

Resilience Rather than Medical Factors: How Parents Predict Quality of Life of Their Sick Newborn

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Objective To assess the influence of resiliency and stress on parental perspectives of the future quality of life (QOL) of neonatal intensive care unit (NICU) newborns at high risk of neurodevelopmental disability.

Study design We conducted a prospective multicenter questionnaire study. Perspectives from parents of newborns at high risk of disability as per neonatal follow-up criteria were compared with a low-risk group consisting of parents of all other NICU newborns. Parental anxiety and resiliency, measured using Brief Symptom Inventory and Sense of Coherence scales, respectively, were associated with QOL projections.

Results Parents returned 129 (81%) questionnaires. Parents considering their newborn as currently sicker were more stressed ($P = .011$) and worried about future physical ($P < .001$) and mental ($P < .001$) health, QOL ($P < .001$), coping ($P = .019$), and financial ($P < .001$) and emotional ($P = .002$) impact on the family. Overall, there was no difference between parents of high-risk and low-risk newborns on QOL projections. Almost all parents projected a good future QOL. Less resilient parents projected more pain ($P = .04$), more financial ($P = .019$), and emotional ($P = .031$) impact on their family, and were 10 times more likely to predict that their newborn would remain chronically ill.

Conclusions Parental projection of future QOL of NICU newborns is not associated with risk of disability. Most parents predict overall a good future QOL and focus more on familial impact. The Sense of Coherence scale may be used in clinical settings to identify less resilient parents. (*J Pediatr* 2018;■■:■■-■■).

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In spite of advancement of medical technology and improved survival of critically ill newborns, those hospitalized in the neonatal intensive care unit (NICU) remain at high risk for future neurodevelopmental disability,¹⁻³ possibly affecting their future quality of life (QOL). Clinicians play an important role in counseling parents.^{4,5} In the context of NICU infants, clinicians appear to have a negative bias in patient's QOL evaluation.^{6,7} Clinicians usually base their prediction of future QOL on neurodevelopmental risk factors, whereby risk of disability is directly associated with a poorer future QOL.^{8,9} As parents are presumed to be the most reliable surrogates,^{10,11} it is important to understand what factors influence how they project future QOL, a complex and multidimensional concept.¹²⁻¹⁵ The birth of a sick child is considered a stressful and difficult experience, and stress may impact parental projection of QOL.¹⁶⁻¹⁹ Resilience is another key factor modulating the way QOL is experienced by individuals.¹² In this regard, Antonovsky's Sense of Coherence scale gives a measure of one's innate ability to respond to life stressors.^{18,20-23} Parents of hospitalized NICU newborns were previously shown to project either a positive or negative future QOL for their child.²⁴ However, whether stress and resilience parameters influenced QOL projection by such parents has not been studied. We hypothesized that parents of a newborn at high risk of neurodevelopmental disability would be more stressed and envision a more negative future QOL and that parental resilience factors would positively modulate this projection (Figure 1; available at www.jpeds.com).

Methods

We conducted a prospective survey study of parents whose child was admitted to the NICU. We developed a questionnaire that was informed by the literature and the results from our initial qualitative research exploring parental projections of QOL²⁴ to address how parents of NICU hospitalized newborns envision the future

BSI Brief symptom inventory scale
NICU Neonatal intensive care unit
QOL Quality of life

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QOL of their child, how they globally envision their own life, and how they rate their anxiety during their child's hospitalization. The final tool had 50 questions taking approximately 15 minutes to complete (**Appendix**; available at www.jpeds.com). The first part of the questionnaire addressed parental projection of future QOL based on 8 previously identified QOL themes²⁴ and the subjective parental evaluation of child's current illness. The second part of the questionnaire addressed parental coping and resilience using Sense of Coherence-13, a validated, shortened version of the original Sense of Coherence-29 scale.^{22,25} The Sense of Coherence is a well-established measure of one's internal ability to respond to stressors and has previously been applied to the neonatal environment.¹⁸ The third part of the questionnaire addressed parental anxiety using the brief symptom inventory scale (BSI), a quick and reliable psychometric self-evaluation measure of anxiety previously validated in adult populations.^{26,27}

Questionnaires were made available in English and French by paper or electronic form. The questionnaire was reviewed by 3 neonatologists, 1 pediatrician, and 4 fellows for content validity. A pilot study of 10 questionnaires was run with parents of NICU hospitalized children for construct validity and corrections regarding the accuracy of content. Sense of Coherence-13 and BSI scales were kept in their original versions.

This multicenter study was held at 3 university-affiliated hospitals in the Montreal region from September 2015 to December 2016. Eligible parents of newborns hospitalized in the NICU were identified by reviewing the daily patient census and were approached once their child was considered in a stable state as per the main responsible physician. Parents were excluded if they were less than 18 years old, if they spoke neither English nor French, or had their child in palliative care. All other parents were eligible for inclusion.

Eligible parents were approached by an investigator not involved in the current clinical care of the patient. Consenting parents were given a paper questionnaire to fill out or an electronic link to the online survey, and were instructed to complete and return the questionnaire within 1 week. Both parents were invited to answer the survey separately for their child. Parents of multiples were asked to complete a separate survey for each child. Parents whose child had been discharged or transferred away from the unit prior to the collection of the questionnaire were not contacted afterward, as the goal of the study was to evaluate their perception during NICU hospitalization. Sample size was based on convenience sampling during the study period to get a maximum of data.

NICU newborns were classified into 2 subgroups based on whether they were at high risk (high-risk group) or low risk (low-risk group) of neurodevelopmental disability. Patient hospital charts were reviewed to determine neurodevelopmental disability risk factors as per NICU follow-up clinic referral criteria (gestational age of <29 weeks, hypoxic-ischemic encephalopathy with Sarnat ≥ 2 , intraventricular hemorrhage grade ≥ 3 , periventricular leukomalacia, severe neurologic or genetic condition, hyperbilirubinemia requiring exchange transfusion, retinopathy of prematurity grade ≥ 3 , diaphragmatic hernia); patients meeting these criteria were classified as high risk and

the others were classified as low risk. Ethical approval was obtained by the Institutional Review Boards of all participating healthcare institutions. Informed consent was obtained from all participants.

Statistical Analyses

Data were analyzed using GraphPad Prism v 7.0 (GraphPad Software, La Jolla, California) and SPSS v 24 (IBM Inc, Armonk, New York). Parental projections were compared between high-risk and low-risk newborns using χ^2 test for binary answers and Mann-Whitney U test for Likert-scale answers. A *P* value of $\leq .05$ was deemed as statistically significant. A positive Sense of Coherence was considered at cutoff above the lowest quartile (25%), which corresponded to an absolute score of 58.5 out of 91 in our population. This quartile cutoff, previously described in the literature,²⁸ divided the participants into a low-resiliency group (lowest quartile) and a moderate to high-resiliency group. A positive anxiety score on the BSI was considered at cut-off above the mean (T score 50), which corresponded to an absolute score of ≥ 15 of 30 in our population. We selected a T score of 50 to identify participants with moderate to high anxiety, and higher T scores (>63) identified very high anxiety.^{29,30} χ^2 analyses were used to identify relationships between the parental projections of future QOL for the primary outcome of parental resiliency and each of the measured other factors possibly impacting their projections, including parental evaluation of child's illness, and parental anxiety. QOL factors of interest that were statistically associated with our primary outcome of parental resiliency were identified and, for nominal data, confirmed using simple linear regression. Multivariate logistic regression models were developed for nominal data to evaluate independent associations between the primary outcome of parental resiliency and QOL factors of interest that were statistically associated on χ^2 analysis. No adjustments were made for multiple comparisons.

Results

Of the 160 eligible parents, 129 (81%) completed all surveys; 77 (59.7%) were parents of high-risk newborns. Parental demographics between high-risk and low-risk groups were similar (**Table I**). Responses on the QOL questionnaire were not impacted by parent sex, sociodemographic status, country of origin, religious belief, having other children, or having a previous child hospitalized in NICU.

Of all parents, 52.8% considered their child to be currently sick, but relatively few parents (5%) projected long-term negative impact on their child's physical or psychological health, their child's coping ability, or on the family as a whole. Parents who considered their child to be currently sick were more concerned that their child would have long-term physical ($\chi^2 = 78.79$ [25,127], $P < .001$) and mental ($\chi^2 = 62.31$ [30,127], $P < .001$) difficulties, more pain or discomfort ($\chi^2 = 76.89$ [25,128], $P < .001$), a decreased life expectancy ($\chi^2 = 11.09$ [5, 128], $P = .05$), and would remain chronically ill ($\chi^2 = 23.83$ [5, 127], $P < .001$). Parents who evaluated their child as currently sick were also more concerned that their child

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