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Original Article

Neonatal Brachial Plexus Palsy in Children Aged 0 to 2.5 Years; Parent-Perceived Family Impact, Quality of Life, and Upper Extremity Functioning



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ABSTRACT

BACKGROUND: To investigate whether parents perceive impact of neonatal brachial plexus palsy on family and quality of life and upper extremity functioning in children less than 2.5 years. **METHODS:** This cross-sectional study used the PedsQL Family Impact Module (36 items/one total/four scales/scores 0 to 100), TNO-AZL (Dutch Organisation of Applied Natural Science and Academic Hospital Leiden) Preschool Children Quality of Life (43 items/12 scales/scores 0 to 100) and 21 upper extremity functioning questions. Associations between neonatal brachial plexus palsy/patient characteristics and family impact, perceived quality of life, and upper extremity functioning were investigated using regression analysis. **RESULTS:** Parents of 59 children (median age, 18 months) participated, 49 with C5–C6/C5–C7 lesions. Median Family Impact Module and TNO-AZL Preschool Children Quality of Life scores were 81.3 to 100.0/100.0 and 78.6 to 100.0/100.0. TNO-AZL Preschool Children Quality of Life scores did not differ significantly to healthy references except for stomach, skin, communication, and motor functioning problems. Parents reported around three upper extremity functioning problems. Greater lesion extent, lower age, still being in follow-up, and right-sided lesions were associated with greater family impact ($P < 0.01$ to $P < 0.1$). No clinically relevant associations were found for perceived quality of life. Greater lesion extent and nerve surgery history were associated with more upper extremity functioning problems ($P < 0.01$). Problems were associated with parental worrying ($P < 0.05$). **CONCLUSIONS:** Parents perceive having a child with neonatal brachial plexus palsy as impacting on their family depending on the side and severity of the lesion, treatment history, still being in follow-up, and age. They perceive the child's quality of life as relatively normal and not significantly different to healthy peers. However, parents noticed upper extremity functioning problems which increased parental worrying. Health care specialists should take these findings into account to better inform or counsel parents in an early stage during treatment.

Keywords: brachial plexus neuropathy, quality of life, health impact assessment, pediatrics, nerve surgery, rehabilitation

Pediatr Neurol 2016; 62: 34–42

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Article History:

Received March 21, 2016; Accepted in final form June 19, 2016

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<http://dx.doi.org/10.1016/j.pediatrneurol.2016.06.015>

Introduction

Neonatal brachial plexus palsy (NBPP) is the result of a stretch injury to the plexus during delivery; its incidence ranges from 1.3 to 2.9/1000.^{1,2} Most injuries are mild, but 20% to 30% of the children are left with diminished upper arm function.^{2–4} Severe lesions can be treated with nerve surgery at a young age (3 to 9 months). Depending on the

clinical course over time, secondary surgery (muscle–tendon transfers/osteotomies) may be indicated later on.^{5–7}

When a child is diagnosed with NBPP, parents face an uncertain future.^{8,9} Over time, it will become apparent to which extent recovery can be expected and if nerve surgery will be indicated. Depending on neurological recovery, a better prediction can be made of future arm function. This period is often stressful and worrying for parents and their families. The prognostic uncertainty and consequences for the child's quality of life (QoL) might have impact on families and their QoL.^{8–10}

Despite these observations, little research has been done on the impact of NBPP on family and parental QoL in the first years of a child's life. One study found that impact on family was not age dependent.¹¹ Another study found that having a younger child with NBPP (age 0 to 2 years) had more impact on maternal QoL.¹² Some studies reported impact on the family in terms of finances, personal strain, social and mastery problems, increased risk of psychological problems or distress, and lower maternal QoL.^{10–14} Another study found that condition severity was associated with paternal stress and psychological adjustment, both affecting family functioning.¹⁵

Little is also known about the parent-perceived QoL of young children (less than 2.5 years) with NBPP. Studies in children with NBPP who are more than two years of age showed that these children have a poorer QoL and limited upper extremity functioning (UEF).^{13,16,17}

To fully understand the impact of NBPP in young children on the family, it is important to know how parents perceive their child's functioning. However, this has not been studied before.

Insight into family impact, QoL, and UEF and possible influential factors is important to be able to provide adequate care, which may help reduce the impact of having a child with NBPP.

Therefore, the goal of our study was to assess the impact of NBPP on family (including parental QoL), perceived QoL, and UEF of young children (less than 2.5 years). In addition, we explored possible factors associated with family impact, parent-perceived QoL, and UEF and compared the parent-perceived children's QoL with that in the general Dutch population.

Method

Study design and patients

This study had a cross-sectional design and was part of a larger study on functioning and QoL of patients of all ages with NBPP. That study was conducted between October 2014 and March 2015 at the multidisciplinary, supraregional NBPP care unit of the Leiden University Medical Center and was approved by its medical ethics committee (P14.071). All patients who visited the NBPP care unit, for whom an electronic medical record was available and who were diagnosed with NBPP, were eligible to participate. Patients with concurrent other medical diagnoses that might influence arm functioning (e.g., cerebral palsy, reduction defects) were excluded.

Recruitment

Eligible patients and/or their parents were sent an invitation (including information) to participate. They were asked whether they wanted to participate online or on paper. All participating patients aged

greater than 18 years and parents of patients aged less than 18 years provided written informed consent. Questionnaires were sent via regular mail, or patients were invited by e-mail to the online questionnaire. Patients and/or parents who had not responded to the invitation or did not complete the questionnaires received a reminder.

The present analysis only used data on children aged 0 to 2.5 years.

NBPP and patient characteristics

Age, gender, lesion extent (C5–C6/C5–C7/C5–C8/C5–T1/C8–T1), affected side (right/left), and treatment history (conservative/nerve and/or orthopedic surgery) were extracted from the medical records, and current status regarding discharge from follow-up (yes/no) was noted.

Parents were asked whether NBPP was present in their families, what kind of household they had (single-parent/two-parent), and whether the child with NBPP was their firstborn (yes/no). Parents were also asked to state whether they had contact with specific health care professionals (apart from the NBPP care unit) or patient organizations and whether their child had been admitted to hospital for NBPP in the past 12 months.

Parent-reported family impact

The 36-item PedsQL Family Impact Module (FIM) measures the impact of a child's chronic condition on their family and yields a Total Scale score, a parental QoL Summary score (Physical/Emotional/Social/Cognitive Functioning subscales; 20 items), a Family Functioning Summary score (Daily Activities/Family Relationships; eight items), a Worry score (five items), and a Communication score (three items). It uses a Likert-type response scale (0: never to 4: almost always), and scores are transformed to a 0 to 100 scale ($0 = 100/1 = 75/2 = 50/3 = 25/4 = 0$). Scores are computed as the sum of items divided by the number of items answered. Higher FIM scale scores indicate lower impact. If more than 50% of the items in a scale were missing, no score was computed. The FIM was found to be reliable and valid and is available in Dutch.¹⁸

Quality of life

The TNO-AZL (Dutch Organisation of Applied Natural Science and Academic Hospital Leiden) Preschool children QoL (TAPQOL) was developed to measure QoL in children aged six months to five years. It is a parent-reported, 43-item generic questionnaire, with 12 scales (three to seven items/scale) covering the domains of physical, social, cognitive, and emotional functioning. Questions relate to the past three months and are scored on a three-point scale (complaint/limitation present: never/occasionally/often). In addition, in seven of the 12 scales (stomach/skin/lung/sleeping/appetite/motor functioning/communication), the child's well-being is also measured in relation to these complaints/limitations, on a four-point scale (fine/not so good/quite bad/bad). Scale scores are transformed to a 0 to 100 scale, with higher scores indicating better QoL. No missing values are allowed in three-item scales, one in scales with four items, and two in scales with seven items. The social functioning/motor functioning/communication scales are only relevant for children aged over 1.5 years.¹⁹

TAPQOL scores were compared with those of healthy, age-matched references, using a sample from the publicly available reference database. The reference data were derived from 340 Dutch babies visiting youth health care centers (consultatiebureaus, visited by all Dutch children regularly in the first four years).²⁰ The sample was selected based on age (six to 30 months) and the absence of health problems, resulting in a reference group consisting of 118 children (median age, 21.0 months; range, ten to 30 months), 45 of whom were male.

Upper extremity functioning

To further understand the QoL issues in NBPP, parent-perceived children's UEF was assessed. No NBPP-specific questionnaires on UEF are available for very young children. Therefore we developed a set of questions regarding activities (15 items), bodily appearance

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