] Categories[‡] Codes^γ Subcodes

Table 3**Representative Quotations****Knowledge Acquisition**

"I don't think they gave me enough information when she was born, they told us what it was and that she should have her sleeve pinned up and that depending on how severe it was it might go away or it might last. Most of the useful information we got was from our physical therapist. Occasionally we would also get information from the library or online." (Parent 38850 – 12 year old female)

"I went to internet. They put out a fabulous publication that explains brachial plexus with kids at birth and what can happen. And you can talk to other mothers online. I spoke with a lot of different mothers who had been there, whose kids have had the surgeries and made it. It's nice to be able to talk to somebody who's gone through what you're going through." (Parent 21398 – 10 year old female)

Multidisciplinary Care

"I remember taking her to her first appointment – our pediatrician called a neurologist on the phone and asked him his opinion and the neurologist said, 'Wait six months. We shouldn't do anything. Just wait. Don't do anything. Just let's wait and see.' I kind of just accepted it at that point but then I started reading more and learning there were things that could be done. And actually, we didn't get her involved in therapy or actually coming out here until she was much older. I think if I could go back, knowing everything I know now, I would have been more aggressive early on but we just listened to the physicians and they felt that they made the best decision." (Parent 91923 – 11 year old female)

"I like the focus here – it's more of a team approach. At our other hospital when she was younger we would have to go see the pediatrician who would tell us to go see the therapist who would make a plan and then we'd have to go back and forth and try to piece things together. But here, it's more comprehensive where the team comes together to make initial goals together with the child. Today after seeing the other doctors and therapists, I'm supposed to see a surgeon, and because he's already here I don't need to do anything or go anywhere or repeat our entire story. Everyone is on the same page." (Parent 91923 – 11 year old female)

Adolescent Autonomy

"At the end I think its half my decision and half my parents." (Adolescent 26926 – 13 year old male)

"My daughter doesn't want to talk about her failures or weaknesses with the doctor. Maybe it would be good to have a separate conversation with the parent without the child in the room and vice versa. Prior to eleven, I think the child is not mentally ready to make the decisions, and at some point the parent's voice needs to be heard more than the child's." (Parent 91923 – 11 year old female)

Treatment Desires

"When we're in dance class I have to get my arm straight and its hard. If there were a treatment to fix my arm I would want it to be straighter, but if there's no treatment then I can work with it" (Adolescent 91923 – 11 year old female)

"I wish I could do more things with my arm and I don't like how it looks so crooked. But being able to do things is more important than the way it looks." (Adolescent 90398 – 10 year old female)

"I would love for her to have the strength when she extends her elbow, so she would look more normal and things would be more symmetric. I think it's more appearance right now that I would want to fix. I think the function is okay." (Parent 91923 – 11 year old female)

"If I consider the whole arm, the area I would most want to see improved is his wrist range of motion. As far as getting surgery for this, I think we would think about the chances of losing more function and the scarring. I don't want to draw more attention to his arm and make it even more obvious to people" (Parent 26926 – 13 year old male)