

## Quality of Life of Parents of Very Low Birth Weight Babies Admitted to the Neonatal Intensive Care Unit

This prospective cohort study was conducted at our tertiary care center from October, 2021 to April, 2022 to compare the parents' health-related quality of life (HRQoL) scores during neonatal intensive care unit (NICU) stay and at 3 months follow-up. Pediatric quality of life inventory (PedsQL) family impact module questionnaires were used in 46 mothers and 39 fathers during NICU stay, and 42 mothers and 38 fathers at 3-month follow-up. Greater proportions of mothers were severely affected and had higher stress levels as compared to fathers both during NICU stay (67.3% vs 48.7%) and at 3 months follow-up (62.7% vs 52.6%). Among the mothers, there was a significant improvement in individual and family functioning median (IQR) HRQL scores at 3-month follow-up [62 (48-83) vs 71 (63-79)]. However, the proportion of mothers severely affected remained the same at NICU stay and 3-month follow-up (67.3% vs 62.7%).

**Keywords:** *Anxiety, Childcare, Stress, Outcome.*

The hospitalization of a baby to the neonatal intensive care unit (NICU) is a stressful event for parents that impacts their quality of life [1]. Parental quality of life is influenced by NICU hospitalization, neonatal morbidities, and individual factors. Understanding their quality of life before and after the transition to home can help to target interventions to better support NICU discharge. Most of the cross-sectional studies assessing the parental quality of life of hospitalized neonates have focused on maternal stress levels while little has been researched regarding paternal stress levels [2]. This study was conducted to assess the stress levels among both parents of neonates hospitalized in the NICU.

This prospective study was conducted after obtaining approval from the institutional ethical committee of the hospital. The parent-infant dyad of all the preterm very low birth weight (VLBW) neonates admitted to the NICU for more than one week and discharged between October, 2021 to April, 2022 were enrolled in the study. Neonates with major malformations, those leaving medical facilities against medical advice, neonatal deaths, readmissions, non-biological parents, and parents not understanding English or Hindi were excluded from the study.

Within one week of the anticipated discharge of the neonate, parents of the eligible preterm VLBWs were approached to complete the Pediatric Quality of Life Inventory (PedsQL) from the family impact module

questionnaires [3]; after obtaining consent. The father and mother were given separate English or Hindi versions of the questionnaire as per their preference [4].

The PedsQL Family Impact module was developed as a parent-report instrument. A 5-point response scale was utilized (0=never a problem; 4=always a problem). Items were reverse-scored and linearly transformed to a 0-100 scale (0=100, 1=75, 2=50, 3=25, 4=0) so that higher scores indicated better functioning (less negative impact). These raw scores were later converted to percentage scores by dividing them by the maximum score in that domain. The maximum score in each domain was based on the number of questions in each domain. The PedsQL scale scores were computed as the sum of the items (total 36 items) divided by the number of items answered (to account for missing data). If more than 50% of the items in the scales were missing in any subdomain, the scale score was not computed [4]. The individual score (28 items) is computed as the sum of the items divided by the number of items answered in the Physical, Emotional, Social, Cognitive, Communication, and Worry Functioning scales. The family functioning score (8 items) is computed as the sum of the items divided by the number of items answered in the Daily Activities and Family Relationships scales [4]. The quality of life was graded as Parent HRQL according to the total score as of "good" if the score is more than 84, "mild impairment" 80-84, "moderate impairment" 75- below 80, and "severe impairment" below 75.

A post-NICU discharge assessment was completed three months after discharge during the infant's OPD visit or by an electronic questionnaire link that was mailed to the parents. Responses wherein less than 50% of the items were reported were not included in the scoring. Data on neonatal medical illness, comorbidities, growth outcomes, discharge medical needs, parent demographics, discharge medical needs, and insurance type were obtained from the clinical database and chart review. Healthcare needs of the infant after discharge like hospital readmissions, and use of medical equipment and medicines were also recorded. The primary outcome of the study was the Parental health-related quality of life (PedsQL) scores during the NICU stay and three months after discharge. The secondary outcomes were to determine the impact of parent demographic factors and neonatal illness on parental health-related quality of life.

Parametric and nonparametric data were analyzed using SPSS version 21. Before and after analysis was

done using the Wilcoxon rank sum test. Statistical significance was set at  $P < 0.05$ .

A total of 48 parent-infant dyads were enrolled out of 70 eligible VLBW infants. Among them, 46 mothers and 39 fathers completed the questionnaire during NICU stay (at median (IQR) 31 (17, 42) days of stay), and 43 mothers and 38 fathers completed 3-month follow-up. The parental and neonatal baseline characteristics are shown in **Table I**. The maternal and paternal HRQL subdomain scores and transformed HRQL scores for individual, family functioning, and combined at baseline and three months are shown in **Table II**. Maternal median (IQR) combined HRQL scores had improved at follow-up than at NICU discharge, unlike paternal scores.

On sub-group analysis between parents with mild-moderate vs severe impairment during the NICU stay, and 3 months follow-up, it was found that the longer the duration of marital life, the more severe the impairment in both maternal and paternal HRQL. Lower mean weight at NICU discharge [1204 (177) vs 1041 (208) g] and 3 months

**Table I Parental and Neonatal Characteristics of Study Participants (N=48)**

Characteristics	Value
<i>Parental characteristics</i>	
Age (y) <sup>a</sup>	
Mother	30.5 (5.5)
Father	35.4 (5.4)
Educated (Graduate or higher)	
Mother	42 (87.5)
Father	44 (95.5)
Employed	
Mother	23 (47.9)
Father	45 (97.8)
Maternal morbidity	32 (66)
Primipara	26 (54)
Urban residence	35 (72.9)
Nuclear family	21 (43.75)
Self-borne treatment charges	34 (72.34)
<i>Neonatal characteristics</i>	
Gestational age (wk) <sup>a</sup>	30 (2)
Males	29 (60.41)
Multiple gestation	10 (20.83)
Post menstrual age at discharge (wk) <sup>a</sup>	35.3 (1.86)
Weight (g) <sup>a</sup>	
At birth	1085 (203)
At discharge	1624 (245)
At 3 mo follow-up	3061 (538)

Data expressed as no. (%) or <sup>a</sup>mean (SD).

**Table II Health Related Quality of Life Scores of Parents at Baseline and at Three Months Follow-up**

Transformed scores	During NICU stay	At 3-mo follow-up	P value
<i>Individual</i>			
Mother	64.2 (51, 84)	72 (63, 78)	0.014
Father	71 (60, 84)	73 (67, 84)	0.092
<i>Family functioning</i>			
Mother	64 (34, 88)	69 (50, 87)	0.068
Father	75 (53, 89)	72 (57, 86)	0.902
<i>Combined</i>			
Mother	62 (48, 83)	71 (63, 79)	0.012
Father	73 (60, 86)	74 (65, 81)	0.233
<i>Severe impairment in maternal scores<sup>a</sup></i>			
Individual	29 (63.04)	29 (67.44)	0.667
Family functioning	29 (63.04)	23 (53.48)	0.364
Combined	31 (67.39)	27 (62.79)	0.642
<i>Severe impairment in paternal scores<sup>a</sup></i>			
Individual	20 (51.28)	21 (55.26)	0.722
Family functioning	19 (48.7)	21 (55.26)	0.569
Combined	19 (48.7)	20 (52.63)	0.731

Data expressed as median (IQR) or <sup>a</sup>mean (SD). Mother n=46 and 43 at base-line and three months; father n=39 and 38 at baseline and follow-up.

follow-up [3325 (543) vs 2936 (503) g] were significantly associated with severe impairment in the paternal HRQL scores. However, there was no significant difference noted between the two maternal sub-groups (mild-moderate vs severe) in the rest of the demographic, natal, postnatal, and neonatal characteristics at NICU discharge and at 3 months.

We found that nearly two-third proportion of mothers and fathers had severe impairment in the HRQL scores during the NICU stay, and half of the parents had severe functional impairment at 3 month follow-up. An earlier study found a nearly severe impairment in half of the parents in the total HRQL at 3 months follow-up as compared to NICU discharge [5]. About 88% of the respondents with poor HRQL were mothers, whose scores in the subdomain of daily activities at NICU discharge as well as at 3 months follow-up, were also similarly low in a previous study [5].

During NICU stay and at three months follow-ups, a greater proportion of mothers had severely impaired HRQL scores as compared to fathers, similar to an earlier study [1] using the Parental Stressor Scale. The higher stress levels in mothers could be due to the childbirth process [6], during preterm birth accompanied by unpreparedness, and maternal morbidities. In a recent systematic review by WHO, the prevalence of postpartum depression in Indian mothers was 22%, with preterm and

low birth weight as significant factors [7]. The gender difference could also be attributed to the different coping mechanisms and different roles and responsibilities of mothers. At three months follow-up, the combined maternal HRQL scores significantly improved as compared to NICU discharge scores unlike the paternal scores similar to an earlier study [5].

The present study helps to sensitize the healthcare workers to the needs of parents who require emotional support and professional assistance during NICU stay and post-discharge. Universal screening and facilitated access to care should be considered as a part of integrated NICU care. Parental programs in NICUs like COPE (Creating opportunities for parent empowerment) that help parents to cope effectively with a preterm birth should be part of the NICU care program [8].

The limitations of the present study include a small sample size given the coronavirus pandemic. Also, long-term follow-up on the impact of parental stress on the child's growth and neurodevelopmental outcomes was not done. Detailed financial aspects were not taken into account apart from the availability of insurance for the parents that were identified as a significant stressor [10]. The average length of NICU stay for a VLBW neonate with and without ventilation has been estimated to be 48 days and 21 days, respectively [9]. A longer duration of NICU hospitalization correlated positively with more stress levels.

To conclude, a higher proportion of mothers had higher stress levels as compared to fathers both during the NICU stay as well at three months follow-up, with a significant improvement in the maternal stress levels at follow-up.

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