



# Maternal Stress and Mental Health Prior to Their Technology-Dependent Infant's Discharge Home From the NICU

Valerie Boebel Toly, PhD, RN, CPNP; Julia E. Blanchette, PhD(c), RN, CDE; Wei Liu, MS; Abdus Sattar, PhD; Carol M. Musil, PhD, RN, FAAN; Amy Bieda, PhD, RN, APRN, PNP-BC, NNP-BC; Sarah Em, BSN

## ABSTRACT

Mothers of infants in the neonatal intensive care unit (NICU) face stressors including turbulent emotions from their pregnancy/unexpected preterm delivery and their infant's unpredictable health status. The study purpose was to examine the psychological state of mothers prior to the discharge of their technology-dependent infants (eg, feeding tubes, supplemental oxygen) from the NICU to home. The study sample consisted of mothers ( $N = 19$ ) of infants dependent on medical technology being discharged from a large Midwest NICU. A descriptive, correlational design using convenience sampling was employed to recruit mothers to examine associations of infant and maternal factors, resourcefulness, and stress with psychological state (depressive symptoms, posttraumatic stress symptoms). Forty-two percent of mothers were at high risk for clinical depression, with 37% in the clinical range for posttraumatic stress disorder. Increased maternal depressive symptoms

were significantly associated with the increased frequency and perceived difficulty of their stress and posttraumatic stress symptoms. Increased posttraumatic stress symptoms were significantly associated solely with elevated depressive symptoms. This study identified factors associated with the mothers' increased psychological distress, providing beginning evidence for future interventions to employ prior to their technology-dependent infant's NICU discharge.

**Key Words:** mental health, mothers, NICU discharge, technology-dependent infant

## BACKGROUND AND SIGNIFICANCE

Across the United States, 9.85% of all infants born in 2016 were born preterm (prior to 37 weeks' gestation) and spent time in the neonatal intensive care unit (NICU).<sup>1</sup> Some of these infants have complex, chronic conditions that include genetic disorders, congenital anomalies, or respiratory distress that require a prolonged stay in the NICU. Approximately 3% of infants with these conditions experience a long-term dependence on medical technologies such as mechanical ventilation, supplemental oxygen, or feeding tubes that are managed at home following discharge.<sup>2</sup> Infants who spend time in the NICU comprise one-third of the population of technology-dependent children.<sup>3</sup> Once discharged, they require vigilant monitoring and care from parents at home. Typically, mothers take on the role as the primary caregiver for their technology-dependent infants during and after the transition to home.<sup>4</sup> Therefore, they must learn how to manage their infant's chronic conditions, medical technologies, and daily care prior to discharge.<sup>5–8</sup> For many, caregiving responsibilities continue for several years while the child remains technology-dependent.<sup>9,10</sup>

**Author Affiliations:** Frances Payne Bolton School of Nursing (Drs Toly, Musil, and Bieda and Mss Blanchette and Em), and Department of Epidemiology and Biostatistics, School of Medicine (Dr Sattar), Case Western Reserve University, Cleveland, Ohio; and Department of Quantitative Health Sciences, Cleveland Clinic, Cleveland, Ohio (Ms Liu).

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**Corresponding Author:** Valerie Boebel Toly, PhD, RN, CPNP, Frances Payne Bolton School of Nursing, Case Western Reserve University, 10900 Euclid Ave, Cleveland, OH 44106 (vab@case.edu).

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Mothers of neonates admitted to the NICU are at high risk for psychological distress including greater anxiety, stress, and indecisiveness<sup>11,12</sup> and higher rates of postpartum depression<sup>13-15</sup> and posttraumatic stress disorder (PTSD)<sup>16-22</sup> than mothers of healthy full-term neonates.<sup>17,23,24</sup> This distress may be attributed to their child's unstable and unpredictable health status and appearance,<sup>25,26</sup> parental role alteration,<sup>26-28</sup> and emotional trauma from their unexpected preterm delivery. While some studies have focused on the high levels of anxiety in parents of neonates with complex conditions such as congenital heart disease admitted to the NICU,<sup>25-28</sup> few have focused on mothers caring for technology-dependent infants discharged from the NICU to home.<sup>13,29</sup> This transition stage is particularly important since these mothers are already at high risk for depression and PTSD following the NICU stay and must maintain constant vigilance as they monitor their infant's condition and manage the life-supporting technology for an indefinite period of time.<sup>3,30</sup>

Preparing for the infant's transition out of the hospital to home without the security and support from healthcare staff can be overwhelming.<sup>31,32</sup> The limited number of investigations concerning mothers' psychological state prior to the discharge of their technology-dependent infant from the NICU to home is a major gap in research that interferes with the development of effective methods to support high-risk families. Postpartum depression and PTSD are associated with a large cost burden from expenditures for both psychiatric and nonpsychiatric healthcare, as well as lost wages and productivity for the mothers, estimated to be approximately \$1 billion in the United States.<sup>33,34</sup>

### Postpartum depression

The overall risk of postpartum depression is estimated to be 13% to 19% within 3 months after giving birth<sup>35,36</sup> and is considerably higher in mothers with babies admitted to the NICU (39%-63% prevalence).<sup>13-15,20,37,38</sup> Mothers at highest risk for postpartum depression are older,<sup>14</sup> delivered by cesarean sections,<sup>18</sup> report increased stress, and had infants born at lower birth weights and gestational age, higher severity of illness, more medical complications (eg, prolonged mechanical ventilation), and longer hospital stays.<sup>14,24</sup> Urban low-income mothers with an infant in the NICU who are not living with the infant's father are at particularly high risk for elevated postpartum depressive symptoms regardless of their stress level or their baby's illness.<sup>14</sup> Thus, mothers of infants who are discharged home dependent on medical technology exhibit many of these high risk factors, particularly due to their infant's severity of illness and medical complications.

### Posttraumatic stress disorder

Mothers of infants in the NICU are also at high risk for PTSD,<sup>19,39</sup> with a reported prevalence between 15% and 23%<sup>19,40</sup> compared with the lifetime prevalence of 8% in the general population.<sup>41</sup> This may be due to a loss of personal control over events, especially survival of the vulnerable infant. The mother may also experience the loss of caregiver and decision-maker roles, apprehension about the infant's fragile health state and appearance, and intrusive memories of traumatic emergency and resuscitation efforts.<sup>42</sup> PTSD is characterized by 8 criteria as described in the *DSM-5 (Diagnostic and Statistical Manual of Mental Disorders [Fifth Edition])*: (a) exposure to death, threatened death; (b) the traumatic event is persistently reexperienced; (c) avoidance of trauma-related stimuli after the trauma; (d) negative thoughts or feelings that began or worsened after the trauma; (e) trauma-related arousal and reactivity that began or worsened after the trauma; (f) symptoms last more than 1 month; (g) symptoms create distress or functional impairment; and (h) symptoms are not due to medication, substance use, or other illness.<sup>43</sup>

### Resourcefulness

Resourcefulness is a set of cognitive and behavioral skills used to attain, maintain, or regain health and involves the ability to perform daily tasks despite potentially adverse situations (ie, personal resourcefulness) and to seek help from others as needed (ie, social resourcefulness).<sup>44</sup> Since resourcefulness is thought to mediate the relationship between stress and mental health, examining the role of resourcefulness in mothers with technology-dependent infants is important, particularly during the critical time period of the infant's discharge home from the NICU. Cognitive-behavioral strategies such as resourcefulness have been associated with better mental health outcomes. Lower levels of resourcefulness are a predictor of mothers' elevated depressive symptoms in past research.<sup>45</sup> An individual's level of resourcefulness has been shown to be amenable to change and may be enhanced through resourcefulness interventions.<sup>46</sup> Thus, resourcefulness is a promising factor to target for intervention work in the quest to reduce the level of depressive and stress-related symptoms in mothers of technology-dependent infants.<sup>46</sup> To date, no research has explored resourcefulness of mothers with infants in the NICU and its effect on maternal mental health and stress.

The purpose of this study was to examine mothers' psychological state prior to discharge of their technology-dependent infant from the NICU to home. Specific research questions were as follows: (1) What is the psychological state (depressive symptoms, posttraumatic stress symptoms) of mothers who will

be caring for infants dependent on medical technology prior to discharge from an NICU to home? and (2) How do neonatal factors (gestational age, birth weight, functional status, type of technology) and maternal factors (age, partner status, household income), stress, and resourcefulness affect mothers' (a) depressive symptoms and (b) posttraumatic stress symptoms prior to discharge? Findings will provide information to aid nurses and other healthcare providers as they prepare mothers of technology-dependent infants for initial discharge from the NICU to home.

## CONCEPTUAL FRAMEWORK

Transition theory helps promote an understanding of the nature and pattern of human response to change, as well as factors to examine during such transitions.<sup>47</sup> These factors are important considerations for nurses who prepare individuals to cope with developmental, situational, and health-illness transitions in a positive fashion that promotes their health and well-being. In this study, transition is a process triggered by the technology-dependent infant's discharge from the NICU that requires intervention by the nurse and other healthcare professionals to facilitate optimal caregiving to the infant. Such interventions promote role mastery and facilitate better outcomes by integrating nursing and social support. Transition theory was used to examine factors affecting mothers who are planning to assume caregiving responsibilities following the discharge of their technology-dependent infant from the NICU to home.<sup>47</sup> Transition theory concepts that were used in this study were the transitional maternal factors (age, partner status, household income) and infant factors (gestational age, birth weight, functional status, and type of technology) that facilitate or hinder achievement of healthy maternal psychological outcomes (depressive symptoms, posttraumatic stress symptoms).

## METHODS

### Research design

A descriptive, correlational design was used to examine the psychological outcomes of mothers prior to the discharge of their technology-dependent infant from the NICU to home.

### Setting and sample

The setting for this study was a 44-bed NICU transitional care unit in a large children's hospital located in the Midwest United States that has approximately 1000 admissions per year. Mothers (primary female caregiver) aged 18 years or older were eligible to participate if

(a) their infant was to be discharged from the NICU to home within 2 to 3 weeks for the first time and was dependent on medical technology (mechanical ventilation, intravenous medication, supplemental oxygen, tracheostomy, feeding tubes); and (b) they were able to read and speak English. Mothers of infants with a terminal diagnosis were excluded because of the profound grief reactions associated with these diagnoses that might be confounded with the main psychological states under study. Convenience sampling was used to obtain a sample of mothers.

### Instruments

The 14-item interval scale ( $\alpha = .86$ ) Functional Status II-Revised (FS II-R) was used to measure a child's functional status.<sup>48</sup> Lower scores indicate poorer functional status. Concurrent validity was established by physician assessments and the number of hospital days.<sup>48</sup>

The investigator-developed Technology Dependency Questionnaire, based on the Office of Technology Assessment<sup>49</sup> rubric for technology dependence, constructed as binary questions (yes/no), was used to determine the type of medical technology used by each infant.

Mothers' depressive symptoms were measured using the 20-item Center for Epidemiological Studies–Depression Scale (CES-D) ( $\alpha = .85$ ).<sup>50</sup> Respondents at increased risk for clinical depression had a score of 16 or more.<sup>50</sup> Concurrent validity was established by the clinician's ratings.<sup>50</sup>

Mothers' posttraumatic stress symptoms were assessed using the 14-item self-report Perinatal Posttraumatic Stress Disorder Questionnaire (PPQ) ( $\alpha = .85$ ) that asks about symptoms related to childbirth and the postnatal period.<sup>18,51</sup> Scores of 19 or more points indicate clinically significant distress that warrants a mental health referral.<sup>18,51</sup> Convergent validity was supported by strong correlations between the PPQ and the Impact of Events Scale and the Beck Depression Inventory-II.<sup>18,51</sup>

Maternal stress was assessed using the Pediatric Inventory for Parents (PIP), a 42-item self-report questionnaire ( $\alpha = .80-.96$ ) rating of stress events associated with caring for a child with medical illness.<sup>52</sup> It includes a list of difficult events faced by parents of children with serious illness related to communication, medical care, emotional distress, and role function. Parents report how frequently the event occurred over the past week and then rate on a 5-point scale how difficult it was for them. Ratings for frequency and difficulty are summed for PIP-Frequency and PIP-Difficulty scores. Higher scores indicate greater stress. Construct validity was shown by strong correlations between the PIP and state anxiety.<sup>53</sup>

The mothers' resourcefulness was measured using the Resourcefulness Scale, a 28-item scale ( $\alpha = .85$ ) that assesses both personal (16 items) and social (12 items) resourcefulness.<sup>54</sup> Higher scores indicate increased resourcefulness. Construct validity was shown with confirmatory factor analysis.<sup>54</sup>

The demographic characteristics of mothers and their technology-dependent infants were measured using an Enrollment Form. This instrument includes questions about the infant's gender, gestational age, and birth weight, multiple birth, NICU admitting diagnosis, length of stay in the NICU, as well as mother's age, education, partner status, race/ethnicity, and household income. Any question that the mother was uncertain about was verified from the infant's chart.

### Procedure

Following institutional review board (IRB) approval, the NICU staff identified potential participants and invited them to hear more about the study. The study was described and informed consent was obtained from the participant on IRB-approved forms. HIPAA authorization was obtained to conduct medical record reviews for the infant's demographic data. Interviews took place in a private place of the mother's choosing on the NICU.

The FS II-R and the Technology Dependency Questionnaire were administered by a member of the research team, but the remaining scales were self-administered to decrease social desirability of responses. Participants received a \$15 gift card at the completion of data collection. Mothers who scored 16 or more on the CES-D and/or 19 or more on the PPQ were given a sheet with mental health resources. Mothers with a CES-D score of 23 or more were screened for suicide risk, with the plan that a mobile crisis unit would be called if indicated.

### Data analysis

All data were summarized using descriptive statistics, for example, means and standard deviations for continuous variables and frequencies and percentages for categorical variables. The primary outcome was the psychological state (depressive symptoms and PTSD symptoms) of mothers who cared for technology-dependent infants prior to their discharge from the NICU to home. Spearman's rank correlation coefficients were used to examine associations among continuous variables of interest. To examine the association between psychological outcomes of mothers and some categorical variables, such as household income, we used the Wilcoxon rank sum test. Furthermore, simple linear regression models were applied to study the effect of neonatal factors and maternal factors on the psychological outcomes of mothers. A covariate with  $P \leq .05$

was considered to be a statistically significant association with the underlying response variable. All analyses were conducted using statistical software R 3.4.0 and Stata 14.0.

## RESULTS

### Sample characteristics

Study recruitment took place over a period of 15 months. Of the 38 mothers eligible and invited by an NICU staff member to hear more about the study, 12 declined and 26 agreed to consider the study, with 19 mothers participating for a participation rate of 50%. Mothers in this study ranged in age from 18 to 41 years ( $M = 25.63$  years;  $SD = 6.27$ ). Approximately half of participants were African American; the majority had a high school education or less (see Table 1). Almost two-thirds were single, never married. The household income varied, but about half had an income of \$20 000 or less per year.

The gestational age of the infants ranged from 23 to 39.29 weeks ( $M = 29.78$  weeks;  $SD = 6.43$ ); birth weight

**Table 1. Maternal and infant demographics (N = 19)**

	<i>n (%)</i>
<i>Characteristics of infants</i>	
Primary diagnosis	
Prematurity	7 (36.8)
Respiratory failure	4 (21.1)
Genetic disorder	3 (15.8)
Respiratory distress	3 (15.8)
Sepsis	2 (10.5)
Dependency on gastrostomy tube	14 (73.7)
Dependency on nasal oxygen	8 (42.1)
Dependency on tracheostomy	3 (15.8)
Dependency on mechanical ventilation	2 (10.5)
Dependency on nasogastric tube	1 (5.3)
<i>Characteristics of mothers</i>	
Race/ethnicity	
African American	9 (47.4)
White	7 (36.8)
Latino or Hispanic	2 (10.5)
Biracial	1 (5.3)
Education	
High school graduate or less	11 (57.9)
Partial college	5 (26.3)
Bachelor's degree or higher	3 (15.8)
Partner status	
Single	12 (63.2)
Married or living with partner	7 (36.8)
Household income	
≤\$20 000	10 (52.6)
>\$20 000	7 (36.8)
Unknown	2 (10.5)

ranged from 500 to 3765 g ( $M = 1546.1$  g;  $SD = 1151.8$ ). About one-third of the infants had a primary medical diagnosis of prematurity, with another one-third were diagnosed with either respiratory failure or respiratory distress. Most infants had either a gastrostomy tube or nasogastric tube, and about half required supplemental nasal oxygen; however, 15.8% had a tracheostomy and 10.5% required mechanical ventilation. A majority of infants (63.2%;  $n = 12$ ) required one type of technology; however, 36.8% ( $n = 7$ ) required 2 or more types of technology. The total length of hospital stay ranged from 33.9 to 270.9 days ( $M = 149.7$  days;  $SD = 68.7$ ).

### Descriptive statistics for key study variables

Scores for depressive symptoms on the CES-D ranged from 2 to 39 ( $M = 14.53$ ;  $SD = 9.90$ ) out of a maximum score of 60; 42% ( $n = 8$ ) scored 16 or more, a cut score indicative of elevated risk for clinical depression, and were given a mental health resource sheet with telephone numbers for local sources of support.<sup>50</sup> Three mothers scored more than 23 on the CES-D and required screening for suicide risk; all denied thoughts of suicide or hurting themselves in any way. The posttraumatic stress symptoms scores on the PPQ ranged from 2 to 37 ( $M = 16.52$ ;  $SD = 12.11$ ); 37% ( $n = 7$ ) scored 19 or more, within the clinical range for reported PTSD.<sup>18,51</sup> The PIP scores for frequency of stress ranged from 72 to 159 ( $M = 114.37$ ;  $SD = 21.85$ ), and the PIP scores for perceived difficulty of stress scores ranged from 52 to 167 ( $M = 101.37$ ;  $SD = 30.60$ ). Both subscales had a maximum score of 210. The scores for the Resourcefulness Scale ranged from 12 to 48 ( $M = 31.11$ ;  $SD =$

9.16) for social resourcefulness from a maximum possible of 60 and from 17 to 75 ( $M = 51.95$ ;  $SD = 13.51$ ) for personal resourcefulness out of a maximum of 80. Mothers' total resourcefulness ranged from 36 to 112 ( $M = 83.05$ ;  $SD = 17.54$ ) out of a maximum of 140.

### Correlates of depressive symptoms and posttraumatic stress symptoms

Three factors significantly correlated with elevated maternal depressive symptoms (see Table 2): lower total resourcefulness, greater perceived frequency, and difficulty of care-related stress events. Only partner status (partnered) and lower household income had a significant positive correlation with posttraumatic stress symptoms (see Table 3).

### Simple linear regression of depressive symptoms and posttraumatic stress symptoms

The results indicate that depressive symptoms in mothers (see Table 4) were significantly associated with increased perceived frequency ( $P = .01$ ) and difficulty ( $P \leq .01$ ) of stress events, as well as higher posttraumatic stress symptoms ( $P \leq .01$ ). Higher posttraumatic stress symptoms in mothers (see Table 5) were significantly associated solely with higher depressive symptom levels ( $P \leq .01$ ).

## DISCUSSION

The goal of this study was to examine mothers' psychological state prior to the discharge of their technology-dependent infant from the NICU and is the first study

**Table 2. Spearman correlation among mothers' psychological state and continuous factors (N = 19)**

	Mothers' psychological state			
	Depressive symptoms		Posttraumatic stress symptoms	
	Spearman $\rho$	<i>P</i>	Spearman $\rho$	<i>P</i>
Gestational age	0.13	.59	0.02	.93
Birth weight <sup>a</sup>	0.06	.80	-0.12	.63
Functional status	-0.42	.07	-0.33	.16
Mother's age	0.06	.82	0.21	.38
Number of adults in the household	-0.40	.09	-0.35	.14
Number of children in the household	-0.24	.32	-0.07	.78
Resourcefulness (personal)	-0.24	.32	0.03	.91
Resourcefulness (social)	-0.29	.23	-0.33	.17
Resourcefulness (total)	-0.47	.04	-0.20	.41
Stress (difficulty total)	0.64	<.01	0.40	.09
Stress (frequency total)	0.47	.04	0.22	.36

<sup>a</sup>Birth weight (in grams) was divided by its standard deviation before performing regression analysis.

**Table 3. Mean differences of maternal psychological state by infant's technology type and maternal partner status and household income (N = 19)**

	Mean differences of mothers' psychological state			
	Depressive symptoms		Posttraumatic stress symptoms	
	Mean difference (95% CI) <sup>a</sup>	P <sup>b</sup>	Mean difference (95% CI) <sup>a</sup>	P <sup>b</sup>
Gastrostomy tube <sup>c</sup>	6.69 (−1.67, 14.57)	.16	0.71 (−11.99, 12.96)	.74
Nasal oxygen <sup>c</sup>	−2.85 (−11.41, 5.10)	.65	0.82 (−9.74, 11.48)	>.99
Tracheostomy <sup>c</sup>	−4.58 (−13.98, 6.56)	.57	1.35 (−12.44, 19.32)	.96
Mechanical ventilation <sup>c</sup>	−0.03 (−10.65, 10.53)	.84	7.24 (−10.35, 24.88)	.55
Partner status <sup>d</sup>	−3.10 (−11.18, 4.87)	.55	8.89 (−1.47, 18.86)	.05
Household income <sup>e</sup>	0.7 (−8.63, 9.54)	.88	11.33 (1.01, 20.69)	.04

<sup>a</sup>The reference group of each categorical factor was used as base to calculate mean difference of mothers' psychological state, and mean difference and the corresponding 95% CIs were obtained by bootstrap method.

<sup>b</sup>P values were obtained by the Wilcoxon rank sum test.

<sup>c</sup>The references for nasogastric tube, gastrostomy tube, nasal oxygen, tracheostomy, and mechanical ventilation are the group giving no response.

<sup>d</sup>The reference for partner status is single.

<sup>e</sup>The reference for household income is \$20 000 or less.

to simultaneously examine the depressive symptoms, posttraumatic stress symptoms, and stress of these mothers.<sup>25–27</sup> In the present study, the presence of maternal depressive symptoms prior to their infant's discharge was similar to findings of other studies of mothers with preterm infants.<sup>14,23,29</sup> However, these scores

were higher than those found by other researchers,<sup>55</sup> who examined a group of mothers whose infants were dependent on respiratory or nutritional support in a Canadian NICU. While 42% of mothers in this study scored 16 or more on the CES-D, indicating elevated risk for clinical depression, other studies have found

**Table 4. Associations among mothers' depressive symptoms, and infant and maternal factors using simple linear regression models (N = 19)**

	Coefficient estimates	95% CI	P
Infant factors			
Gestational age, wk	0.08	(−0.70, 0.87)	.83
Birth weight <sup>a</sup>	0.25	(−4.93, 5.42)	.92
Functional status	−1.56	(−3.18, 0.06)	.06
Nasogastric tube <sup>b</sup>	−13.22	(−34.23, 7.79)	.20
Gastrostomy tube <sup>b</sup>	6.69	(−3.97, 17.34)	.20
Nasal oxygen <sup>b</sup>	−2.85	(−12.73, 7.02)	.55
Tracheostomy <sup>b</sup>	−4.58	(−17.89, 8.73)	.48
Mechanical ventilation <sup>b</sup>	−0.03	(−16.09, 16.03)	>.99
Maternal factors			
Number of adults in the household	−4.25	(−9.36, 0.86)	.10
Number of children in the household	−0.83	(−4.43, 2.77)	.63
Mother's age, y	0.24	(−0.56, 1.04)	.53
Partner status <sup>c</sup>	−3.10	(−13.19, 7.00)	.53
Household income <sup>d</sup>	0.70	(−10.36, 11.76)	.89
Resourcefulness (personal)	−0.12	(−0.49, 0.25)	.51
Resourcefulness (social)	−0.40	(−0.92, 0.11)	.11
Resourcefulness (total)	−0.18	(−0.45, 0.09)	.18
Stress (difficulty total)	0.23	(0.11, 0.34)	<.01
Stress (frequency total)	0.25	(0.06, 0.44)	.01
Posttraumatic stress symptoms	0.56	(0.26, 0.87)	<.01

<sup>a</sup>Birth weight (in grams) was divided by its standard deviation before performing regression analysis.

<sup>b</sup>The references for nasogastric tube, gastrostomy tube, nasal oxygen, tracheostomy, and mechanical ventilation are the group giving a "no" response.

<sup>c</sup>The reference for partner status is single.

<sup>d</sup>The reference for household income is \$20 000 or less per year.

**Table 5. Associations among mothers' posttraumatic stress symptoms, and infant and maternal factors using simple linear regression models (N = 19)**

	Coefficient estimates	95% CI	P
Infant factors			
Gestational age, wk	-0.06	(-1.02, 0.91)	.90
Birth weight <sup>a</sup>	-0.64	(-7.12, 5.83)	.84
Functional status	-1.71	(-3.74, 0.32)	.09
Nasogastric tube <sup>b</sup>	-5.83	(-32.67, 21.01)	.65
Gastrostomy tube <sup>b</sup>	0.71	(-12.98, 14.40)	.91
Nasal oxygen <sup>b</sup>	0.82	(-11.39, 13.02)	.89
Tracheostomy <sup>b</sup>	1.35	(-15.17, 17.88)	.86
Mechanical ventilation <sup>b</sup>	7.24	(-12.06, 26.53)	.44
Maternal factors			
Number of adults in the household	-5.32	(-11.55, 0.91)	.09
Number of children in the household	-1.45	(-5.82, 2.92)	.49
Mother's age, y	0.13	(-0.86, 1.12)	.79
Partner status <sup>c</sup>	8.89	(-2.75, 20.54)	.13
Household income <sup>d</sup>	11.33	(-0.32, 22.98)	.06
Resourcefulness (personal)	0.054	(-0.40, 0.51)	.81
Resourcefulness (social)	-0.48	(-1.11, 0.16)	.13
Resourcefulness (total)	-0.10	(-0.45, 0.25)	.56
Stress (difficulty total)	0.16	(-0.02, 0.35)	.08
Stress (frequency total)	0.10	(-0.18, 0.38)	.45
Depressive symptoms	0.84	(0.39, 1.30)	<.01

<sup>a</sup>Birth weight (in grams) was divided by its standard deviation before performing regression analysis.

<sup>b</sup>The references for nasogastric tube, gastrostomy tube, nasal oxygen, tracheostomy, and mechanical ventilation are the group giving a "no" response.

<sup>c</sup>The reference for partner status is single.

<sup>d</sup>The reference for household income is \$20 000 or less per year.

similar depressive symptom prevalence (39%-48%) in mothers with infants in the NICU.<sup>13,14,23,56</sup> Therefore, the high level of depressive symptoms is a consistent issue in mothers with infants in the NICU prior to discharge that often remains undetected unless objectively measured in a consistent manner.

Mothers of infants to be discharged home from the NICU remain at high risk for PTSD symptoms.<sup>19,39,51</sup> In the present study, a little over one-third of the mothers scored within the clinical range for posttraumatic stress symptoms, similar to that reported by DeMier et al<sup>57</sup> but considerably higher than past reported prevalence of 15% to 23% for mothers of infants in the NICU.<sup>19,37,40</sup> The elevated posttraumatic stress symptoms in mothers in our study may reflect the increasing complex, medically fragile, vacillating health state of their infant over the NICU course that necessitated the continued use of lifesaving technology. These technology-dependent infants comprise approximately 3% of all infants admitted to the NICU.<sup>2</sup>

Findings in this study related to the high frequency and difficulty of stress experienced by these mothers are similar to those of parents of older children requiring gastrostomy tubes, the most prevalent technology used.<sup>58</sup> The high stress is concerning because past research indicates that better parental adherence

to their children's treatment regimen is associated with decreased frequency and perception of less difficult stress,<sup>59</sup> suggesting that caregiving may be compromised during periods of high stress. Therefore, the increased maternal stress places the already vulnerable infant at further risk for illness and subsequent emergency department visits and hospital readmissions.<sup>60,61</sup>

There were several maternal and infant factors related to the mothers' elevated depressive symptoms (see Table 4). While the maternal factors with a strong positive association included increased posttraumatic stress symptoms, stress frequency, and perceived stress difficulty, perception of stress difficulty had the strongest association with depressive symptoms. Thus, mothers' perception of the stress difficulty related to their situation is an essential factor requiring assessment and potential intervention prior to their infant's discharge. Other researchers have reported a strong relationship between depressive symptoms and posttraumatic stress symptoms<sup>14,38</sup> with stress,<sup>15,23,62,63</sup> but the results have not been consistent across studies.<sup>14,17</sup>

We also found that functional status, number of adults in the household, and total resourcefulness were not significantly associated with maternal depressive symptoms; however, each had a moderate Spearman  $\rho$  correlation. In addition, using Cohen's  $d$  analysis,

we found a large effect size for functional status ( $|d| = 1.194$ ), number of adults in the household ( $|d| = 1.775$ ), and total resourcefulness ( $|d| = 4.812$ ).<sup>64</sup> The lack of significant association may be attributed to the sample size. Because of the small sample size, the standard errors (SEs) of the coefficients of these predictors are relatively large, consequently affecting the  $P$  values and evaluation of statistical significance. With a larger sample size, the SEs would be smaller, potentially leading to smaller  $P$  values and statistically significant associations among the maternal predictors and depressive symptoms.

While inconsistent with our findings, past studies reported a significant positive relationship between depressive symptoms and resourcefulness.<sup>65-67</sup> In one study,<sup>45</sup> personal resourcefulness, not social resourcefulness, was positively related to greater depressive symptoms in parents of technology-dependent children. However, it included children of all ages and not exclusively high-risk NICU infants as in our present study. The mean total resourcefulness score of the participants in our sample ( $M = 83.05$ ) indicates moderate resourcefulness and a moderate need for resourcefulness interventions. Using criteria from past research, 21% ( $n = 4$ ) of mothers with technology-dependent infants in our study had a very high to somewhat high need and 68% ( $n = 13$ ) had a moderate need for interventions to boost resourcefulness.

In this study, infant functional status had an inverse relationship with mothers' level of depressive symptoms; poorer infant functional status was significantly related to more maternal depressive symptoms. This is similar to findings from Miles et al<sup>15</sup> and Thyen et al<sup>68</sup> but contrary to findings by others<sup>14,38,45</sup> that may be explained by a difference in the measurement tool<sup>14</sup> and age of the children.<sup>45</sup>

Depressive symptoms was the sole predictor positively associated with posttraumatic stress symptoms in this study. This is consistent with other studies of mothers with infants in the NICU<sup>21</sup> including urban mothers with infants in the NICU.<sup>22</sup> However, while not significantly associated with posttraumatic stress symptoms, we found that partner status and household income were significantly correlated with maternal posttraumatic symptoms. In addition, using Cohen's  $d$  analysis, partner status had a moderate effect size ( $|d| = 0.766$ ) and household income had a large effect size ( $|d| = 1.022$ ).<sup>64</sup> Again, these values suggest the need for an adequately powered investigation of associations among demographic predictors and posttraumatic stress symptoms, with larger sample sizes.

The transition theory was used to guide this study.<sup>47</sup> In particular, transitional maternal and infant factors that facilitate or hinder achievement of healthy mater-

nal psychological state (depressive symptoms, posttraumatic stress symptoms) were examined. Study findings indicate that there are few maternal and infant factors correlated with maternal psychological state that may help predict a difficult transition from the NICU to home. Maternal factors that were significantly correlated with posttraumatic stress symptoms included lower household income and single partner status. However, no maternal or infant factors were significantly correlated with depressive symptoms. Therefore, few maternal or infant factors significantly predicted mothers of technology-dependent infants at risk for elevated depressive symptoms and posttraumatic distress symptoms.

### Limitations

Despite the extension of the concepts of stress, maternal depressive and posttraumatic stress symptoms, and resourcefulness to the population of mothers whose infants will be discharged from the NICU to home dependent on lifesaving medical technology, there are some important limitations to this study. The small sample size may lead to unstable estimates of the relationships between variables and thus reduces confidence in the findings, even with corrections to compensate for low power. However, the sample size, while small, provides beginning evidence for future research with this population.

Relative to accruing the sample, the 50% participation rate underscores how challenging it was to obtain agreement to interview the mothers, and several refused to hear more about the study ( $n = 7$ ), declined to participate after hearing about it ( $n = 5$ ), or did not show up for appointments or return calls after agreeing to do so ( $n = 7$ ). Reasons for declining participation were spontaneously verbalized and related to expected length of stay of the infant, reluctance to talk to any more health-care professionals, experiences in other research studies, and lack of time due to responsibilities at home, work, or caring for their other well children at home. In past studies, mothers of technology-dependent children have welcomed the opportunity to speak with study staff about their experiences with their child and have had a participation rate of 90% or more.<sup>3,10</sup> This study of technology-dependent infants being discharged home from the NICU for the first time had a low participation rate of 50%, however, double that of past studies (21.4%) of parents with high-risk infants in the NICU<sup>16</sup> but lower than other prior studies (66% participation rate) of mothers with preterm infants in the NICU.<sup>23</sup>

Additional limitations are the lack of sufficient variation in geographic location, partner status, and education. Furthermore, while there was some variation in income, 50% of the participants had a household income

of \$20 000 or less per year that may serve to confound our findings due to an established inverse relationship between income and stress levels. Finally, because of the infant's extended length of stay and number and severity of health-related events the infant experienced that necessitated the use of lifesaving technology, it is difficult to determine causality related to the mother's posttraumatic stress symptoms, that is, prolonged length of stay, resuscitation events, critical illness, or the infant's actual dependence on the technology itself.

### Future research

Future research with this population of mothers and their infants being discharged from the NICU must solve issues related to the low study participation rate as experienced in this study as well as past studies. This cohort of women was worried and distracted, which, as shown here, may require different approaches to engage and recruit them such as meeting them at a private place of their choosing away from the NICU, for example, in their home. Given the encouraging findings about relationships between variables, however, a larger study, with a more diverse sample, particularly one with a longitudinal element, would provide greater confidence about relationships and better insights into how mothers proceed on their caregiving trajectory after the immediate transition has passed.

This study did not measure social support, which may correlate with social resourcefulness. Future research should incorporate measures of emotional support and instrumental support (eg, help with childcare, household tasks, transportation) and also assess maternal psychiatric history, including previous challenges with depressive symptoms or clinical depression, use of antidepressant or anxiolytic medications prior to the birth of this infant, and previous episodes of postpartum depression.<sup>69</sup> Finally, future research should explore augmenting resourcefulness to address the high level of psychological distress in these vulnerable mothers before and after discharge from the NICU.

### CONCLUSION

A high percentage of mothers of technology-dependent infants discharged home have increased depressive and posttraumatic stress symptoms, indicating a high risk for clinical depression and PTSD. It is important to perform a mental health assessment of these mothers several weeks prior to their infant's discharge using the same or similar measures as used in this study and refer these mothers to mental health resources and support within the hospital setting. Furthermore, it is vital that members of the interdisciplinary team educate mothers regarding community resources for hospital-based sup-

port groups, local support groups, and online support groups prior to discharge.<sup>70</sup>

In addition to mental health resources, a majority of mothers with technology-dependent infants may benefit from an intervention to promote resourcefulness<sup>71</sup> due to low levels of resourcefulness, particularly social resourcefulness, prior to discharge.<sup>46</sup> Social resourcefulness skills include relying on family and friends, exchanging ideas with others, and seeking help from professionals and experts.<sup>71,72</sup>

Preparing a mother for the discharge of her technology-dependent infant from the NICU to home is inherently a time of high stress. Preparation for discharge requires an interdisciplinary team of healthcare professionals and may require weeks of coordinated teamwork depending on the amount of technology the infant will require at home.<sup>8</sup> A previous study found that the most frequently reported source of stress by mothers during transition to home from the NICU was not being involved or informed in care or decisions related to their infant.<sup>31</sup> Therefore, it is imperative that the mother is included in all discussions and the decision-making process with the healthcare team. Furthermore, provision of an objective mental health assessment and holistic support of mothers whose infants will be discharged home dependent on medical technology is of paramount importance to ensure a smooth transition and optimal caregiving for these vulnerable infants.<sup>73</sup>

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