



Utilization of NICU Infant Medical Indices to Classify Parental Risk for Stress and Family Burden

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ABSTRACT

Introduction: This study was conducted to examine whether the parental report of objective infant medical indices (e.g., birth weight, length of stay) can be used to identify parents at risk for psychosocial sequelae.

Methods: Parents ($N = 199$) cohabitating with their partner and child who was discharged from a neonatal intensive care unit (NICU) 6 months to 3 years prior to the administration of the study completed an online survey, which included parent-reported infant health, parenting stress, family burden, and family resources.

Results: A hierarchical cluster analysis identified the following three clusters of parents at risk for stress and family burden as determined by infant medical severity and access to resources:

lowest risk ($n = 77$), moderate risk ($n = 68$), and highest risk ($n = 8$).

Discussion: This work highlights how a measure using parent-reported infant health severity, which was developed for this study, can be used to better understand family outcomes following NICU hospitalization. *J Pediatr Health Care.* (2020) *34*, 54–62

KEY WORDS

Neonatal intensive care unit (NICU), infant health, parental stress, family burden, family resources

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About 7% to 15% of newborns delivered each year are admitted to a neonatal intensive care unit (NICU) in the United States (March of Dimes, 2011). Parents of hospitalized infants (hereafter referred to as NICU parents) typically describe the NICU experience as an emotional roller coaster because of the fast changes in their child's medical care and the emotions that coincide (Obeidat, Bond, & Callister, 2009). For example, parents may learn that their child is gaining weight one day only to find out that they require a feeding tube the next. As a result, parents experience a variety of emotions, including feeling overwhelmed, sad, stressed, tired, relieved, happy, angry, and helpless (Holditch-Davis et al., 2009). Increased parental psychological distress has also been associated with the child's impaired cognitive, social, and behavioral development (Treyvaud et al., 2009; Treyvaud, 2014). The health changes of the infant and feelings of stress, guilt, and anxiety about the child's health can lead to adverse mental health outcomes for parents or long-term impairments in parenting styles (Boykova, & Kenner, 2012). Furthermore, the sights and sounds, as well as psychosocial implications of the NICU, can serve as traumatic stressors for parents, leading to a more difficult adjustment to normal life following the child's hospitalization (Geller, Bonacquistic, & Patterson, 2018).

The stressors of a NICU hospitalization do not end after discharge. NICU parents must learn to manage their child's ongoing health issues, in addition to typical parenting responsibilities. In fact, in very low-birth-weight populations, parenting stress remains elevated for the first 18 months and does not become similar to stress reported by parents of full-term infants until the child is approximately 2–3 years of age (Treyvaud, 2014). Therefore, the first few years following NICU admission is a critical time to examine parents and families because of the high risk for stress and adverse psychological symptoms. Because of advances in neonatal care over the past 20 years, infants born at lower gestational ages have a higher likelihood of survival (Grunberg, Geller, Bonacquisti, & Patterson, 2019; March of Dimes, 2011). Infants with lower birth weights are at increased risk for complex medical conditions and neurodevelopmental impairments (Gray, Edwards, O'Callaghan, & Cuskelly, 2012; Stephens, Bann, Poole, & Vohr, 2008). Among extremely low-birth-weight infants (<23 weeks), 42% of them experienced moderate to severe neurodevelopmental impairment (e.g., cerebral palsy; Stephens et al., 2008). Infants with increased neurodevelopmental delays may have greater functional limitations. They may require increased medical resources (i.e., rehospitalizations, medical devices, medical appointments) as well as more time and attention from parents and families (Feeley, Gottlieb, & Zekowitz, 2005). Extant literature indicates that parents with infants with greater medical complications and neurodevelopmental impairments report increased stress and greater family burden than parents of healthy infants (Lorenz, Wooliever, Jetton, & Paneth, 1998; Stephens et al., 2008). Therefore, families with fewer resources report more negative psychosocial sequelae (Doucette, & Pinelli, 2004; Treyvaud, 2014).

Although research indicates that more severe medical complications impact family outcomes, the specific medical indices of the infant that help identify which families may be at increased risk remain unclear (Grunberg et al., 2019). In addition, parental and family outcomes during the first few years following hospitalization remain understudied (Holditch-Davis et al., 2009; Lefkowitz, Baxt, & Evans, 2010; Obeidat et al., 2009; Shaw et al., 2009). Furthermore, a current systematic review indicates that there is no gold standard measure of infant medical severity within the NICU population (Grunberg et al., 2019). Most of the measures that exist require information from the medical team or medical chart, which makes the dissemination of research more difficult. Understanding which indices of infant medical risk help identify parents at risk for adverse psychosocial sequelae is warranted to improve screening and interventions for parents during and after their child's NICU hospitalization. Moreover, an infant health severity measure that only requires parental report would be useful for increased dissemination and accessibility of NICU research.

The purpose of the present study, which was part of a larger thesis project (Grunberg, 2016), was to expand on the current literature by determining which specific infant health indices can be used to identify parents at elevated risk for

stress and family burden in the aftermath of their child's NICU hospitalization. A secondary aim was to determine whether it is feasible to use the parental report of infant medical risk, given that this can be used to inform the development of a parent measure of infant health issues. This study uniquely examined infant medical risk, parental stress, and family burden using cluster analysis, an analytic technique that can group parents based on shared experiences. Understanding which factors help to differentiate parents at low, moderate, or high risk for negative psychosocial adjustment (e.g., increased stress and greater family burden) may inform screening techniques in the NICU.

METHODS

Participants

Inclusion criteria

Biological mothers of living, singleton infants who were admitted to a NICU, and their male partner or spouse, were eligible for participation in this study. Each parent was invited to participate as individual survey respondents, meaning that one or both could be deemed eligible and participate. The infant of potential participants must have been discharged from the NICU 6 months to 3 years prior to the administration of the study. Mothers and partners were required to be in an intimate relationship with each other and cohabitating along with the infant since NICU discharge. The reason parents were surveyed online was to gather a large sample and obtain parents of infants with a variety of health issues. This design helps to capture parents and infants who spent time in level I, II, III, or IV NICUs, which means that the hospitals ranged in severity. Based on the literature, parenting stress remains elevated for the first few years following discharge (Treyvaud, 2014). As the first 6 months are often a time of transitions, we sought to understand how parental stress and family impact were associated with infant medical issues years after NICU admission and discharge. The current study was part of a larger thesis project (Grunberg, 2016), which was investigating couple functioning as an outcome of interest. The examination of couples also helps increase internal validity given that single parents may report increased stress because of a number of additional responsibilities and potentially less support with parenting. Participants were required to be at least 18 years old at the time of the study, reside in the United States, understand written English, and have Internet access. All participants provided a waiver of consent. This protocol was reviewed and approved by the Drexel Institutional Review Board (approval number: 1507003801).

Recruitment

Participants included 199 parents of children who had a NICU hospitalization and who were recruited via the Internet and posted flyers at Drexel University and The Children's Hospital of Philadelphia. The study was advertised on online support communities, and social networking Web sites (e.g., Facebook, Craigslist, YouTube) and on printed

flyers, with information relevant to parenting and a link to the 2016 Qualtrics survey (<http://www.qualtrics.com>). Completion of the entire anonymous survey required at least 20 minutes. Three hundred seventy-two participants began the survey, 136 were ineligible based on inclusion criteria, and 69 were excluded because of missing data. Sociodemographics of participants with incomplete data did not differ from those with complete data. Of the 199 eligible parents who completed the survey, all of them identified as biological mothers or fathers.

Measures

Sociodemographics questionnaire

Information regarding participants' sex, age, race/ethnicity, religious identity, education level, annual household income, employment status, couple or relationship status, infant's sex, reproductive history, mental health history, and stressful life events that have occurred since the infant's birth were collected using a questionnaire created for this study.

Infant medical indices

A questionnaire created for this study measured infant health during NICU admission and at the time of survey completion through parental self-report. Items included infant diagnosis/diagnoses, birth weight, gestational age at birth, length of NICU hospitalization, medical procedures and devices used during the infant's NICU stay (i.e., oxygen, ventilator, feeding tube, tracheostomy, phototherapy, or Replogle Tube), whether the infant was on extracorporeal membrane oxygenation (ECMO) during NICU hospitalization, and medical devices used following discharge (i.e., oxygen, cardiorespiratory monitor, feeding tube, tracheostomy, ventricular shunt, central line).

The infant's current health was assessed by asking parents to identify additional diagnosis/diagnoses since discharge, developmental disabilities, medical devices currently used (i.e., oxygen, cardiorespiratory monitor, feeding tube, tracheostomy, ventricular shunt, central line, nebulizer), current medications, number of rehospitalizations in the first year postdischarge (or since discharge for infants discharged < 1 year ago), and number of health care specialists seen in the first year postdischarge or since discharge (e.g., neurologists, occupational therapist, physical therapist, speech therapist, neurosurgery).

The number of rehospitalizations and specialists was limited to the first year because assessing these items within a specific time frame helps to standardize these indices for infant health severity. The health indicators were determined based on published literature, consultations with NICU developmental psychologists and a neonatologist, and a review of accumulated knowledge regarding neurodevelopmental outcomes following preterm births (Nosarti, Murray, & Hack, 2010). Objective indicators of infant health were selected to minimize the subjective bias of parental reports. The only items that parents were asked to recall included gestational age and birth. All other infant medical questions

(e.g., diagnoses, medical devices) included options that parents could select from to minimize recall bias.

Research suggests that retrospective reports of childhood health are of reasonable reliability to warrant their judicious use in population research (Haas, 2007). Furthermore, those with more education and individuals who identify as non-Hispanic Whites, compared with other racial and ethnic minorities, were more consistent in their reports. Given the much shorter time since hospitalization and the emotional experience of this birth, parents have a higher chance of accurately recalling information about their child's health. Finally, given the same characteristics, they have a greater likelihood of accurately recalling this information (Table 1).

Parental stress

A 36-item self-report measure of stress associated with parenting, the Parenting Stress-Index, Short Form (PSI-SF) includes three subscales: parental distress, parent-child dysfunction interaction, and difficult child (Abidin, 1995). Higher scores indicate higher levels of parental stress, and a score of 90 or above on the PSI-SF indicates clinically significant parental stress. The PSI-SF has been used previously with mothers of preterm infants and demonstrated a strong reliability and validity (Abidin, 1995), including strong internal consistency for the parental stress total score (Cronbach $\alpha = .92$; Abidin, 1995). The Cronbach α coefficient for parental stress total score was .94 in the current study. In previous studies, the PSI-SF demonstrated strong criterion, discriminant, and predictive validity (Abidin, 1995).

Family impact

The revised version of the Impact on Family (IOF-R) Scale was used to assess the perceived burden of an ill child on the family (Stein & Jessop, 2003). This self-report measure reflects parental perceptions of changes in family life and attribution of those changes to the child's illness. Higher scores indicate more perceived family burden because of the child's illness. The IOF-R total score is highly correlated with the original total score ($r = .97$), and internal consistency for the IOF-R has been adequate (Cronbach $\alpha = .85$; Stein & Jessop, 2003). Cronbach alpha coefficient for parental stress total score was .97 in the current study. Higher IOF-R scores have been significantly associated with maternal psychiatric symptoms ($r = .47$), poor health for the child ($r = -.39$), and poorer psychological adjustment for the child ($r = -.37$; Stein & Jessop, 2003).

Family resources

Perception of adequate resources needed for the family was assessed using the revised version of the Family Resource Scale (FRS-R; Van Horn, Bellis, & Snyder, 2001). Higher scores indicate more perceived family resources (i.e., basic needs, money, time for self, time for family). Factor analyses revealed four distinct subscales: basic needs, money, time for self, and time for family, and the internal consistency for overall FRS score is acceptable (Cronbach $\alpha = .72-.84$; Van Horn et al., 2001). Cronbach alpha coefficient for family

TABLE 1. Participant sociodemographics variables

Variables	Total (N = 199)	Females (n = 182)	Males (n = 17)
Ethnic-racial background	n (%)	n (%)	n (%)
White	163 (81.9)	148 (81.3)	15 (88.2)
African American/Black	13 (6.5)	13 (7.1)	0 (0)
Latina/Latino/Hispanic	8 (4.0)	8 (4.4)	0 (0)
Bi/multiracial/ethnic	7 (3.5)	7 (3.8)	0 (0)
Other ^a	7 (3.5)	5 (2.7)	2 (11.8)
Not reported	1 (0.5)	1 (0.5)	0 (0)
Relationship status			
Married	169 (84.9)	154 (77.3)	28 (14.0)
Unmarried, but living with partner	30 (15.1)	15 (7.5)	2 (11.7)
Income			
< \$25,000	21 (10.6)	19 (10.4)	2 (11.8)
\$25,000–\$49,999	46 (23.1)	44 (24.2)	2 (11.8)
\$50,000–\$74,999	45 (22.6)	39 (21.4)	6 (35.3)
\$75,000–\$99,999	39 (19.6)	36 (19.8)	3 (17.6)
\$100,000–\$124,999	17 (8.5)	16 (8.8)	1 (5.9)
\$125,000–\$150,000	14 (7.0)	13 (7.1)	1 (5.9)
>\$150,000	16 (8.0)	14 (7.7)	2 (11.8)
Not reported	1 (0.5)	1 (0.5)	0
Education			
Some high school	2 (1.0)	2 (1.1)	0 (0)
High school graduate	13 (6.5)	13 (7.1)	0 (0)
Some college or associate's degree	72 (36.2)	63 (34.6)	9 (52.9)
4-year college or bachelor's degree	67 (33.7)	60 (33.0)	7 (41.2)
Advanced degree ^b	43 (21.6)	42 (23.1)	1 (5.9)
Other ^c	1 (0.5)	1 (0.5)	0 (0)
Not reported	1 (0.5)	1 (0.5)	0 (0)
Employment			
Employed full-time	77 (38.7)	63 (3.5)	14 (8.2)
Employed part-time	31 (15.6)	31 (17.0)	0 (0)
Home maker	74 (37.2)	72 (39.6)	2 (11.8)
Full time student	5 (2.5)	5 (2.7)	0 (0)
Unemployed	7 (3.5)	7 (3.5)	0 (0)
Other ^d	5 (2.5)	4 (2.2)	1 (5.9)

^aOther includes participants who identified as Asian/Pacific Islander, Native American/Alaskan Native, or Indian.

^bAdvanced degrees includes participants with Master of Science, Master of Arts, Doctor of Medicine, Doctor of Philosophy, or Doctor of Jurisprudence.

^cOther included participant who received vocational education.

^dOther included individuals who work from home, self-employed, and combination of student and employment.

resources total score was .94 in the current study. The FRS-R also demonstrated good predictive and external validity in previous investigations (Van Horn et al., 2001).

Data Analysis

A hierarchical cluster analysis was conducted to determine clusters or groups of parents who shared characteristics with regard to their infants' health severity and psychosocial functioning (Blashfield, 1980). The goal was to identify groups of parents whose characteristics are similar within groups but different among groups. The variables included in the analysis were infant medical indices during NICU hospitalization and at the time of survey completion, as well as parental functioning variables.

Infant medical indices variables included gestational age at birth (weeks), birth weight (grams), length of time of NICU hospitalization (weeks), number of medical devices used during NICU stay, number of medical devices being use at time of discharge, number of medical devices currently in use,

number of rehospitalizations, number of health care specialists an infant saw during the first-year postdischarge, and the number of medications currently prescribed.

Parental variables included parental stress, family burden, and family resources (i.e., basic needs, money, time for self, and time for family). Because these variables were measured on different scales (e.g., birth is measured in grams and gestational age measured in weeks), they were scaled (standardized) for analyses. It is important to standardize these variables for analyses because otherwise, the largest raw value (i.e., grams) would carry the most weight when differentiating groups.

RESULTS

Participant Sociodemographics

Descriptive statistics for all sociodemographics of the sample were examined (Table 1). Of the 199 eligible participants who completed the survey, most were female ($n = 182$, 91.5%) and identified as non-Hispanic White ($n = 163$,

81.9%). There was a range regarding estimated annual household income and educational attainment across participants, with the greatest percentage earning \$25,000–\$74,999 ($n = 91$, 45.70%) and having achieved up to, but not past, a bachelor's (4-year college) degree ($n = 67$, 33.70%). Participants' mental health and reproductive history are provided in Table 2. More than three fourths ($n = 88$, 44.4%) of the parents reported having a history of mental illness, 25.9% ($n = 51$) engaged in mental health treatment previously, and 35.4% ($n = 70$) endorsed a history of pregnancy loss.

Infant Health Characteristics

Mean gestational age at birth was 31.54 weeks ($SD = 4.64$) and ranged from 23 to 42 weeks of gestation. Mean birth weight was 1,791.54 g ($SD = 1,001$) and ranged from 454–5,687 g. On average, infants were in the NICU for 7.63 weeks ($SD = 6.30$) with a range of 0.29–30 weeks. The average length of time since the infant was discharged from the NICU was 66.68 weeks (1.28 years, $SD = 44.65$) and ranged from 26 to 156 weeks (6 months to 3 years).

During the NICU stay, 67 infants were on oxygen, ventilator, and a feeding tube (33.6%), and almost all infants were on some combination of these three devices. Most infants were not on ECMO ($n = 185$, 97%). Most infants were discharged without medical devices ($n = 133$, 66.8%). For infants discharged on a medical device, a cardiorespiratory monitor was the most common ($n = 20$, 10.0%). Moreover, most infants were not prescribed medical devices at the time of study completion ($n = 176$, 88.4%). For infants using medical devices postdischarge, a feeding tube was the most common ($n = 9$, 4.5%).

Common diagnoses for infants during NICU admission included reflux ($n = 65$, 32.7%), apnea ($n = 62$, 31.2%), respiratory distress syndrome ($n = 55$, 27.9%), and chronic

lung disease ($n = 39$, 19.6%). A total of 54 infants were diagnosed with an additional medical condition after discharge (27.4%), and 47 were diagnosed with a developmental disability (23.6%). Of the 54 infants with additional diagnoses, 21 were diagnosed with a developmental disability (39.6%). Most infants were not rehospitalized following discharge ($n = 146$, 73.4%) and were not currently prescribed medication at the time of the survey ($n = 138$, 69.3%). Most infants saw at least one additional health care specialist during the first year following discharge ($n = 161$, 80.9%).

Descriptive Statistics

Mean parental stress, as measured by PSI-SF, was 73.72 ($SD = 22.14$) and ranged from 36 to 156. Thirty-seven participants (20.4%) had a score of >90, indicating severe parental stress in the current sample. Mean family burden, as measured by IOF-R, was 16.31 ($SD = 17.25$) and ranged from 0 to 59. Mean family resources, as measured by FRS-R, was 80.10, with an SD of 17.10 and a range of 3–105.

Main Findings

Data were analyzed using RStudio (version 1.0.136). For statistical evaluation, complete data sets were defined as those in which the participant answered every question for all measures. Of the 199 participants, 153 had complete data, and only participants with complete data were included in analyses. Sociodemographics of participants with incomplete data did not differ from those with complete data.

Five clusters were initially selected based on the Dendrogram, a graph produced from R code used to determine how to differentiate several groups. Three of the clusters (3, 4, and 5) had very small sample sizes but were distinct from clusters 1 and 2 based on infant and parental variables. These clusters were combined to represent the group at the highest risk. Most participants fell in the first two clusters (lowest and moderate risk). The characteristics of the three main groups of clusters are presented in Table 3.

Descriptive statistics were conducted on all clusters to examine characteristics (Table 4). Tests of differences were examined for lowest-risk and moderate-risk groups only because the sample size for highest-risk groups was too small to have meaningful results. Independent t tests were conducted to determine differences between low-risk and moderate-risk groups. Results revealed that these clusters significantly differed on all variables except medications, family resources, and parental stress (Table 5). The lowest-risk group had significantly lower means on all variables than the moderate-risk group.

DISCUSSION

The current study, which was part of Grunberg (2016) thesis, expanded on the current literature by using a novel analytic technique (i.e., hierarchical cluster analysis) to identify which parents may be at greatest risk for negative psychosocial sequelae after their infants' NICU hospitalization. Three main clusters were identified based on infant health characteristics, parental stress, family burden, and family resources.

TABLE 2. Participant mental health and reproductive history (N = 199)

History of mental illness	n (%)
Yes	88 (44.4)
No	110 (55.6)
History of mental health treatment	
Yes	51 (25.9)
No	146 (74.1)
Number of children	
1	95 (47.7)
2	59 (29.6)
3	31 (15.6)
4	7 (3.5)
5	6 (3.0)
6	1 (0.5)
History of pregnancy loss history ^a	
Yes	70 (35.4)
No	128 (64.6)
History of fertility treatments ^a	
Yes	22 (11.1)
No	176 (88.9)

^aMen reported on female partner's reproductive history.

TABLE 3. Description of clusters

Parents at lowest risk (n = 77)	Parents at moderate risk (n = 68)	Parents at highest risk (n = 8)
Least severe infant health during NICU and postdischarge	Moderately severe infant during NICU and postdischarge	Most severe infant health during NICU and postdischarge
Moderate parental stress	Moderate parental stress	High parental stress
Low family burden	Moderate family burden	High family burden
		Few family resources

Note. NICU, newborn intensive care unit.

Clusters represented parents with the least severe infants and least family burden, parents with moderately ill infants and moderate levels of stress and family burden, and parents with most severely ill infants and greatest levels of parental stress and family burden and fewest family resources. However, results for the highest-risk group should be interpreted with caution given the small sample size.

Most participants (n = 145, 94.77%) were categorized into low- and moderate-risk groups. Although low-risk and

moderate-risk groups differed on nearly all infant medical indices and family burden, they did not differ on the number of infant medications, family resources, or parental stress. Parental stress did not differ between these groups. It is hypothesized that this finding could be related to the fact that longer NICU stays and more frequent NICU rehospitalizations may result in increased face time and communication between parents and members of the medical and psychosocial teams in the NICU. This additional interaction,

TABLE 4. Cluster descriptive statistics (N = 153)

Variable ^a	Cluster	Mean	SD	Min-max
NICU medical devices	Low risk	1.70	1.03	0–5
	Moderate risk	2.87	0.75	1–5
	High risk	2.75	0.71	2–4
Discharge medical devices	Low risk	0.21	0.55	0–3
	Moderate risk	0.53	0.70	0–2
	High risk	3.62	2.26	1–8
Current medical devices	Low risk	0	0	0
	Moderate risk	0.18	0.38	0–1
	high risk	1.50	1.20	1–3
Specialists	Low risk	1.30	1.41	0–6
	Moderate risk	4.40	2.52	0–10
	High risk	6.38	3.02	3–11
Rehospitalizations	Low risk	0.14	0.42	0–2
	Moderate risk	0.60	0.93	0–4
	High risk	1.75	3.06	0–9
Medications	Low risk	0.55	1.23	0–6
	Moderate risk	0.68	1.07	0–3
	High risk	4.88	2.47	2–7
Length of NICU stay	Low risk	2.88	2.14	0.29–42
	Moderate risk	12.22	4.85	4–30
	High risk	16.62	6.32	11–30
Gestational age (weeks)	Low risk	34.88	3.27	29–42
	Moderate risk	28.08	3.32	23–40
	High risk	27.89	2.31	24–30
Birth weight (grams)	Low risk	2,475	873	1,051–4,990
	Moderate risk	1,188	581	480–3,207
	High risk	876	239	614–1,354
Parental stress	Low risk	72.17	20.88	40–128
	Moderate risk	71.43	19.84	36–143
	High risk	101.50	28.23	73–126
Family burden	Low risk	9.86	13.90	0–52
	Moderate risk	21.68	17.04	0–57
	High risk	43.12	12.90	24–59
Family resources	Low risk	80.27	16.25	16–105
	Moderate risk	82.66	14.58	23–105
	igh risk	66.62	12.22	43–82

Note. NICU, newborn intensive care unit.

^aAll variables were standardized.

TABLE 5. Differences between the low-risk and moderate-risk groups

Variable	Low-risk group (n = 77)	Moderate-risk group (n = 68)	t	P
NICU medical devices	1.70	2.87	-7.87	<.001
Discharge medical devices	0.21	0.53	-3.05	.002
Current medical devices	0.00	0.17	-3.79	<.001
Specialists	1.30	4.40	-8.96	<.001
Rehospitalizations	0.14	0.60	-3.75	<.001
Medications	0.55	0.67	-0.69	.494
Length NICU stay	2.88	12.22	-14.66	<.001
Gestational age (weeks)	34.88	28.08	12.38	<.001
Birth weight (grams)	2,475	1,188	10.56	<.001
Family resources	80.28	82.66	-0.94	.352
Parental stress	72.17	71.43	0.22	.837
Family burden	9.86	21.68	-4.54	<.001

Note. NICU, newborn intensive care unit.

in turn, may increase parental confidence when managing their child's illness postdischarge. Using the current data set, it was reported elsewhere that a multivariable regression analysis revealed that more rehospitalizations were associated with less parental stress (Grunberg, 2016). As a result, there may be confounding factors that influence stress that was not addressed in the current study. Another hypothesis to explain this finding could be that the current sample included more low to moderate medically at-risk infants and therefore limit the ability to detect differences in parental stress given the small number in the high-risk group. For example, the high-risk group had higher means for parental stress, which suggests that increased stress could be a function of infants with more severe medical outcomes, particularly those born extremely premature. It has been reported that parents of extremely low-birth-weight infants experience high levels of stress compared with parents of infants born full term (Singer et al., 1999). In the current study, low- and moderate-risk groups represent more mild-moderately ill infants. Therefore, it is possible that stress is a more useful predictor of parental functioning among those with the most severely ill infants in the NICU.

Parents of infants with increased health issues during a NICU hospitalization (e.g., birth weight, medical devices, length of time in NICU) and after discharge (e.g., number of specialists, rehospitalizations, medical devices) reported increased family burden. These findings are in agreement with the thesis by Grunberg (2016), which highlighted that family burden, as compared to parental stress and couple functioning, was most influenced by infant medical risk (i.e., infant use of ECMO, the longer length of stay, more medical devices). These findings are also consistent with reports that infants who are born with lower gestational ages experience increased medical complications during and after hospitalization and require increased attention and support from parents, which can take a significant toll on the family (Geller et al., 2018; Stephens et al., 2008). Specific infant medical indices and levels of family burden can be used to identify parents who may need additional psychosocial support. The

present findings indicate that screening techniques should focus on infant medical severity and family burden within the NICU setting to identify parents at risk for negative psychosocial outcomes. Currently, clinicians often assess parental mental health or stress in the NICU but do not consider the burden of the child's health on family functioning. Assessment of family burden may be valuable for health care professionals to connect families to increased support in the NICU, as well as to appropriate support services after discharge.

The findings also indicate that parental report of infant medical severity is feasible given that they were consistent with previous literature that suggests that ongoing medical issues influence parental outcomes (Stephens et al., 2008; Treyvaud, 2014). In addition, these indicators of infant health could be used to sort parents into low-, medium-, and high-risk groups depending on stress and family burden. Given that all data were checked for face validity before analyses, it appears that a psychometrically sound parental report measure of infant medical severity is warranted.

Clinical Implications

The transition from the NICU to home can be difficult for parents, especially among those with infants with medical complexities. Parents must learn to manage their child's illness without medical team assistance, maintain family and work, and manage their self-care and relationship in the context of having increased responsibilities for their child's care. Identifying at-risk families may help to inform more effective screening tools during and after their child's hospitalization, as well as provide valuable information for the development of psychosocial interventions that continue throughout this adjustment period. Parents of infants at a more severe medical risk, during and after discharge, should be targeted with early intervention aimed to improve family and child outcomes. Intervention may promote family coping by improving communication with the medical team, addressing the value of self-care, and increasing visibility regarding the influence of parental mental health on child development. The current

study also indicates that parents appear to be reliable reporters of child health. Therefore, the development of a parental report measure of infant medical risk would help to increase dissemination of a classification system that identifies families at greater risk for negative psychosocial sequelae.

Limitations and Future Directions

The current study's self-report, cross-sectional, retrospective research design included potential bias. In addition, parents were retrospectively asked to report about their infant's health during NICU admission, which may have been up to 3 years earlier. As such, recall about the experiences and severity of the child's health may differ from what transpired. However, retrospective reports of childhood health are reasonably reliable to warrant their use in population research (Haas, 2007). Haas (2007) reported that >16 years after childhood health issues, parents were able to accurately identify illness >50% of the time and when identifying dichotomous data, they were accurate 91% to 95% of the time.

The highest-risk group was very small, and as a result, tests of differences could not be used to distinguish among all groups. Infant medical severity ranged from mild to severe; however, most parents had infants who were mild to moderately ill. Recruiting more parents may help to increase variance and allow for more accurate differentiation among groups of parents.

It is important to note that the current sample only included parents who were in an intimate relationship with their partners' since their child's hospitalization. Although this approach helps to increase internal validity, this sample does not reflect the range of families who have a child in the NICU. For example, single parents, including those for whom the stress of the NICU experience might have contributed to separation or divorce, may report less parental coping and greater parental stress and family burden. A better understanding of the experiences of parents with a broader range of family circumstances may help determine additional factors that place families at increased risk for stress and family burden. Grunberg (2016) thesis research indicated that parental stress was inversely related to couple functioning ($r = -.40$, $p < .001$), which highlights the need to explore various relationships among parents in future work.

Furthermore, including nontraditional families would also provide valuable information regarding diverse family experiences following the child's hospitalization. Most of the participants were biological mothers and may not accurately represent the entire family experience. It would be valuable to figure out how to successfully recruit larger numbers of men for these studies because sex may be an important component to consider when understanding the impact of the NICU experience on the family.

Despite these limitations, the extant literature is the first to use cluster analysis to group parents on distress levels as a function of their infant's medical severity. Given this analytic technique, it provides additional information to the findings of Grunberg (2016) thesis because it demonstrates how all of these variables could be used to distinguish parents at

increased risk for distress. This information provides key information on which specific medical indices of infant health may be particularly challenging for parents. These findings may help inform clinicians and researchers how indices of infant health can be used to identify parents who may benefit from additional support during and after infant hospitalization. Clinicians should consider using these specific factors to develop and modify psychosocial interventions for both parents (regardless of sex) and examine treatment efficacy between groups.

CONCLUSIONS

The current study used hierarchical cluster analysis to distinguish how NICU parents group together based on specific infant health characteristics and parental functioning variables. Three clusters were identified, and parents were categorized into low-, moderate-, or high-risk groups for negative psychosocial adjustment. The low and moderate groups significantly differed on all outcomes except medications, family resources, and parental stress. Future research should consider collecting more data to increase the sample size to more accurately differentiate among the high-risk groups. These findings might also help the health care workforce (e.g., physicians, nurse practitioners, nurses, psychologists) identify which parents to target for additional psychosocial support during their NICU admission and after discharge. Psychosocial interventions should be tailored to each group to improve biopsychosocial outcomes and development for NICU parents, families, and children.

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REFERENCES

- Abidin, R. R. (1995). *Parenting Stress Index: Professional manual* (3rd ed.). Lutz, FL: Psychological Assessment Resources.
- Blashfield, R. K. (1980). Propositions regarding the use of cluster analysis in clinical research. *Journal of Consulting and Clinical Psychology, 48*, 456–459.
- Boykova, M., & Kenner, C. (2012). Transition from hospital to home for parents of preterm infants. *Journal of Perinatal and Neonatal Nursing, 26*, 81–87.
- Doucette, J., & Pinelli, J. (2004). The effects of family resources, coping, and strains on family adjustment 18 to 24 months after the NICU experience. *Advances in Neonatal Care, 4*, 92–104.
- Feeley, N., Gottlieb, L., & Zelkowitz, P. (2005). Infant, mother, and contextual predictors of mother-very low birth weight infant interaction at 9 months of age. *Journal of Developmental and Behavioral Pediatrics, 26*, 24–33.
- Geller, P. A., Bonacquistic, A., & Patterson, C. A. (2018). Maternal experience of neonatal intensive care unit hospitalization: Trauma exposure and psychosocial responses. In M. Muzik, & K. L. Rosenblum (Eds.), *Integrating Psychiatry and Primary Care* (pp. 227–247). Switzerland: Springer.
- Gray, P. H., Edwards, D. M., O'Callaghan, M. J., & Cuskelly, M. (2012). Parenting stress in mothers of preterm infants during early infancy. *Early Human Development, 88*, 45–49.

- Grunberg, V. A. (2016). *Neonatal intensive care unit infants, parental stress, couple and family impact: How family resources may attenuate the stress*. Retrieved from <http://hdl.handle.net/1860/idea:6811>
- Grunberg, V. A., Geller, P. A., Bonacquisti, A., & Patterson, C. A. (2019). NICU infant health severity and family outcomes: A systematic review of assessments and findings in psychosocial research. *Journal of Perinatology, 39*, 156–172.
- Haas, S. A. (2007). The long-term effects of poor childhood health: An assessment and application of retrospective reports. *Demography, 44*, 113–135.
- Holditch-Davis, D., Miles, M. S., Weaver, M. A., Black, B., Beeber, L., Thoyre, S., & Engelke, S. (2009). Patterns of distress in African-American mothers of preterm infants. *Journal of Developmental and Behavioral Pediatrics, 30*, 193–205.
- Lefkowitz, D. S., Baxt, C., & Evans, J. R. (2010). Prevalence and correlates of posttraumatic stress and postpartum depression in parents of infants in the neonatal intensive care unit (NICU). *Journal of Clinical Psychology in Medical Settings, 17*, 230–237.
- Lorenz, J. M., Wooliever, D. E., Jetton, J. R., & Paneth, N. (1998). A quantitative review of mortality and developmental disability in extremely premature newborns. *Archives of Pediatrics and Adolescent Medicine, 152*, 425–435.
- March of Dimes Perinatal Data Center. (2011). *Special care nursery admissions*. Retrieved from https://www.marchofdimes.org/peristats/pdfdocs/nicu_summary_final.pdf
- Nosarti, C., Murray, R. M., & Hack, M. (2010). *Neurodevelopmental outcomes of preterm birth: From childhood to adult life*. New York, NY: Cambridge University Press.
- Obeidat, H. M., Bond, E. A., & Callister, L. C. (2009). The parental experience of having an infant in the newborn intensive care unit. *Journal of Perinatal Education, 18*, 23–29.
- Shaw, R. J., Bernard, R. S., DeBlois, T., Ikuta, L. M., Ginzburg, K., & Koopman, C. (2009). The relationship between acute stress disorder and posttraumatic stress disorder in the neonatal intensive care unit. *Psychosomatics, 50*, 131–137.
- Singer, L. T., Salvator, A., Guo, S., Collin, M., Lilien, L., & Baley, J. (1999). Maternal psychological distress and parenting stress after the birth of a very low-birth-weight infant. *JAMA, 281*, 799–805.
- Stein, R. E., & Jessop, D. J. (2003). The impact on family scale revisited: Further psychometric data. *Journal of Developmental and Behavioral Pediatrics, 24*, 9–16.
- Stephens, B. E., Bann, C. M., Poole, W. K., & Vohr, B. R. (2008). Neurodevelopmental impairment: Predictors of its impact on the families of extremely low birth weight infants at 18 months. *Infant Mental Health Journal, 29*, 570–587.
- Treyvaud, K. (2014). Parent and family outcomes following very preterm or very low birth weight birth: A review. *Seminars in Fetal and Neonatal Medicine, 19*, 131–135.
- Treyvaud, K., Anderson, V. A., Howard, K., Bear, M., Hunt, R. W., Doyle, L. W., . . . Anderson, P. J. (2009). Parenting behavior is associated with the early neurobehavioral development of very preterm children. *Pediatrics, 123*, 555–561.
- Van Horn, M. L., Bellis, J. M., & Snyder, S. W. (2001). Family Resource Scale-Revised: Psychometrics and validation of a measure of family resources in a sample of low-income families. *Journal of Psychoeducational Assessment, 19*, 54–68.

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