Mixed Methods Socio-cultural Study of the Process of Maternal Stress Response in the Neonatal Intensive Care Unit (NICU) in South Korea

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Abstract

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Despite the significant comorbidity of high-level stress and maternal postpartum psychological problems with regard to the neonatal intensive care unit (NICU), and an increasing rate of preterm births in South Korea, there is a paucity of research on the fundamental reasons why stress response occurs and how it occurs among mothers of infants in the NICU in South Korea. In particular, the influences of interpersonal and socio-cultural factors on the process of stress responses of mothers who have infants in the NICU have not been identified clearly. Hence, to explore the stress response process among mothers of infants in NICUs, relevant to their social and cultural context, three studies were conducted using a multiphase mixed methods design study, in two level IV NICUs in two tertiary hospitals in South Korea.

First, a cross-sectional exploratory study (N=31) showed that the perceived stress level and stress symptoms of NICU mothers were elevated, based on the perceived stress scale (PSS 10) and ten subscales of the Symptoms of Stress (SOS) Inventory, respectively. The four most

frequently reported stress symptoms were *depression* (especially loneliness), *emotional irritability*, *muscle tension*, and *peripheral manifestations*. There was a significant positive association between the stress level and the symptoms of stress.

Second, a grounded theory study (N=32) sought the process of stress response among NICU mothers in South Korea. The results from the analyses of open coding, axial coding, and selective coding were used to formulate a theoretical model and to reveal a central phenomenon contributing to the process of stress response among mothers of infants in the NICUs in South Korea. The causal condition was *giving birth to a child with problems*, the contextual condition was *leaving my baby in the NICU*, and *continuous comparisons* and *high sensitivity to hierarchy ('Gahp-Eul' relation)* emerged as the socio-cultural intervening conditions. The NICU mothers used two strategies, *seeking safe support* and *adapting*, to manage their stress. The two categories of *having mother's role* and *various stress levels and symptoms* were identified as the consequences of the strategies. *Struggling with stigma* emerged as the central phenomenon in the stress response process among the NICU mothers in South Korea.

Third, a sequential qualitative descriptive study (N=30), was conducted to explain the NICU maternal stress response process relevant to the South Korean social and cultural context, in particular. *Uneven/unfair power balance* ('Gahp-Eul' relation), and *ranking the roles* appeared as common ideas in the maternal perceptions of different roles in the NICU, both of which seemed to hinder mothers' capacity to relieve their stress.

Despite study limitations, the results of this multiphase mixed methods research improve our understanding of maternal stress and identify remediable factors that influence this stress response process for mothers in the NICU. The findings reveal how interpersonal and socio-cultural factors, such as continuous comparisons and being sensitive to uneven/unfair power

balance, widely affect the stress response process among NICU mothers in South Korea. Therefore, the findings from this dissertation support the need for more effective nursing care, the development of new nursing interventions, and new family-centered NICU policies that promote management of stress as well as the prevention of postpartum psychological problems among NICU mothers.

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Over the eight years of my PhD program, I have come to realize that there are no coincidences. All the events in my life have a certain significance, even if I am not aware of it at the time, and sooner or later fit together like pieces of a puzzle to form a bigger picture. I am humbled by this realization and ever grateful.

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Therefore, I hope the results of this dissertation will in turn prove helpful to NICU mothers and infants in the future. And I hope that throughout my life, I am able to add some light and warmth to the lives of those around me, as a small yet steady candle may.

CHAPTER 1

Overview

Significance

To date, there have been numerous studies regarding psychological problems of mothers with an infant in the NICU, such as postpartum depression and anxiety disorder (Aagaard & Hall, 2008; De Magistris, Coni, Puddu, Zonza, & Fanos, 2010; Mendelsohn, 2005; Wray, Lee, Dearmun, & Franck, 2011; Yurdakul et al., 2009). In addition, researchers have described significant comorbidity between stress and psychological problems among NICU mothers (Lefkowitz, Baxt, & Evans,2010). Nonetheless, many gaps in research remain, which this dissertation seeks to address (Figure 1-1).

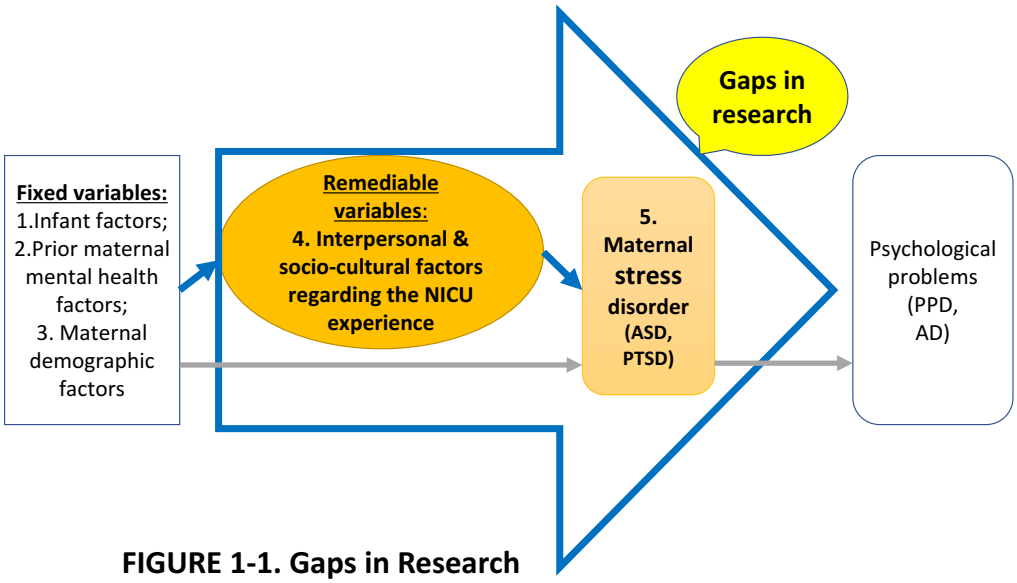

FIGURE 1-1. Gaps in Research

First of all, which types of factors would be remediable in response to nursing intervention? The key factors associated with psychological problems of NICU mothers can be categorized as follows: (1) infant factors, (2) prior maternal mental health factors, (3) maternal

demographic factors, (4) interpersonal and socio-cultural factors, and (5) maternal stress disorder.

Infant factors include variables such as low birth weight, less than 37 weeks of gestational age, and the state of congenital medical complications. These factors are obvious predictors of maternal psychological problems, as the infant's health status directly relates to hospitalization, and the infant's hospitalization is likely to increase the maternal stress level as well as the risk of psychological problems (Beck, 2003; Blom et al., 2010; Mew, Holditch-Davis, Belyea, Miles, & Fishel, 2003; Vigod, Villegas, Dennis, & Ross, 2010; Wray, Lee, Dearmun, & Franck, 2011).

Prior maternal mental health factors, such as prenatal depression, prenatal anxiety, or a history of previous depression, are significantly associated with the incidence of psychological problems (Beck, 2003; Bergstrom, Wallin, Thomson, & Flacking, 2012). In particular, the mother's trait anxiety is highly correlated with psychological problems in the NICU (Melnyk, Crean, Feinstein, & Fairbanks, 2008).

Demographic factors, such as marital status or socioeconomic status, are directly associated with psychological problems in mothers of NICU infants. Research has indicated that mothers with low incomes reported more depressive symptoms (Beck, 2003; Melnyk et al., 2008).

These three factors – infant factors, prior maternal mental health factors, and demographic factors – are significant, but fixed variables. That is, they are not remediable through nursing interventions. On the other hand, *interpersonal and socio-cultural factors*, such as NICU staff attitudes (Younger, Kendell, & Pickler, 1997), family experience of cultural stigma in the NICU (Heidari, Hasanpour, & Fooladi, 2012), and family functioning (Beck,

2003), are not fixed variables, because they can be affected by nursing interventions such as supportive counseling (Bergstrom et al., 2012) and education (Jang, 2005). Among the main factors contributing to the NICU mothers' psychological problems, interpersonal and socio-cultural factors may be the most significant to future nursing interventions because that they are remediable.

Second, why does maternal stress disorder occur and how is it experienced in the NICU? Because a long-lasting high level of stress is often linked to stress disorder, the level of maternal stress must be considered in family-centered NICU care. The level of maternal stress is not only a variable that mediates the effects of the other variables in psychological problems among mothers of NICU infants, but also a point of strategic importance. Also, it can be an outcome variable itself in research on nursing intervention. Despite the significance of understanding NICU mothers' stress responses, there are gaps in research on how and why stress response occurs among mothers of infants in the NICU and what the process is.

Finally, why does Korean culture matter? According to a report from the Migration Policy Institute, more than one million Korean immigrants resided in the United States (U.S.) as of 2015, and they came overwhelmingly from South Korea (Zong & Batalova, 2017). Although Korean culture in South Korea differs from that of Korean Americans in the U.S., an understanding of the culture of South Korea is useful to better understand Korean-American maternal responses, and possibly those of Asian-American mothers from other East Asian cultures. Moreover, more Korean mothers and their infants are likely to be experiencing NICU care as the preterm birth rate has increased dramatically in recent years (Lim, 2011). The latter strongly suggests there is an urgency need to address factors influencing maternal stress and stressors, through the implementation of effective nursing intervention programs.

Consequently, a more comprehensive understanding of NICU maternal stress responses within the socio-cultural context as well as the NICU context is needed to develop effective nursing approaches. Little is known, however, about stress responses among NICU mothers, including what interpersonal and socio-cultural factors cause stress among mothers with infants in the NICU, and in that context, how mothers respond during NICU hospitalization and what factors influence their responses.

Aims and Strategy

The primary purpose of this dissertation research was to generate a theory to explain the stress response process among mothers with infants in the NICU, with specific focus on their social and cultural context. The ultimate purpose of this dissertation research was to distinguish salient features of the interpersonal and socio-cultural factors deemed most likely to be remediable among a range of factors influencing the stress response to facilitate the design and implementation of nursing interventions in the future. The specific research aims were as follows:

Aim 1. To describe the stress level and symptoms among mothers of infants in NICUs in South Korea, and to describe the relationship between stress level and symptoms of stress.

Aim 2. To identify the conditions and processes under which the stress responses are resolved or not resolved, and to specify socio-cultural factors that enhance or hinder management of the stress response process.

Aim 3. To describe maternal perceptions of their own roles in the NICU, and that of their infants, families, and the NICU staff with regard to NICU experiences, and to understand the meaning of such roles to the mothers during the stress response process.

To address the primary purpose of this study, grounded theory methodology was determined to be the most adequate within a multiphase mixed methods design. A grounded theory approach is particularly appropriate for under-studied areas, to generate a theory that accounts for key social processes, and to identify conditions under which the processes occur or do not occur (Speziale & Carpenter, 2007). Moreover, a mixed methods research design is likely to be an effective solution, when answers to the research problem are vague with only numbers from a quantitative method or words from a qualitative method (Creswell & Plano Clark, 2011). Using mixed methods often complements research approaches and enhances validity of findings. A multiphase mixed methods design allows the researcher to combine a collection of quantitative and qualitative data sets concurrently and/or sequentially over multiple phases of programmatic research (Creswell & Plano Clark, 2011). That is, the multiphase mixed methods design enables the researcher to conduct incremental sets of research to advance programmatic research, such as the development of new nursing interventions.

This dissertation includes three papers based on the three research aims. A multiphase mixed methods design was used to address each specific aim: a cross-sectional exploratory study for the first aim, a grounded theory study for the second aim, and a qualitative descriptive study for the third. The sample of mothers was recruited from two level IV NICUs at Asan Medical Center (AMC) and Samsung Medical Center (SMC), in Seoul, South Korea. Purposive, convenience, and snowball sampling methods were used. In total, thirty-two mothers described their stress responses by participating in one or more of the three-phase studies. The mothers were compensated for their time with gift certificates of ₩15,000, ₩15,000, and ₩20,000 (≈$14, $14, $18) respectively, at completion of each study. Thus, if a mother had participated in all three-phase studies, she received three gift certificates, in total ₩50,000 (≈$45).

Content of the Dissertation

Three studies are described in this dissertation. Chapter 2, addressing the first aim, describes the findings from analysis of the quantitative survey data collected from 31 NICU mothers. This cross-sectional exploratory study provides fundamental information about the current stress levels and major symptoms among the NICU mothers in South Korea.

Chapter 3 addresses the central purpose and second aim of the dissertation. In this phase, the researcher conducted repeated in-depth, personal interviews with mothers. This provided not only complementary date sets (e.g. quantitative and qualitative data), but served to enhance the trustworthiness of the data (e.g. member checking during the interviews, material collection for an audit trail, and detailed descriptions of the interview context). The interviews were usually conducted three times: (1) an initial baseline interview to assess the stress level and symptoms for each mother, (2) an in-depth interview to share the individual stress level and symptoms with each mother, and to investigate the proposed inquiry process, and finally (3) a closing interview to address any additional questions and to conduct member checking to verify the prior interviews. The total number of interviews ranged from one time (one mother out of 32 mothers) to four (two mothers out of 32 mothers). A theoretical model was formulated from this grounded theory study that delineated the maternal stress response process and identified the relevant socio-cultural factors in South Korea.

Chapter 4 addresses the third aim of the dissertation. In this third phase, the researcher conducted a qualitative descriptive study to further explain the maternal stress response process among mothers with an infant in the NICU in South Korea. Specifically, the uneven/unfair power balance (‘Gahp-Eul’ relation) in the NICU, and the hierarchical ranking of roles emerged as key themes relevant to the South Korean social and cultural context.

Finally, Chapter 5 is a brief summary of the mixed methods socio-cultural study of the process of maternal stress response in the NICU in South Korea. The last chapter presents a synthesis of the findings from all the studies and points to the implications for future research as well as clinical practice.

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CHAPTER 2

Perceived Stress and Symptoms of Stress Among NICU Mothers in South Korea

Abstract

Objective: To describe maternal perceived stress and stress-related symptoms among mothers of infants in the NICU in South Korea, and to examine the relationships between perceived stress and symptoms of stress.

Design: A cross-sectional exploratory design

Setting: Two level IV NICUs, 38-bed and 58-bed, in two tertiary hospitals in South Korea.

Participants: Thirty-one mothers, literate in Korean, whose infants were at the time hospitalized in the NICU.

Methods: A sample of 31 NICU mothers completed the 10-item Perceived Stress Scale (PSS 10) and the 94-item Symptoms of Stress Inventory (SOS). Data were analyzed using descriptive statistics and Pearson correlation coefficients (IBM SPSS Statistics Premium 24).

Results: The overall NICU maternal stress level was high (M = 20.26, SD = 5.47), and the mean score of total stress symptoms was 0.60 (SD = .38). The most frequent stress symptom reported by NICU mothers was depression (M = 1.00, SD = .83), followed by emotional irritability (M = .94, SD = .89), muscle tension (M = .83, SD = .69), and peripheral manifestations (M = .64, SD = .39). There was a strong positive correlation between perceived stress and symptoms of stress (r = .67, $p < .001$). Perceived stress level had stronger positive correlations with depressive symptoms (r = .65, $p < .001$), habitual pattern symptoms (r = .62, $p < .001$), and symptoms of cognitive disorganization (r = .60, $p < .001$) than with other Symptoms of Stress subscales.

Conclusion: The findings suggest NICU nurses need to be aware that the depression symptoms and/or emotional irritability symptoms common in NICU mothers are most likely symptoms of their stress. Mothers with more vs. less stress are likely to experience depression, as well as symptoms related to habitual patterns (e.g., sleep disturbances), and cognitive disorganization (e.g. difficulty concentrating).

Keywords: NICU; perceived stress (PSS 10); symptom of stress (SOS); cross-sectional; South Korea

Background and Significance

Admission to the neonatal intensive care unit (NICU) involves not only the neonate but also the mother of the infant in many abrupt changes. Mothers who have infants in the NICU experience stress because of these changes. The mothers often suffer emotional distress (Aagaard & Hall, 2008) and/or physical fatigue (Busse, Stromgren, Thorngate, & Thomas, 2013) during the hospitalization period, and are likely to experience posttraumatic stress disorder (PTSD) and postpartum depression (PPD) (Lefkowitz, Baxt, & Evans, 2010; Yurdakul et al., 2009). Furthermore, a severe level of maternal stress is often closely related not only to maternal postpartum psychological problems such as PTSD, PPD, or delayed attachment (Barlow, Underdown, Williams, Bishop, & McKenzie-McHarg, 2009; DeMier et al., 2000; Lefkowitz et al., 2010), but also to the children's health problems (Chung, McCollum, Elo, Lee, & Culhane, 2004; Locke et al., 1997). There are many studies about the stress level among NICU mothers (Alkozei, Mcmahon, & Lahav, 2014), the stress source associated with NICU care (Alkozei et al., 2014; Raeside, 1997), and the maternal psychological problems with regard to NICU admission (Yurdakul et al., 2009). In addition, there have been studies on the emotional and/or psychological symptoms of stress, such as depression and anxiety, among NICU mothers

(Jubinville, Newburn-Cook, Hegadoren, & Lacaze-Masmonteil, 2012; Shaw et al., 2009). However, to date, there is a paucity of research on stress, and comprehensive stress-related symptoms among NICU mothers. To better understand the stress and the symptoms of stress experienced by NICU mothers remains a research priority in order to prevent NICU mothers from suffering from postpartum psychological problems.

Methods

Design and Subjects

A cross-sectional, descriptive survey study design was used to investigate the NICU mothers' perceived stress level and symptoms of stress, and to examine the relationship of the NICU mothers' stress level with the symptoms of stress. Using convenience sampling, purposive sampling, and snowball sampling, data were collected in two level IV NICUs - one 38-bed and the other 58-bed - in two major tertiary hospitals in South Korea. Prior to data collection, the study was approved by the University of Washington Institutional Review Board and each of the two hospitals (AMC IRB and SMC IRB). In order to avoid unnecessary burden to NICU mothers, if mothers had experienced severe mental illness, had severe cognitive impairment, had more than one infant in the NICU, or had experienced the loss of their infants in the NICU, they were excluded from this study. Participation was voluntary, and the mothers were informed that they could refuse to answer the survey without any adverse consequences. Data were collected from mothers who: had a child in the NICU, had a perception of experiencing stress in the NICU, were able to read and speak Korean, and lived in South Korea. When potential participants expressed an interest in this study via email, phone call, text message, or in person, the researcher first checked their eligibility for the study, then made a one-on-one meeting appointment at a time and location convenient for each mother. During the individual meeting,

the potential participants were told about the purpose of the study and what the study would require of them, and then were asked to sign a consent form, and answer a self-report survey. Out of thirty-two participants in this study, thirty-one mothers completed the questionnaires (response rate = 96.9 %). The participants were compensated for their time with a ₩15,000 (≈$14) gift certificate.

Measures

The 10-item Perceived Stress Scale (PSS 10) was used to measure stress level in mothers (Cohen, Kamarck, & Mermelstein, 1983; Cohen & Williamson, 1988). The PSS attempts to assess the degree to which situations in one's life are considered stressful. The questions in the PSS ask how often respondents experienced unpredictable, uncontrollable, and overloaded situations in their lives during the previous month. Items are rated on a 5-point Likert scale ranging from 0 (never) to 4 (very often). A higher score means a higher level of stress. The PSS 10 has been shown to have good reliability and validity in the US (Cohen & Williamson, 1988) and South Korea (Lee, Mun, Lee, & Cho, 2011). In this study, Cronbach's alpha was .84.

The Symptoms of Stress (SOS) Inventory was used to assess the multidimensional responses in which respondents' experience stress (Thompson & Budzynski, 1989). The SOS Inventory is a 94-item, self-report questionnaire, comprised of ten subscales: Peripheral manifestations (7 items such as cold hands or feet), cardiopulmonary symptoms (15 items including heart palpitations), central nervous system symptoms (5 items such as migraine headaches), gastrointestinal symptoms (9 items including appetite change), muscle tension (9 items capturing tension throughout the body), habitual patterns (15 items such as sleep pattern change), depression (8 items such as loneliness), anxiety/fear (11 items), emotional irritability (8 items), and cognitive disorganization (7 items including difficulty in concentrating).

Cardiopulmonary symptoms (15 items) are divided into cardiopulmonary symptoms of arousal (7 items typically associated with sympathetic arousal) and upper respiratory symptoms (8 items such as colds). SOS items are rated on a 5-point Likert-type frequency scale ranging from 0 (never) to 4 (almost always), with higher scores reflecting more frequently experienced stress symptoms. The SOS has been shown to have good reliability and validity in the US (Thompson & Budzynski, 1989) and South Korea (Hah & Lee, 2010). In this study, Cronbach alpha for the total SOS was .95; and ranged from .63 to .92 for the 10 subscales.

Infant characteristics (e.g. gestational age, birth weight), maternal characteristics (e.g. age, history of anxiety/depression, complications during pregnancy), and socioeconomic status (e.g. education, income, occupation) were gathered using a demographic survey. This demographic survey, the PSS 10, and the SOS inventory, were included in the self-report survey package. For accuracy, all of the English version instruments were translated into Korean by the researcher and back-translated into English by a bilingual. The back-translated English versions were compared with the original English version instruments for comparability.

Data Analysis

To describe the study sample, descriptive statistics were used (IBM SPSS Statistics Premium 24). For continuous variables, I calculated means and standard deviation; for categorical and discrete variables, I calculated frequencies and percentages. Pearson correlation coefficients were used to examine the associations between perceived stress (PSS10) and symptoms of stress (SOS). Significance was determined at a $p = .05$, 2-tailed. The internal consistency of instruments was estimated using Cronbach alpha coefficient.

Results

The general characteristics of the study sample are presented in Table 2-1.

Table 2-1. General Characteristics of the Sample (N = 31)					
Variables	**N**	**%**	**Range**	**Mean**	**SD**
Infant Gestational Age (Weeks +Days)			24+0 - 40+4	31.8	5.7
GA < 37	22	71.0			
37+1 <GA with congenital disorder	9	29.0			
Birth Weight (g)			370 - 3770	1786.3	1051.2
Birth weight <1500	16	51.6			
1501<Birth weight<2500	5	16.1			
2501<Birth weight	10	32.3			
First baby					
Yes	16	51.6			
No	15	48.4			
Maternal Age (years)			23 - 40	32.7	4.2
History of Anxiety and/or Depression					
Yes	3	9.7			
No	28	90.3			
Pregnancy Complications					
Yes	8	25.8			
No	23	74.2			
Ethnicity					
Korean	30	96.8			
Mongolian	1	3.2			
Education					
High school graduate	5	16.1			
College level graduate	24	77.4			
Graduate school graduate	2	6.5			
Employment					
Yes	14	45.2			
No	17	54.8			
Marital status					
Common-law	4	12.9			
Married	27	87.1			
Annual household income (1,000 won)			27,000-300,000	66,741.9	50,192.9
Less than 60,000 (≈$54,000)	18	58.1			
More than 60,000 (≈$54,000)	13	41.9			

The mothers were predominately Korean (n = 30, 96.8%) in their thirties (M = 32.7 years, SD = 4.2), married or had a domestic partner (n = 31, 100%), and well-educated (n = 31, 100% high school or higher level of education). Three-fourths of the mothers had no medical complications during their pregnancy periods, and the majority of mothers (n = 28, 90.3%)

reported no history of anxiety and/or depression. More than half of the mothers were not employed (n = 17, 54.8%) and had an annual household income of less than 60,000,000 won (n = 18, 58.1%). The majority of the infants were born preterm (n = 22, 71%, fewer than 37 weeks gestational age, M = 31.8 weeks, SD = 5.7), with a very low birth weight (n = 16, 51.6 %, less than 1500g or 3lbs 5oz), and first-born infants (n = 16, 51.6%).

Table 2-2. Maternal Perceived Stress and Symptoms of Stress (N=31)

Surveys	Mean	SD	Range	Scale Mean	Scale SD
10-item Perceived Stress Scale (PSS 10)	**20.26**	**5.47**	**11-32**	-	-
Symptoms of Stress Inventory (SOS)	56.81	35.37	10-129	**0.60**	**0.38**
1. Peripheral manifestations	4.45	4.37	0-15	0.64	0.39
2. Cardiopulmonary					
2.1 Symptoms of arousal	2.71	3.12	0-13	0.39	0.45
2.2 Upper respiratory symptoms	2.29	2.42	0-8	0.29	0.30
3. Central-neurological symptoms	2.16	2.22	0-8	0.43	0.44
4. Gastrointestinal symptoms	4.16	4.16	0-15	0.46	0.46
5. Muscle tension	7.48	6.24	0-24	0.83	0.69
6. Habitual patterns	7.87	5.97	0-22	0.52	0.39
7. Depression	8.00	6.64	0-32	1.00	0.83
8. Anxiety / Fear	6.10	4.68	0-16	0.55	0.43
9. Emotional irritability	7.48	7.16	0-30	0.94	0.89
10. Cognitive disorganization	4.16	3.27	0-12	0.59	0.47

The maternal perceived stress level and frequently occurring symptoms of stress (SOS) are presented in Table 2-2. The mean of perceived stress was 20.26 (SD = 5.47). The mean of SOS total scores was 56.81 (SD = 5.47). The *SOS total mean score* was defined by calculating the sum of all items answered divided by total number of items answered (Thompson & Budzynski, 1989). Thus, the SOS total mean score of 0.60 (SD = 0.38) was calculated by dividing 56.81 (item sum score) by 94 (total number of items). Likewise, for each subscale, the sum of subscale items was divided by the number of subscale items (Table 2-2). With respect to symptoms of stress, the subscales with the highest values were: (1) depression (M = 1.00, SD =

0.83), (2) emotional irritability (M = 0.94, SD = 0.89), (3) muscle tension (M = 0.83, SD = 0.69), and (4) peripheral manifestations (M = 0.64, SD = 0.39). Thus, the symptoms most frequently endorsed by mothers in the NICU reflected common psychophysiological manifestations stress coupled with elevated depressive symptomatology.

Table 2-3. Correlations between Maternal Perceived Stress and Reported Symptoms of Stress (N=31)

	PS	S1	$S2_{-1}$	$S2_{-2}$	S3	S4	S5	S6	S7	S8	S9	S 10
S1	.26	1										
$S2_{-1}$	.28	.48**	1									
$S2_{-2}$	.08	.71***	.67***	1								
S3	.38*	.46**	.56**	.57**	1							
S4	.44*	.49**	.55**	.30	.37*	1						
S5	.42*	.26	.46**	.31	.47**	.28	1					
S6	.62***	.33	.47**	.32	.56**	.44*	.72***	1				
S7	.65***	.16	.29	.03	.33	.32	.63***	.64***	1			
S8	.56**	.27	.52**	.34	.54**	.14	.74***	.65***	.67***	1		
S9	.48**	.46**	.42*	.51**	.68***	.35	.40*	.46*	.34	.60***	1	
S10	.60***	.01	.31	.07	.46*	.12	.22	.46**	.30	.64***	.55**	1
SOS	.67***	.56**	.69***	.56**	.74***	.56**	.77***	.83***	.70***	.83***	.76***	.54**

* p = .05, ** p = .01, *** p = .001, 2-tailed
PS = Perceived stress; SOS = Symptoms of Stress; S1 = SOS 1. Peripheral manifestation;
$S2_{-1}$ = SOS 2-1. Arousal symptoms; $S2_{-2}$ = SOS 2-2. Upper respiratory symptoms;
S3 = SOS 3. Central-neurological symptoms; S4 = SOS 4. Gastrointestinal symptoms;
S5 = SOS 5. Muscle tension; S6 = SOS 6. Habitual patterns; S7 = SOS 7. Depression symptoms;
S8 = SOS 8. Anxiety/Fear symptoms; S9 = SOS 9. Emotional irritability; and
S10 = SOS 10. Cognitive disorganization

The correlations capturing the relationships among perceived stress, total symptoms of stress, and each subscale of the SOS are summarized in Table 2-3. The analysis showed a strong positive correlation between total symptoms of stress and perceived stress (r = .67, p < .001). Depressive symptoms such as 'alone and sad' and perceived stress had the strongest positive correlation (PS & S7, r = .65, p < .001). Habitual pattern symptoms such as 'difficulty in staying asleep at night' (PS & S6, r = .62, p < .001) or cognitive disorganization symptoms such as

'difficulty in concentrating' (PS & S10, r = .60, $p < .001$) also had strong positive correlations with perceived stress. In addition, the maternal perceived stress had strong correlations with symptoms of anxiety/fear, including 'being uneasy or apprehensive' (PS & S8, r = .56, $p = .001$); emotional irritability such as 'becoming angry or mad easily' (PS & S9, r = .48, $p < .01$); gastrointestinal symptoms such as 'constipation' (PS & S4, r = .44, $p < .05$); muscle tension symptoms such as tension in 'shoulders' (PS & S5, r = .42, $p < .05$); and central-neurological symptoms such as 'migraine headaches' (PS & S3, r = .38, $p < .05$).

Discussion

This study explored reported perceived stress and the symptoms of stress as well as the associations between the stress and symptoms of stress among NICU mothers in South Korea. There has been considerable research showing significant associations between NICU maternal stress and postpartum depression symptoms (Alkozei et al., 2014; Jubinville et al., 2012). However, comparisons between the results of this study and other existing studies can only be limited, as no previous research examined maternal perceived stress and symptoms using the PSS 10 and SOS Inventory measures. Nevertheless, according to Cohen & Williamson (1988), the average score of PSS 10 among females in the U.S. was 13.7 (SD = 6.6, N = 1406). Thus, the stress level of the NICU mothers in this study, 20.26 (SD = 5.47), was considerably higher than the average reported in the U.S. Although the measures of this study differed from other studies, the significant positive association between stress and depression symptoms previously observed by other researchers was supported by this study as well (r = .65, $p < .001$).

According to Hah & Lee (2010), the most frequent stress symptoms reported by Korean female college students were: depression, emotional irritability, gastrointestinal symptoms, cognitive disorganization, and cardiopulmonary symptoms (age 22.3 ± 1.94 years; n = 797). The

maternal depression and emotional irritability symptoms seen in this study were similar to those in the Hah & Lee (2010) study. However, the mothers in this study (age 32.7 ± 4.2 years; n = 31) experienced muscle tension in 'shoulders' and/or 'tension headaches,' and peripheral manifestations such as 'hot or cold spells' more frequently than gastrointestinal symptoms or cardiopulmonary symptoms.

The findings suggest that the SOS inventory can facilitate the effective assessment of maternal stress. First, some physiological stress symptoms often occur regardless of perception of stress. Thus, the SOS inventory can be useful for NICU mothers to recognize their stress, because the SOS inventory is a multidimensional assessment instrument, encompassing everything from peripheral manifestations to cognitive disorganization. In addition, symptoms of stress may vary by personality. Although this study found that depression, emotional irritability, muscle tension, and peripheral manifestations are more frequently reported stress symptoms among the NICU mothers, if a NICU nurse understands that some NICU mothers' emotional irritability stems from their high levels of stress with regard to the NICU experiences, which will be helpful for the NICU nurse to provide NICU mothers effective nursing intervention. Finally, the use of the SOS inventory is feasible for the NICU mothers. They usually spent less than 5 minutes (2-10 minutes) to answer the 94-item questionnaire. The strong reliability and validity of the SOS inventory was supported by not only the good Cronbach alpha of .95, but also by the many significant correlations with PSS and SOS subscales (Table 2-3).

Limitations

Despite new findings of this study, there are limits to the representativeness and generalization of the results of this study to all NICU mothers. First, the participants were recruited by convenience sampling, purposive sampling and snowball sampling. Second,

although all the participants were not all native Koreans, all the participants had been assimilated into Korean culture. Finally, according to a free power analysis software via on-line, the sample of this study (n = 31) may provide power of .90 to detect a r = .50 at a .05 significant level, but according to Cohen's statistical power analysis (1988), larger sample size allows a more accurate statistical analysis. Hence, the limitations with regard to the sample need further study in the future.

Conclusion

The findings of this study reveal that the mothers frequently experience depression symptoms (e.g. loneliness) and/or emotional irritability/distress symptoms in the NICU in South Korea. Also, NICU nurses need to be aware that the depression, habitual pattern symptoms, and cognitive disorganization symptoms are likely to reveal the NICU mothers' as being under a high level of stress. The findings of the study would support more effective nursing practices, the development of nursing interventions, and NICU policies in order to reduce maternal stress and symptoms of stress in the NICU.

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CHAPTER 3

A Grounded Theory Study of the Maternal Stress Response Process in the NICU in South Korea

Abstract

Objective: To explore the conditions and processes of stress experiences among mothers with an infant in the NICU, and to discover socio-cultural factors that enhance or hinder management of the stress response process.

Design: Qualitative design using grounded theory methodology.

Setting: Two large level IV NICUs of two major tertiary hospitals in South Korea.

Participants: Thirty-two mothers whose infants were hospitalized in the NICUs participated in this research, and 30 mothers of the 32 mothers (94%) completed all study questionnaires and the three-phase interviews.

Methods: In-depth interviews with the mothers, field notes descriptive of the interview context, and questionnaires were collected. Qualitative data were analyzed using open coding, axial coding, and selective coding. Quantitative data describing the sample were analyzed using frequencies, standard deviations, means and other descriptive statistics (IBM SPSS Statistics Premium 24).

Results: A theoretical model was formulated from the findings. With respect to the stress experience, the overarching category of *giving birth to a child with health problems* emerged as the causal condition. The category *leaving my baby in the NICU* emerged as the context. Two socio-cultural categories, *continuous comparisons*, and *high sensitivity to hierarchy ('Gahp-Eul' relation)* emerged as the intervening conditions. *Seeking safe support* and *adapting to the NICU*

emerged as key strategies. The two categories of *having mother's role* and *stress levels and stress symptoms* were identified as the consequences. Furthermore, the core category *struggling with stigma* emerged as the central phenomenon underpinning the process of stress responses among mothers with an infant hospitalized in the NICU.

Conclusion: The findings of this grounded theory study delineate a framework for understanding how and why stress responses occur among mothers of infants in the NICU in South Korea. In addition, the results reveal how the socio-cultural factors influence the stress response process of mothers with infants in the NICU.

Keywords: Grounded theory; NICU; maternal stress; socio-cultural factor; South Korea

Background and Significance

Comorbidity of Stress and the Maternal Postpartum Psychological Problems in the NICU

Mothers of infants in the neonatal intensive care unit (NICU) often express feelings of guilt, loss, grief, depression, and anxiety, and are overwhelmed with stress and alienation in the NICU (Aagaard & Hall, 2008; Beck, 2003; Jang, 2005; Lee, Norr, & Oh, 2005). Indeed, the birth of a high-risk infant and the subsequent hospitalization of the infant are critical events for any mother. For many mothers of NICU infants' admission to the NICU is a traumatic experience (Aagaard & Hall, 2008; Mendelsohn, 2005; Wray, Lee, Dearmun, & Franck, 2011). The maternal mental health problems with respect to the experience of having an infant in the NICU, and the level of stress and/or anxiety in these mothers are more severe than in mothers of healthy full-term infants (Yurdakul et al., 2009). High levels of stress and/or anxiety and the high prevalence of postpartum depression in mothers of NICU infants are strongly correlated (Melnyk, Crean, Feinstein, & Fairbanks, 2008; Yurdakul et al., 2009). In this population,

postpartum depression (PPD) commonly co-occurs with anxiety, acute stress disorder (ASD), and posttraumatic stress disorder (PTSD) (Lefkowitz, Baxt, & Evans, 2010). In the NICU, many maternal postpartum psychological problems are mediated by the level of stress (Beck, 2003; Lefkowitz, Baxt, & Evans, 2010; Younger, Kendell, & Pickler, 1997). Hence, to identify ways to prevent maternal postpartum psychological problems associated with infant admission to the NICU, it is logical to begin with a systematic investigation of the stress response among mothers with infants in NICUs.

Socio-Cultural Phenomena in South Korea & Stress Response of Mothers of NICU Infants

Although the recent birth rate in South Korea is the lowest among the Organization for Economic Cooperation and Development (OECD) countries, the rate of preterm births has increased from 2.56 % in 1995 to 5.94% in 2010; the rate of low birth weight infants (LBWIs, < 2,500 g) has likewise increased from 3.03% in 1995 to 5.02% in 2010 (Lim, 2011). Infant mortality in Korea (3.0 in 2011) is, however, lower than the average of OECD countries (4.0 in 2011) (Kim, Jeon, Park, Sriram, & Lee, 2016). This suggests that as the incidence of NICU hospitalization among Korean neonates increases, more Korean mothers are likely to experience the challenges of having an infant in the NICU.

In addition, the suicide rate in South Korea is the highest among the OECD countries, and suicide is the most common cause of death among adults under 40 (Ra & Cho, 2013). Given the associations between depression and other mental illnesses and suicidal behavior, the focus on stress responses among Korean mothers of NICU infants is even more critical. Moreover, the specifically high rates of suicide in South Korea point to the need to understand socio-cultural influence on stress responses. The problem at hand is complex as observed in the emerging research on postpartum psychological problems among NICU mothers that reveals the influence

of interpersonal and structural factors on the maternal stress response. Such factors include, for instance, the attitudes of NICU staff (Younger et al., 1997), family functioning (Beck, 2003), and the incongruity between maternal expectations and reality as a mother, and the cultural stigma associated with having a child in the NICU (Heidari, Hasanpour, & Fooladi, 2012).

Despite the significant comorbidity of stress and maternal postpartum psychological problems in the NICU, and the increasing rate of preterm births in South Korea, little research has addressed how and why stress responses occur among mothers of infants in the NICU in South Korea. The purpose of this study was to generate a theory to explain the maternal stress response process in the NICU in South Korea, relevant to their social and cultural context in particular.

Methods

To address the study aims, a grounded theory methodology was used. This approach is particularly appropriate for under-studied areas, to generate a theory that accounts for social processes, and to identify conditions under which the processes do or do not occur (Speziale & Carpenter, 2007).

Setting and Sampling

In the grounded theory method, sampling often begins with the initial purposive sampling and ends when theoretical saturation is achieved. Achieving the purpose of this study depended upon specific observations and generated data from in-depth interviews. Participants were not randomly selected for recruitment to the study, but were selected as best-case examples of the population of mothers with infants experiencing stress in response to their infants' admission to a NICU in South Korea. To be included in the study, a mother had to (1) have a perception of experiencing stress regarding the NICU hospitalization; (2) have an infant hospitalized in a

NICU; (3) speak Korean; and (4) live in South Korea. The perception of experiencing stress was determined by each participants' personal definition. Exclusion criteria were (1) severe cognitive impairment; (2) history of severe mental illness; (3) multiple gestations (e.g., twins, triples); and (4) experience of having lost an infant in the NICU. The samples were recruited from two level IV NICU settings in two major tertiary care hospitals, Samsung Medical Center (SMC), and Asan Medical Center (AMC) in Seoul, the capital of South Korea. Due to the high level neonatal care available at these hospitals, usually only very high-risk newborns are admitted to these units.

To recruit the sample, (1) purposive sampling, (2) convenience sampling, and (3) snowball sampling strategies were used to achieve theoretical saturation. For *purposive sampling*, some mothers were identified by the NICU staff (e.g., nurse practitioners, RNs, neonatologists) as individuals who would be suited to this study. To prevent perception or actual coercion, the NICU staff, instead of the researcher, introduced the study to potential study participants using the Recruitment Flyer developed by the principal investigator (PI), and following the Recruitment Guide Protocol by the PI. Only when the potential participant had indicated a positive answer to the following question, "Are you interested in participating in this research?" was she then asked if she would be willing to participate in the study. For *convenience sampling*, the Recruitment Flyers were posted on the notice boards in the hospitals, including those in the NICU waiting rooms. For *snowball sampling*, participants involved in the study were asked to recommend other mothers whom they thought would be suitable participants for the study.

Protection of Human Subjects

This study met the Human Subject approval requirements for the two hospitals and the University of Washington prior to participant recruitment. After obtaining IRB approvals, the researcher explained the study purpose, and the inclusion and exclusion criteria to the staff of the two NICUs, and solicited their assistance in recruiting study participants.

At a time convenient to potential participants, the purpose of the study and what the study would require of participants were explained to individuals who met study criteria and agreed to participate. Participation in this study was entirely voluntary, and potential study participants were informed that NICU treatment for infants would in no way be affected by the mothers' willingness or refusal to participate. The interviews were conducted and the questionnaires administered during each infant's hospitalization period, at a time and location convenient for the mother. Study participants were compensated for their time with gift certificates at the time of interview completion. All data were kept strictly confidential. Study participants had the absolute right to withdraw from the study at any time and were informed that they could choose to answer or not answer any questionnaire or interview questions. Following explanation of the study, individuals were given the opportunity to ask any questions they had, and then were asked to sign the IRB-approved consent form.

Thirty-two NCU mothers participated in this research, and 30/32 mothers participated in all three step interviews and two sets of questionnaires from July 2014 to August 2014. Sampling had been continued until no new data appeared. The number of participants was sufficient to achieve theoretical saturation.

Data Collection

Audio recorded, in-depth interviews with the mothers, field notes for description of the interview context and/or other relevant observations, and questionnaires regarding background data were collected. All individual data were kept strictly confidential, and the three interviews were all done in a one-on-one format; however, participants were welcome to have someone accompany them to the interview, if they wished.

The data collection process included three step interviews, including a baseline interview, an in-depth interview, and a closing interview. The baseline interview provided information on the formalities of the research process, and the collection of basic data, including mother and infant demographic data, and measures of maternal perceived stress, and symptoms of stress. Stress and stress symptoms were assessed using the 10-item Perceived Stress Scale (PSS 10) by Cohen, Kamarck, & Mermelstein (1983), and the Symptoms of Stress Inventory (SOS) by Thompson & Budzynski (1989), respectively.

The in-depth interview was conducted subsequently to share with the mother results of the measures of stress and stress symptoms, and to listen to the mothers regarding the interview queries. To provide the opportunity for the mother to guide the inquiry process, the interviewer began with the open-ended question: "Could you please tell me about your current birth experience and how the admission of your baby to the NICU has affected you?" For the in-depth interview, participant permission was requested prior to beginning the audio recording.

The closing interview was used to verify with the participant the researcher's summary and interpretation of the earlier interviews by reviewing a summary of what was the participant had said during interviews. The session was also used to gather data on the Maternal Self-Report Inventory (MSRI). The MSRI (Shea & Tronick, 1988) was used to assess the maternal role

identity. All surveys were transcribed first in Korean. Approximately, 20 % of the transcription were translated into English, and back translated into Korean for enhanced credibility and fittingness of the interviews.

Data Analysis

To enhance theoretical sensitivity, the concurrent data analysis method was conducted during the data collection period, using the following strategic questions (Strauss & Corbin, 1990):

- What is going on for the mothers in this study?
- What is the basic problems with which NICU mothers must deal?
- What do these data describe?
- What constrains or facilitates the stress response for NICU mothers?
- What helps or hinders NICU mothers in coping with their stress?
- What accounts for most of the variation or differences in the level of stress between mothers in the NICU?

To increase reliability of the findings, ongoing comparative analysis was conducted by the PI through methodological consultations with three doctoral level, qualitative researchers. To discover core categories and to generate a theory that explains the process of stress response among NICU mothers, open coding, axial coding, and selective coding methods were used (Strauss and Corbin, 1990). All the quantitative data were analyzed using the IBM SPSS Statistics Premium 24 software program.

Results

The demographic and survey information from participants are presented in Tables 3-1 and 3-2. The majority of infants were born extremely preterm (fewer than 28 weeks gestational

age), with an extremely low birth weight (less than 1000g or 2lbs 3oz), and first-born infants (Table 3-1).

Table 3-1. Characteristics of Infants and Mothers					N=31
Variables	**n**	**%**	**Range**	**Mean**	**SD**
Infant Gestational Age (Weeks +Days)			24+0 - 40+4	31.8	5.7
GA <28	12	38.7			
28+1 <GA<37	10	32.3			
37+1<GA	9	29.0			
Birth Weight (g)			370 - 3770	1786.3	1051.2
Birth weight<1000	11	35.5			
1001<Birth weight<2000	6	19.3			
2001<Birth weight	14	45.2			
First baby					
Yes	16	51.6			
No	15	48.4			
Maternal Age (years)			23 - 40	32.7	4.2
Maternal age < 24	2	6.5			
25 <Maternal age <30	8	25.8			
31<Maternal age <34	11	35.4			
35 <Maternal age	10	32.3			
History of Anxiety/Depression					
Yes	3	9.7			
No	28	90.3			
Pregnancy Complications					
Yes	8	25.8			
No	23	74.2			
Education					
High School	5	16.1			
Community college	6	19.4			
College	18	58.1			
Graduate school	2	6.5			
Employment					
Housewife	17	54.8			
Part-time job	10	32.3			
Full-time job	4	12.9			
Marital status					
Common-law	4	12.9			
Married	27	87.1			
Annual household income (1,000 won)			27,000-300,000	66,741.9	50,192.9
Less than 60,000 ($53,000)	18	58.1			
More than 60,000 ($53,000)	13	41.9			

The mothers were predominately in their thirties, married, and well-educated. The majority of the mothers had no medical complications during their pregnancy, and no history of anxiety and/or depression prior to their pregnancy (Table 3-1).

As codes and categories were identified and the relationship among the categories was revealed, a theoretical model emerged delineating the stress response process of NICU mothers, as illustrated in Figure 3-1.

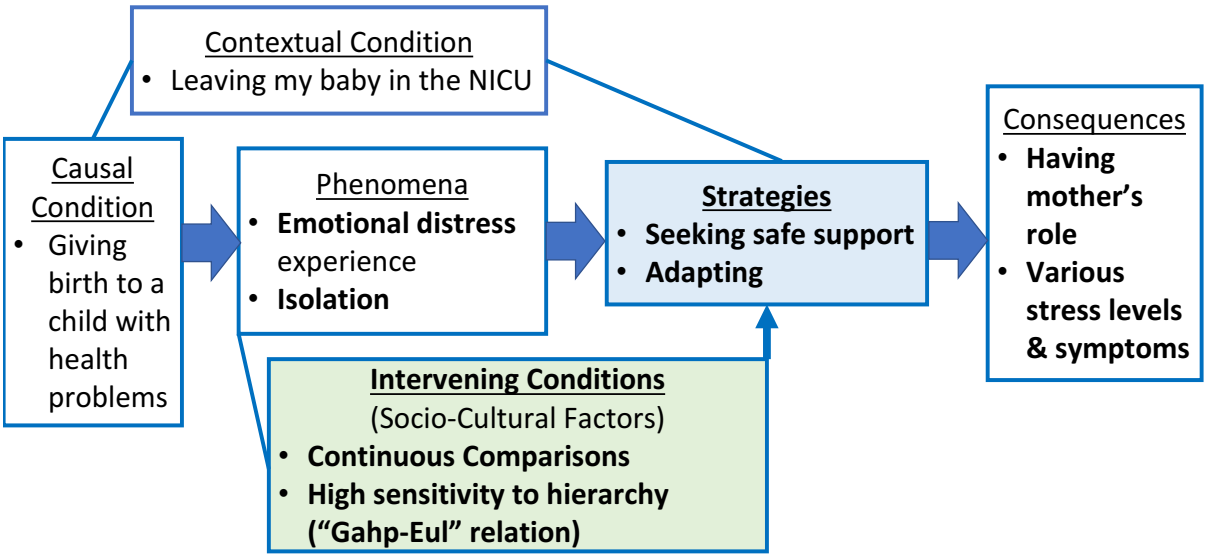

FIGURE 3-1. Theoretical Model of NICU Mother's Stress Response Process: **Struggling with Stigma**

The theoretical model (Figure 3-1) consists of a construct level capturing the stress response process and including causal condition, contextual condition, phenomena, intervening conditions, action/interactional strategies, and consequences (Strauss and Corbin, 1990). Within this construct level, there are ten thematic categories designated as: (1) giving birth to a child with health problems, (2) leaving my baby in the NICU, (3) emotional distress experience, (4) isolation, (5) continuous comparisons, (6) high sensitivity to hierarchy ('Gahp-Eul' relation), (7) seeking safe support, (8) adapting, (9) having mother's role, and (10) various stress levels &

symptoms. An underlying core category, struggling with stigma, was uncovered through the selective coding method. Elements of the theoretical model and supporting evidence are described below.

Causal Condition: Giving birth to a child with health problems

In modeling a process, the identified causal condition leads to the occurrence of a phenomenon (Strauss & Corbin, 1990). In the analyses, the category of *giving birth to a child with problems* emerged as the causal condition for maternal stress. According to mothers, the current birth caused the stress occurrence (phenomenon). The current maternal childbirth experiences - such as emergent delivery, emergent caesarean section, unexpected delivery, premature rupture of membranes, premature baby, and/or congenital disorder - were categorized as *giving birth to a child with problems*, as reflected in the following narratives:

> *- It was right on the day week 26 started, I ate out with my friends [to celebrate the coming birth], and was going home when my water broke. I went to the emergency room right away…*

> *-My baby was doing fine the week before. That day I had my regular prenatal visit so I came to the hospital. The doctor looked at the ultrasound and said that something was not quite right and I had to be hospitalized right away, we should probably keep an eye on things for a day or two. So, I checked into the hospital by myself… my husband said he would come but I told him not to, and my mother also said she would come but I told her not to, I would just be there for a day or two. She still came because she was worried, and less than 15 minutes after she arrived, they said I had to have an emergency operation. And that something might happen to the baby... I was made ready immediately*

and went into the operating room, and then my doctor held my hand and told me we were likely to lose the baby. But at the same time my husband was getting angry at me and the doctor over the phone, asking why we were pushing for an early birth when the best place for the baby was in the womb. He didn't know the situation… I was already on the operating table, but I couldn't have the surgery unless my husband, as [my] guardian, okayed it, so the doctor kept saying the baby would probably not make it… And then the baby's heart started beating again, and the doctor told me if he operated they might be able to save the baby too, so I had to make a decision [as the baby's guardian]. So, I said I would have the operation, and my husband said ok too, so my baby was born by caesarean section… it didn't even take 10 minutes.

- At 22 weeks, I had a detailed ultrasound, when they said it looked like there was a heart defect, so I changed hospitals, to a large university hospital. But there, they said it looked like a complicated heart defect, so I ended up at this hospital… and I thought I prepared myself mentally and gave birth, but when it became reality, it was too much to bear.

Contextual Condition: Leaving my baby in the NICU

Right after birth, all the infants of mothers in this study had been admitted to a NICU. The category of *leaving my baby in the NICU* emerged as the contextual condition. Contextual condition refers not only the location pertaining to a phenomenon, but also "the particular set of conditions within which the action/interactional strategies are taken" (Strauss & Corbin, 1990, p. 96). In the NICU, the mothers experienced maternal-infant separation and a sense of being overwhelmed. This contextual condition regarding infant admission to the NICU was related to

maternal emotional distress and isolation experiences (phenomena), as well as to maternal seeking safe support and adapting (strategies). The following narratives reveal the mother's leaving my baby in the NICU experiences:

-It's extremely stressful to check out of the hospital and leave my baby here, you know. For me to leave the baby here and go…

- I think the most stressful part for me was being apart from my child, feeling separated.

- I think I feel that way every time I come to visit. All the babies here, everything they're going through, it makes me sad. Whenever I see [the babies here], [I think] 'It must be hard on you too. I hope you all grow and go home healthy…' There's no mother here to pick them up immediately when they cry… I think I feel sorry for all of them.

-After visiting hours were over, all the mothers here said the same thing. That they felt bad leaving their babies here and going to eat [a meal] by themselves.

- Other hospitals have set visiting hours and the time is short too, but here it's from 10 to 10, so it's nice to be able to come and see my baby anytime. My house is nearby so if I want to rest, I can go home and rest and then come back for a while…

- I don't live in Seoul. I made reservations at 00 [postpartum] Care Center, near my house, but I can't go because I am too anxious. Because my baby's here… if I go to home, I can't come to see my baby every day, you know. So, when I check out of the

hospital tomorrow, I'm going to go and stay at my younger sibling's house in Seoul until my baby has its operation and can leave the hospital.

- When I was here [in the maternity ward], it was bearable because I could come [to the NICU] often every day. But today, I'm going to check out of the hospital, so my heart feels heavy, thinking of my baby… Every time I saw my baby today, I didn't want to cry but whenever I saw him, I felt bad for him, so I couldn't help crying…

Phenomena: Emotional distress and Isolation

The maternal stress response of mothers with an infant in the NICU is not only the topic of this inquiry, but also the phenomenon of this theoretical model. The categories of *emotional distress experience* and *isolation* emerged as the phenomena. In other words, the major stress experiences and problems faced by mothers whose newborn infants are hospitalized in the NICU were emotional distress and isolation.

Emotional distress experience. The mothers reported experiencing emotional distress in the NICU in the form of shock, disappointment, frustration, sense of loss, loss of self, blame and/or self-blame regarding giving birth to a child with physical health problems. The following narratives are provided as exemplars of the maternal emotional distress experiences in the NICU:

- It was a great shock for me, the memory of that day (emergency cesarean section)… What do they call it, posttraumatic stress disorder? I still… it's been about 100 days since the surgery but I sometimes think it's like a dream… So, for a while I asked my husband and my mother and my family to not talk about happened that day. It's too painful…

- The first time I saw my baby, it was really such a big, a huge shock. Now that I've seen [her] several times, I've gotten used to [her] so it's better, but at first it was really… [a big shock]

- I was lying in the recovery room and I asked my family what my baby was like, and they said [she] was beautiful so that's what I thought… A couple of days later when I could walk, I went to see the baby and I broke down and cried. [I realized] my family had just said that to comfort me… my baby was in a really bad condition.

- My mother-in-law says things happened the way they did because I went out too much. Now I can talk about it, but at the time I really hated her. I didn't even want to take phone calls [from her].

- The first time I visited, the [NICU] attending physician talked to my husband and me, and I think the professor was being kind but I felt [the words] were very cruel. But my husband says the professor's words were really nice, that when our baby was first hospitalized it was much worse. I can understand the medical staff has to think of all the possibilities… but it was too cruel.

- Having a baby is supposed to be a blessing, so when you have a baby it's natural for everyone to congratulate you and for you to be congratulated… but I didn't have that experience. I had a baby but everyone was worried… I felt like somehow our baby was born without any blessings.

-Really, the resident can't talk like that… even if it were someone else, in this kind of situation, I don't think she should talk like that. No mother would want her child to be ill, so how can she say… Of course, she didn't say it in a mean tone, but the words were… the words themselves, when she said, "Why didn't you stay a bit longer…" I thought, no, this isn't right. It hurt me.

- My in-laws don't, but my mother does... I get stressed because of my own mother. Mother-in-law is not really my own family, so… I believe, especially nowadays, there aren't any mothers-in-law who are really hard on their daughters-in-law. It's my own mother who treats me badly... she says a million things are my fault.

- I feel like it's my fault, 00 was born prematurely, and all kinds of thoughts go through my head… like the kind of exercise I was doing at the time…was it because I did that kind of exercise and I shouldn't have?

- The baby's condition wasn't good so I thought to myself, maybe he's sick because I gave birth at an old age…

- I felt I was mostly in control before I had my baby, about 80% [of the time]... After I had my baby, my parents and in-laws [got more power], so I think I have less than 40% say in matters related to my baby. When I try to say something, I get the feeling [they

think] 'It's your fault the baby was born prematurely', so now when our parents say something should be done a certain way, I just say "Okay, I'll do that."

- When I told [my mother-in-law] our baby was in the hospital, she said "Why doesn't anything go smoothly with you two" and cried. I know she doesn't have any bad intentions… but I cried and she cried…

-When I first saw my baby, I was so shocked… I didn't know whether or not I should show our baby to the in-laws when they came. Still, since my mother-in-law is bold and broad-minded, I thought she might not mind, so I said, "Would you like to go and see the baby?" but she said no. I was really surprised by that. She said the baby was small as it were and it might be bad luck if she saw him, so she would see him later when he was bigger. And she said she had almost killed her daughter-in-law by asking her for a grandchild.

- To be honest… other people don't even drink a single cup of coffee [when they are pregnant] but to be honest, I drank coffee and secretly ate a lot of bad things too, but now I regret all of that. I wonder if [my baby] would've been alright if I had been more careful…

- Actually, I had a miscarriage last year, too… At the time, I thought it was because my job was demanding, but… I feel bad for my baby, that my baby [isn't healthy] because of me. [I feel sorry] all the time.

Isolation. The mothers described their emotional and physical isolation experiences. To conceal or seclude themselves from society, family, friends, and/or the community, they lied or pretended to be okay about giving birth to a child with health problems. The following narratives are provided as reported instances of isolation experiences:

-Since I broke off some relationships after this happened, I actually have just my family to comfort me. But family members don't always say nice things either, so I can't talk about everything honestly… so I feel isolated.

- Honestly, I didn't want to tell [my mother-in-law] that my baby was in the hospital. You know, you don't want to… Actually, I didn't tell anyone. My mother knows my baby is here [in the hospital], but when she calls and asks, "How is the baby doing?" I'll say "Oh, he's fine. He's doing well." I don't tell her the details. I just don't want to talk about it. You know, [people] don't really want to talk about things like that…

- After I had my baby, what everyone said when they called me was, "Poor –", or "everything will be alright." I really didn't like that. It would've been better if they had said, "Congratulations on your baby…" So, when I got phone calls from people who weren't really close family, I didn't want to answer the phone…

-We didn't tell anybody about my baby. Even when my own mother called to ask, "Is she doing well?" I'd always say, "Yes, 00 is ok, 00 is adjusting well," that's it… I don't really want to talk about it.

- I didn't want the sympathy of others, so I went to the school to take a maternity leave, and the vice principal said… oh, this is the poor teacher, the poor teacher whose baby was born prematurely. I realized, 'Oh, people think I'm someone to be pitied', and I broke off relationships with friends, with people from work, even family. I wouldn't answer even when they tried to contact me, but a month ago I started talking a little. I'm even doing this interview…

- When we got married, my husband didn't tell [my in-laws] about my health issues, but since something like this happened, now I just don't want to tell my mother-in-law. I don't want to [reveal] that this happened because of my illness.

- I don't even talk to my husband about everything on my mind. It's so hard for even me, and if I told him about my burden, it would be really hard on him… So, I just keep everything inside, for my husband… but then I also feel it's unfair that I should be the only one suffering so.

-I can't show my feelings in front of the baby, and I can't show anything in front of the family I love because that could make it harder for them, and I can't show anything to other people because they would have a hard time understanding anyway, so showing them this situation would just be a burden to them…

-Since I'm the one who meets our doctor or professor, I know all about our child's condition… but I filter things out when I talk to my husband. One mother tells me, tell

him everything, share everything with him. But, it's like…if I think, I'll tell him this week… the situation is possibly worrisome, the baby may have an intellectual disability. So, I think, I'll tell him this weekend, I'll tell him around Saturday, but then he talks about the future. When our child goes to elementary school, when he goes to college… when he talks about things like that, I can't say what I meant to say.

- [After the current birth] Existing relationships change a bit... I withdraw a bit, because there's a lot of things you can't share…

In one case, the mother shared knowledge of the premature birth with her mother-in-law, but the mother-in-law concealed the birth from her relatives. That "upset" the mother as she felt emotional isolation from her in-law family members. The following narrative is provided to illustrate the mother's isolation experience:

- Although it was an emergency situation, nothing happened to my baby because of the cesarean section… but when I told my mother-in-law that my baby was in the NICU, she didn't tell anyone [that I had a baby]. She didn't even tell my sister-in-law. I was really upset so I said, "Why didn't you tell anyone?" and she answered, "I didn't because I thought you'd worry if I did," but I felt really bad. So even now, [the relatives in the country] don't even know that their daughter-in-law in Seoul had a baby…

Intervening Conditions: Continuous comparisons and High sensitivity to hierarchy

Intervening conditions are structural, broad and general conditions that serve to "either facilitate or constrain the action/interactional strategies" pertaining to the phenomenon (Strauss

& Corbin, 1990, p. 103). Two sets of social factors, *continuous comparisons* and *high sensitivity to hierarchy ('Gahp-Eul' relation)*, emerged as the intervening conditions in this study. These two socio-cultural factors and the previous phenomena of isolation and emotional distress are closely associated. These intervening conditions facilitate or constrain the action/interactional strategies of mothers' seeking safe support and adapting in the NICU (Figure 3-1).

Continuous comparisons. All the mothers in this study experienced being compared with others and/or making evaluative comparisons with other babies and/or other NICU mothers. They shared the relative evaluations of the NICU staff and other hospitals only with 'really safe' supportive persons. The following narratives depict these findings:

> *-Even though I had my baby at an old age, the year I had my baby, a lot of my friends [of the same age] had their first child too, and they're all healthy… They all had healthy and normal babies, but I didn't. So, my shame… My friends try to comfort me but my self-esteem got lower and lower because of that. Whenever I met my friends or their children…*

> *- I'm so jealous of the mother next to me because of her baby. There's so much difference… (sighing) in size between him and my baby… My baby is so small, I mean, so much smaller than I thought, that it was a bad shock.*

> *- After I had my baby, I was in a 6-person room at first, but there were people waiting to give birth and others who had given birth… The mother next to me had a baby that weighed 2.5 kg. She worried that the baby was too small and cried because the baby*

didn't take breast milk very well, but… It was life or death for my baby, so that was a bit uncomfortable.

- I thought if it were possible, it would be nice if the mothers in a similar situation in the [maternity] ward were together. Because you kind of want to hide the fact that you gave birth to a baby that way… I envy the women near me who had healthy babies and were congratulated as they left the hospital… I didn't hear any congratulations… that wounded me.

- I could hear baby noises from other rooms, but my baby wasn't at my side, so that was hard for me. I'd think, if our baby had been born healthy, it would be here… So, I kept the door closed, but when I went out into the hall or opened the door I'd once again hear babies crying in other rooms…

-In fact, when I'm on the bus on my way to the hospital [NICU], I see mothers walking with their babies in strollers… And that's actually not a special privilege, it's a normal thing…but I'm not living that normal everyday life, and it was what I imagined, so…

In South Korea, new mothers very often use a postpartum care center during their postpartum period. Indeed, all the mothers in the study had made their postpartum care center reservations. However, after giving birth to children with problems, almost all the mothers canceled their reservations to avoid ongoing evaluative comparisons with and by others.

- I'm more comfortable at home. If I stay at a postpartum care center, [other people] would keep asking "Where's your baby?" and I'd continuously be compared [with other mothers], so I'd be more stressed… so I don't really want to go there.

- The mothers here can't really get postpartum care, you know why. We can't go into a postpartum care center…

- I really hated that other people were talking about me. Someone said one out of ten [babies] were premature, but why did it have to be me…

High sensitivity to hierarchy ('Gahp-Eul' relation). The high sensitivity to hierarchy condition emerged through a Korean expression, 'Gahp-Eul' relation. The 'Gahp' and 'Eul' words were often used by the mothers when they mentioned their experienced uneven balance of power and/or the expression of arrogant and bossy attitudes in the NICU, their family, or society in general. These observations are illustrated in the narratives below:

- I think in the hospital, the medical staff are above everyone else. So, they are the 'Gahp.' Then, there's our baby, then our in-laws and parents, and then my husband and I are at the very bottom. So, we are the 'Eul.' That's what I feel like. That's also the order [of the people whom] I rely on. I feel that way because I can see that there's a big difference in my baby depending on how our doctor treats him.

- Here, the word of the doctor or nurse has the most power, and depending on what [they] say [about the baby] today, I can feel like I am in heaven or hell.

-When Professor 00 told my mother-in-law in a sharp way, "That [the baby was born prematurely and is now in the hospital] is not the mother's fault at all", I liked that… [because] whenever I tried to respond to her questions like "Wasn't the baby born prematurely because you went out too often?" or "Are you sure this is the best hospital [for the baby]?" she wouldn't budge. But at the professor's words… and my husband said the professor was the best in this field… after that, even [my mother-in-law] didn't say much.

- When I talk with the other [NICU] mothers, everyone [says] we're paying the hospital, but there's a "Gahp-Eul" relationship in the hospital too… and we feel like the doctors and nurses are "Gahp" and we're "Eul". Because even though they're nice to us, of course, our babies are here… Actually, they spend more time with our babies than we do. So often, we can't say the things we want to, in case my annoyance [with the medical staff] ends up affecting our baby… So, I think carefully about everything I say… and just keep silent…

- It's less stressful when I meet a doctor that tells me in detail how my baby is doing. [The doctor] last month would come and talk to us when we were sitting next to our baby, but the doctor this time, he is the 'Gahp.' He talks [about the baby's condition] only when we request a consultation through the nurse. We have to know exactly what the situation is but… we hear about it [only] from the nurse.

- When the [assigned] nurse is busy with other things and the other nurses are also busy with their work and there's a baby near my baby that's crying… Really, at that moment, I really want to go and hold that baby… but I'm not supposed to, so I'm uncomfortable… To be honest, at times like that I want to at least hold my own baby as much as possible, but I'm reluctant to ask the busy nurses for my baby when he's sleeping well, too… I am always nervous and mindful [of the nurses].

- If I could have my way, I'd like to show my baby my face more often and I'd see [the baby] more often, too, but if I stay here too long I'm afraid I might hinder the nurses at their work… So, I end up coming out in a hurry even if I didn't mean to.

-If the medical staff were a mother bird, we and our baby just have to swallow what the mother bird gives us. And we have to just wait… Unless the staff gives us a prescription, the baby can't live, and if the staff says an operation is necessary, we have to sign the papers, and if they say they need to use a strong antibiotic, we have to agree no matter what. We don't know anything. If we ask, the doctor just gives a brief answer. The only thing we can do is search the internet. But there's a limit to that, so we keep asking the doctor questions and then [he] gets annoyed, so it's hard for us to ask.

Action/Interactional Strategies: Seeking safe support and Adapting

Strategies are the purposive actions used "to manage, handle, carry out, respond to a phenomenon under a specific set of perceived conditions" (Strauss & Corbin, 1990, P. 97). In

analyses of mothers' responses, the categories of the *seeking safe support*, and *adapting* to the NICU emerged as the action/ interactional strategies.

Seeking safe support. After their current deliveries, to manage their *emotional distress* and *isolation* under the intervening conditions, the mothers attempted to seek out persons who they saw as secure and safe from additional emotional distress, helpful in adjusting to the new environment, and supportive in taking care of the new baby. The following narratives are provided to exemplify the mothers' successful experiences in seeking safe support:

- Well, my husband said that, "If it hadn't been for you… only you could have done so well in that situation." When he said that, it was really supportive.

- Yes, I tell my husband about all my stress, my doubts. I don't hide anything from my husband. I talk about everything. I even told him about my secret stash, so [he said] then it's not a secret stash… I was hurt by my friend, so… it was a childhood friend, but I don't meet her anymore.

- My husband is the type of person that quietly takes care of anything that happens, so [I] really depend [on him] a lot. I'm hasty and easily excited and when something like this [emergency childbirth] happens, I don't deal with it easily but he's the type that easily, calmly takes care of things in order. These days we talk on the phone maybe twenty times a day… We always talked often. So when I don't feel good about something, I can talk [about it with my husband] right away and deal with it…

- Going through this ordeal, I was really surprised… "Was my husband always such a strong person?" He used to be a bit timid but I think he's changed a lot now. I'm grateful for that and our relationship is better now.

- People ask me what I talk about with my father, but I talk about everything I can't talk about with other people. When I tell my father, he always says, "Good thing [you talked to me]. There's a lot of people who wouldn't understand. It would be a waste of your time" and he listens to everything I say and helps solve my problems…

- Yes, I have [special] friends like that so when I'm in this hospital, they're the ones who come right away. I couldn't tell other people that I'd had the baby, you know... even old friends I'd gone to school with. But, with them, I can communicate, really talk…If I talk about it with other people, I get sad again, so I have to explain [why I get sad] again, and go through that experience again, and explain in detail why I've gotten this way… But, with them, I can talk very safely…

- I don't do anything special when I get stressed. I just talk with my husband a lot, and these days I think I talk with my mother a lot, too. In fact, since this happened, my husband and I have spent a lot of time together, just the two of us, at the hospital, so we've talked a lot… And with my mother, too… now I understand a bit about how a mother feels… I have honest conversations with her and I know that what she says is for my good, so I've grown closer to my mother as a result of this. And it's the same with my husband too… I don't think I could've gone through this without my husband and mother.

In some cases, the participants' mothers and/or mothers-in-law were willing to help the mothers, particularly during the postpartum period. However, if a mother felt that the help was unsafe or not supportive, she would seek another safe person:

- Since this happened to her first grandson, my mother-in-law said she'd come to our house to look after the children (the baby's older sisters), but honestly, I don't trust her. I've never left [the children] in her care. My husband and I have raised them on our own until now, but since this suddenly happened and my mother-in-law came to stay at our house, I'm kind of at a loss. I rely on my husband a lot and he said, "You just focus on our baby there, and I'll take care of everything at home," so I'm just focusing on our baby here. My husband runs his own business so he can be flexible with his schedule, without having to ask a boss, so that's a relief. But still I worry, will my mother-in-law do a good job?

-Since things happened this way, I couldn't go to a postpartum care center. My mother-in-law came to help with my postpartum care, but I can't even lie in the living room watching TV or pump breastmilk the way I want to, so it's really uncomfortable. She prepares every meal for me but she talks too much and… I just feel it would be better for her not to stay too long.

Some mothers wished that their husbands were the secure/safe, helpful, and supportive person in their stress response process. The following narratives are provided to substantiate the mothers' unsuccessful experiences in seeking safe support:

- If I'm mad at a doctor at the hospital today and I tell my husband, I want him to just take my side but he's totally neutral. Of course, that annoys me.

- When I was raising my first child, I was under a lot of stress because my husband didn't get involved. I know he works but he should still play with the child when he comes home and so on… but he sometimes wanted to be by himself. That made me upset and wounded me, too. [The hurt] would pile up and once in a while I'd erupt…

- Since this happened with my baby, I've rarely spoken to my husband. I just don't want to. On one hand I'm sorry [it happened]… and it's hard enough for me to take care of myself so I want him to take care of himself, but he just answers "Ok." Then I get annoyed. He says if it were our baby's destiny to live he'd live, so I shouldn't obsess about him. But shouldn't we try to do everything to save our baby? The way he thinks is so strange. He says things that are no comfort to me at all.

If the mothers failed or were not fully successful in seeking a safe support person, some would seek a safe support group or community via the internet. Using the internet was a critical source of information for the mothers, because, according to the mothers, it was 'safe,' 'helpful,'

and ‘supportive.’ In this point, some mothers were apt to become addicted to searching the internet. The following narratives demonstrate other experiences in seeking safe support:

-Yesterday, there was a mother who had been here for a very long time and they were finally checking out of the hospital… I heard from her that there’s a group of mothers of premature babies that gets together. I wish there was something like that provided by the hospital. It’s frustrating because some people know [about the group] and some don’t.

- Nowadays there’s a lot of online communities with people in similar situations, so I search a lot on the Internet. I don’t need to reveal who I am, and on some sites, I can just read the postings and then leave…

-It’s those who had, have the same disease… nowadays online communities like that are really active so, I can sympathize with those parents or get information from those parents and… get information about the vague future… like, oh, this is what my child is going to go through in the future… I think those communities help, and information about future problems…

- At first, I was confused and at a loss… [thinking], why did this happen to me… I was worried and didn’t know what to do… But nowadays, it’s easy to use the internet and since I’ve been getting some information I need online, I’ve gotten a lot more used to [the situation] since then.

Adapting. Although they needed time to adapt, adapting was the other important strategy used by the mothers to respond to their stress in the NICU under the intervening conditions. Learning the new rules in the NICU usually started with the mothers' adaptation to the NICU. The category of *adapting* includes not only adapting to the NICU environment but also adapting to the situation of having an infant with health problems. Due to psychological loss of a healthy and/or full-term child, the mothers experienced psychological and emotional adaptation process. If they were successful in adapting, they described their experiences regarding the NICU hospitalization as comfortable and positive. The following narratives are provided:

> *-Even when I was looking at my baby and touching her and holding her, oh, it just didn't seem real. When I had my first child, I thought, "Oh, you are my son." But when I gave birth to this baby so early, I thought all kinds of things… like, even, "Are you really my daughter I gave birth to?" So, I think it took time to adapt…*

> *-At first, I even thought it would have been better if this baby hadn't been born, that I should've stopped at one child… I had thoughts like that, but since the baby's born, we have to get through this together, and I think what happens in the future is more important.*

> *-I honestly thought if [my baby] were born at 530g it wouldn't be able to live. But now I'm so happy and proud of our baby. So, I'm grateful to the doctors and nurses.*

-At first, I was stressed because it was so different from the childbirth I had imagined, but now I even feel like it's given me more time to prepare as a mother… I wasn't ready to be a mother, but since I've been going through this, I now realize, 'oh, this is what a mother has to do' and I try to learn a lot. I still have time before my baby leaves the hospital, so I'm preparing myself mentally for that and I think it's better [for us]. I actually think if I had carried the baby to term and started [being a mother] right away, I would have been at a total loss as to what to do.

-To be honest, I don't know how to let go of my stress. Maybe the reason I started suffering from depression five years ago was because I didn't know how to release stress. But even though the baby was born too early, I had to stop taking medication for depression because I had the baby and I was breastfeeding. I think our son is doing me a favor. It's been two months since I stopped taking the medication but I'm sleeping well and I'm doing ok. I think I'm more comfortable with everything now.

Consequences: Having mother's role and Various stress levels and symptoms

In the theoretical model, the consequences are the results of the strategies used to handle the phenomenon (Strauss & Corbin, 1990). *Having mother's role*, and *various stress levels and symptoms* were identified as consequences of seeking safe support and adapting. Because not only successful, but also unsuccessful strategies have consequences, the participants' reports varied regarding maternal role achievement as well as levels of stress and stress symptoms. To complement participants' descriptions of their maternal roles, this study incorporated

quantitative assessments of perceived maternal role (MSRI) as well as perceived stress (PSS 10) and symptoms (SOS).

Table 3-2. The Scores of MSRI, PSS, and SOS of the Participants				
Surveys	**N**	**Mean**	**SD**	**Range**
Maternal Self-Report Inventory (MSRI)	30	93.50	13.15	56-117
10-item Perceived Stress Scale (PSS 10)	31	20.26	5.47	11-32
Symptoms of Stress Inventory (SOS)	31	56.81	35.37	10-129

Having mother's role. After undergoing childbirth with problems, the participants ultimately attained the maternal role in the NICU through the use of identified strategies (seeking safe support and adapting), under the contextual condition (leaving my baby in the NICU) and with intervening conditions (continuous comparisons and high sensitivity to hierarchy). The range of the MSRI scores reflecting maternal role was wide (range = 56–117, M = 93.50, SD = 13.15), as the participants' narratives differ greatly. Some mothers carried out the maternal role actively, whereas the others did so more passively:

-After I am discharged from the hospital, you know, I should keep visiting NICU, because I think kangaroo care is really good...

-I'm holding [my] baby and saying, "It's ok, I'll be a good mother, I'll help you grow up strong and beautiful." So, I'm releasing my stress when I say things like "Thank you for holding on." When I do kangaroo care, there are mothers who are really quiet but I keep talking… I know my baby is listening to me, even while she's sleeping… That's good for the baby of course, and it's also a way of releasing stress…

-You know, the baby's here, like that, and I feel guilty… So I do what I can…pump milk and take it over quickly, and do kangaroo care, like other mothers do…

-Today, I was really surprised because my baby was sucking on a pacifier. He was sucking on a pacifier while on CPAP. The evening nurse said he was sucking very well. If they sell them in stores I want to get him [one].

Various stress levels and symptoms. The study participants expressed their experienced stress. As shown in Table 3-2, the PSS scores ranged from 11 to 32, (M = 20.26, SD = 5.5), and the SOS scores ranged from 10 to 129 (M = 56.81, SD = 35.37). A higher score means a greater level of stress. The following two narratives reveal how the strategies (*seeking safe support* and *adapting*) used influenced consequences. The two mothers narrated about the same level of emotional distress and isolation experiences (phenomena) after their giving birth. In addition, the two mothers had almost the same socio-economic status, and experienced the same causal condition, and contextual condition in the same hospital. One mother, however, was more sensitive to the intervening conditions than the other:

-Because we're considerate of each other, take care not to make it harder for each other… I don't show any emotion [to my husband], and my husband, he must be having a hard time too, but he doesn't show any emotion… so we both probably have some stress that's not being released. (GA 34, 37-year-old mother, PSS=32, SOS=110, MSRI=56)

-You know, I am the kind of person who has to talk to release stress. Women have to talk, right? Now, I talk with a doctor whom I'm a bit close to, and when my other friends call, I talk to them... (GA=29, 34-year-old mother, PSS=12, SOS=19, MSRI=98)

Maternal Stress Response Process in the NICU: Struggling with Stigma

In grounded theory study, selective coding is used to uncover patterns, systematizing and solidifying connections among the categories. A core category is "the central phenomenon around which all the other categories are integrated" (Strauss & Corbin, 1990, p.116). By means of selective coding, the phenomenon of *struggling with stigma* emerged as the core category integrating other categories in the model. Although no participant mentioned the word stigma directly, the ten categories derived from the mothers' narratives reflect this one comprehensive category, struggling with stigma. The stress response for NICU mothers was a process, meaning "the linking of sequences of action /interaction as they pertain to the management of, control over, or response to, a phenomenon (Strauss & Corbin, 1990, P.143). That is, in Figure 3-1, even if a mother did not play enough of a mother's role and her stress levels were high at some time, the mother could still have a chance to seek another safe support and/or to use another adapting process to get her desired consequences. The two intervening conditions, continuous comparisons and high sensitivity to hierarchy, were linked to and identified with the struggling with stigma.

Discussion

This study explored the conditions and the process of stress responses for mothers whose infant was hospitalized in a NICU in South Korea. The research uncovered two important socio-cultural factors related to the maternal stress response process. As shown in Figure 3-1, findings reveal that Korean socio-cultural factors are linked to and/or affect every aspect of the NICU mothers' stress response process except the causal condition.

According to Nisbett (2003), "For Asians, feeling good about themselves is likely to be tied to the sense that they are in harmony with the wishes of the groups to which they belong and

are meeting the group's expectations" (Nisbett, 2003, p.49). Thus, in this cultural context, if a mother has delivered a preterm infant, or in other words, has failed to give birth to a healthy full-term child, she is apt to be tormented by feelings of guilt and shame over the NICU experience, as a daughter/daughter-in-law as well as a mother, because she has not met the family or broader social expectations. The common emotional distress experiences of the NICU mothers in this study - disappointment, loss of self, blame and self-blame, and isolation and self-isolation - likely stem from these cultural factors.

The two intervening conditions, continuous comparisons and high sensitivity to hierarchy, relate to the core category of this study, struggling with stigma. As shown in Figure 3-1, the culture of comparison with others is, for example, closely related to the phenomena of isolation, and the strategy of seeking safe support. Furthermore, because of the high sensitivity to interpersonal hierarchy ("Gahp-Eul" relation), it may be hard for the NICU mothers to seek or find safe support. Traditionally a Korean business term, the word "Gahp" means a buyer, purchaser, or client. "Eul" is used to refer to a supplier, vendor, provider, or contractor. "Gahp" and "Eul" were terms used only in business contracts, but more recently the terms have been used to refer to any unfair balance of power. Unfairness may lead to high sensitivity to interpersonal hierarchy, but there is no academic research on this phenomenon in health care environment yet. Nevertheless, the NICU mothers were apt to regard the help of their mothers-in-law as unsafe or not supportive, because they felt the "Gap-Eul" relation between themselves and their mothers-on-law. Likewise, the NICU staff/nurses were not likely to be the safe support for the mothers. This finding regarding the NICU nurses and mothers was unexpected, because usually NICU nurses are assumed to be a supportive resource for NICU mothers.

Limitations

There are several limitations in this study. First, the participants included only mothers, not fathers. Although the topic of this study was the maternal stress experience in the NICU, the findings revealed that the father played an important role with respect to the mother's stress response process. Because the NICU father's role as a safe support might be paramount to others in managing the mother's stress, it would have been informative to assess and confirm the husband-wife relationship with the fathers at the time of the final interview. Second, despite the fact that purposive sampling compensates for the weaknesses in convenience sampling and snowball sampling, it is possible that mothers with very high stress levels were excluded from this study. Thirty mothers of the 32 volunteer participants completed all three interviews and two sets of questionnaires. According to the field notes on the two mothers that withdrew from the study, both of them seemed to be under extreme stress. One cried almost continuously for 10-15 minutes, as the interviewer sat next to her comforting her nonverbally during the first meeting. When the interviewer asked if they should meet at another time, the mother only expressed her thanks, and then said she just wanted to focus on her baby, which was an expression of withdrawal. The other mother participated in parts of the survey, but she refused any interviews with audio recording. Finally, she refused to participate further, saying she didn't want to leave a bad record of her baby. Third, the proposed theoretical model is a tentative theory for understanding the maternal stress response process among mothers with an infant in the NICU. In addition, some socio-cultural factors, to be specific, the "Gahp-Eul" relation, may change over time. These limitations should be addressed in future studies.

Conclusion

The theoretical model developed in this study delineates how and why stress response occurs among mothers of infants in the NICU in South Korea. In addition, the influences of interpersonal and socio-cultural factors on the process of stress responses of mothers who have infants in the NICU have been identified. This study would support more effective nursing practices, the development of nursing interventions, and NICU policy in order to reduce NICU mothers' struggling with stigma.

References for Chapter 3

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CHAPTER 4

Mothers' Perceptions of Roles in the NICU in South Korea

Abstract

Objective: To describe maternal perceptions of the role of: the mother; the child; the family; and the NICU staff, with regard to NICU experiences; and to understand the significance of such roles to the mothers during their stressful experience of having a child in the NICU.

Design: Qualitative description using level I, II, III coding methods in grounded theory.

Setting: Two level IV NICUs in two large tertiary hospitals in Seoul, South Korea.

Participants: Thirty mothers who had infants in the NICUs.

Methods: During the final stress response interview, the mothers were asked to talk about their ideas concerning the roles of: the mother; child; family; and NICU staff in the NICU. The data were analyzed using the methods of line-by-line and in vivo coding (level I), categorizing codes (level II), and identifying themes (level III) in grounded theory.

Results: *Uneven/unfair power balance* ('*Gahp-Eul' relation)* and *ranking of roles* emerged as the themes of this study. The NICU mothers' perceptions of each role – that of the mother, child, family, and NICU staff – were categorized into a *directing role* vs. *supporting role* with *active manner* vs. *passive manner*. There were gaps between the ideal or expectations for each role in the NICU, and the reality with regard to the categories. Also, the gaps were associated with the themes, uneven/unfair power balance ('Gahp-Eul' relation), and ranking the roles.

Conclusion: The negative role experience in the NICU can prevent the mothers from using the NICU staff or their family members as safe support resources in the NICU. These findings can provide NICU staff with a better understanding of the perceptions of NICU mothers. In order to

improve NICU care, it is imperative that NICU staff members eliminate, or at least lessen, the '*Gahp-Eul' relation*.

Keywords: NICU; mothers' perceptions; Gahp-Eul relation; socio-cultural factor; South Korea

Background and Significance

Although it is well known that family-centered developmental care is important for optimizing patient care in the hospital, mothers in the neonatal intensive care unit (NICU) often emotionally lose their maternal roles. According to qualitative research on mothers who have infants in the NICU, the mothers experience 'their baby' rather than 'my baby' (Heermann, Wilson, & Wildelm, 2005, p.178), and 'striving to be a real normal mother' (Aagaard & Hall, 2008, p. e31).

Even though the survivability of high risk infants is increasing, due to advancing technology in neonatal care, the experience of having an infant in the NICU remains a highly stressful life event. In this context, Beck (2003) emphasized that NICU nurses can support NICU mothers, and several studies have confirmed the important role of nursing support, not only in helping the mothers, but also in reducing maternal stress in the NICU (Aagaard & Hall, 2008; Segre, Orengo-Aguayo, & Siewert, 2016; Tandberg, Sandtrø, Vårdal, & Rønnestad, 2012; Zhang, Lee, Chen, & Liu, 2016).

Other studies of the supportive behavior of nurses in the NICU have pointed out that differences in the perceptions of nurses and mothers (Mok & Leung, 2006; Valizadeh, Zamanzadeh, Akbarbegloo, & Sayadi, 2012). Moreover, the perception of roles in the NICU, such as mother, child, family, and NICU staff, may differ depending on socio-cultural conditions. A study conducted in Taiwan indicated that a support system was critical because it

enabled the mothers actually to become the mother of their preterm infant in the NICU (Lee, Long, & Boore, 2009). Lee et al. (2009) identified that, not only NICU nurses and doctors, but also family members were able create a support system for the mothers. Furthermore, a grounded theory study (Kim, 2017) conducted in South Korea indicated that 'seeking safe support' by mothers was an important strategy for mothers to manage their stress in the NICU.

Hence, this study aims to describe maternal perceptions of their own roles, and that of the child, the family, and the NICU staff in the NICU, and to understand the significance of such perceptions, to explore the support system possibilities available to NICU mothers.

Methods

This qualitative descriptive study was part of a large mixed methods study of maternal stress response in the NICU in South Korea. The data were collected in two level IV NICUs in two large tertiary hospitals in Seoul, South Korea. After obtaining IRB approval, purposive sampling, convenience sampling, and snowball sampling strategies were used to recruit participants. Participation was entirely voluntary; mothers who wanted to participate in this study contacted the researcher directly. During their last interview session, a total of 30 mothers made a 3 to 10 minute-long response to one of the following questions:

- Could you tell me what you think about your own role and the role of your child, family, and NICU staff, with regard to the NICU experience?
- Could you tell me your thoughts about the role of the mother, the child in the NICU, family, and NICU staff, regarding the NICU experience?
- Regarding the NICU, what do you think the roles of the medical staff, the baby, the mother, and the mother's family are?

Transcribing, translating, analyzing data, and establishing trustworthiness

Demographic data were collected using a questionnaire survey (Table 4-1). All interviews were audio-recorded, and then transcribed verbatim in Korean, in order to compare the coding results with that done by two Korean doctoral candidates who were familiar with qualitative research methods. A 70-85 % congruent ratio of the line-by-line and in vivo level I coding results were seen in every meeting with the researcher's peers for the comparison of coding work.

Randomly chosen, approximately 13 % of the transcribed interviews (four mothers' out of thirty mothers') were translated into English for co-coding work with a qualitative research professor. This data analysis work included level I open coding, level II categorizing work, and level III identifying themes. The translated data were verified by back translation from English to Korean. For translation verification, all data for quotes and coding terms in Korean were translated into English, back-translated into Korean, and edited in English to deliver as closely as possible the nuances of what the participants had said in Korean.

To establish the trustworthiness of the data collection and data analysis, the following methods were utilized: frequent peer debriefing with the academic chair of the researcher; as much member checking as possible during the interview; material collection for an audit trail; detailed description of the interview context; and comparison of coding work with multiple doctorate qualitative researchers.

Results

According to Speziale & Carpenter (2007), there are three levels in coding in grounded theory. Level I coding, also known as open coding, is critical in ensuring a thorough examination of the data; thus line-by-line and/or in vivo coding is necessary to catch as many codes as

possible. Level II coding is the process used to categorize the open coding results. The last level, level III coding, is essential for identifying themes describing the 'basic social-psychological process' from the data (Speziale & Carpenter, 2007, p.146). The work of the level II and III coding is similar in purpose to Strauss & Corbin's axial coding, but this method enables the researcher to identify themes describing the socio-psychological process, rather than to reveal a theoretical model delineating a key social phenomenon.

The themes of *uneven/unfair power balance* ('*Gahp-Eul' relation)* and *ranking of roles* emerged as the themes describing the mothers' perception of the role of the mother, the child, the family and the NICU staff in the NICU. The mothers' descriptions of each role could easily be categorized into directing roles vs. supporting roles with active or passive manners in the NICU.

Table 4-1. Characteristics of Mothers and Infants (N=30)

	N (%)	Mean	SD	Range
Infants:				
Gestational age (in weeks)		31.63	5.76	24.0-40.57
Birth weight (in grams)		1749.17	1048.29	370-3770
NICU stay (in days)		41.67	47.38	1-173
First baby				
Yes	16 (53)			
No	14 (47)			
Mothers:				
Age (in years)		32.53	4.17	23-40
Education				
High school	5 (17)			
Community college	6 (20)			
College	17 (57)			
Graduate school	2 (6)			
Marital status				
Common-law	3 (10)			
Married	27 (90)			
Work outside home?				
Yes	14 (47)			
No	16 (53)			
Annual household income (1,000won)		66,741	50,192	27,000-300,000

The mothers described the roles in the NICU with hierarchy, such as 'director' and 'assistant director,' 'main character' and 'supporting actors,' and/or 'Gahp' and 'Eul.' There was a gap between the ideal or expectation for each role in the NICU and the reality, and because of the gap, the mothers experienced emotional distress. The following narratives exemplify the mothers' experiences:

- *Ideally, [I'd] like our baby to be the main character, and the medical staff the directors, and I an assistant director. [I] wish the family were just the audience, so they don't get involved… And [I'd] like the nurses in charge of our baby to be supporting actors whose role is to take good care of our baby and help her shine. Because it's the nurses that are with her 24 hours a day… But in reality, it's just a Gahp-Eul relationship. [I] wish the Gahp were our baby, but the Gahp is the medical staff and my baby and I are the Eul, so I feel a bit bad…*

- *[I] wish my baby and I together were the exact center of the NICU and got support, but the reality is different… There's [support] for the baby, but nothing for me…*

- *[Ideally, I] wish the professors were the staff, [my] parents were the audience, and I were the director. But I can't be the director, because that's what the professor is. Then I [could be] something like the assistant director? Wouldn't things be great if that were the case? Then ideally, on the stage that is NICU, the main character is the baby, the director is the professor, and I am the assistant director that exchanges opinions with the director… and the residents do what the staff needs to do, [take care of] things like the*

lights and stage props… The supporting actors, the other characters, would be the nurses, and [I'd] like the family to be the audience. But the reality is different so… it's a shame.

- *The main character [in the NICU] is the baby… The other actors, like the supporting roles, are the nurses, because they care for the baby… The directors are also the nurses, I think the directors are actually the nurses. [I] think the nurses do a whole lot of things [in the NICU]. [On the other hand] the residents… If I were the director, [I'd] prefer [they] didn't have a role… [I] really wish [they] wouldn't even come near the baby…if [they] are going to just say useless things, not give a correct answer, [I] wish [they] wouldn't come.*

To be specific, the mothers identified themselves as a 'helper' for the baby, 'mother in name only,' 'the wounded,' 'marginalized person,' 'Eul,' and 'self-blaming person' (Table 4-2). The mothers were apt to perceive themselves as an assistant for the baby, but only in a very limited capacity. The mothers experienced stress when they wanted to do something actively as an assistant for the baby (*supporting role* with *active manner*), but in reality, they were only able to do small things passively.

Table 4-2. Mothers' Perception of their Roles in the NICU	
Role Description	**Exemplar Quotes**
Helper	*- The mother is a dependable/trustworthy assistant for the baby.* *- I think [I am] an assistant/somebody who helps the baby.* *- I think [I] provide stability/security to the baby.*
Mother in name only	*- Since I'm the mother⋯ outwardly [at least]⋯ I have to do what I can [for the baby]⋯ I have to be by [the baby's side] and talk [to her] a lot, so she feels some stability⋯ [But] I feel bad/frustrated because that's all I can do ⋯*
The wounded	*-The mothers are the people who have been hurt…*
'Eul'	*- [They're] nice to us here, but to tell the truth, since the baby was hospitalized, [we've] spent almost 30 million won on hospital fees for the baby and myself until now. If [you] go to the department store and spend that much in such a short period of time you're the Gahp, but because the baby's sick, I'm the Eul. Even though I'm the one paying, here I get blamed [for things] so I think sometimes it's unfair. I'm a major customer for the hospital, but the NICU mothers often say, to others we seem like the Gahp that spends money, but here we are always the Eul.. we talked about that a lot.*
Marginalized person	*- I'm a marginal person. I don't do anything for [the baby, as her mother], I can't even give her enough breastmilk, as I have less [breastmilk] now, I take [her] 40cc and that's it...*
Self-blaming person	*I am the assailant, and [because of me] my baby is a sufferer⋯*

The children were described as the 'center' in the NICU, 'main character,' 'customer,' 'someone to be thankful for,' 'stranger,' and/or 'good son' (Table 4-3). Although the mothers considered the baby to be the core, center, or main character in the NICU, they believed that the baby's role was just being supported. Thus, there was little gap between the expectations for the child in the NICU and the reality.

Table 4-3. Mothers' Perception of the Role of their Child in the NICU	
Role Description	**Exemplar Quotes**
Center/Core	*-The sick child is the core [in the NICU], the main person who has to become healthy…*
Main character	*- The baby is the main character within the NICU. I did wrong for the baby, but he's been doing a great job.*
Customer	*-The baby is always at the center. The medical staff are people who help the baby, that's how I felt at first, but nowadays I feel a bit like our baby is the customer and the medical staff are people who provide services.*
Someone to be thankful for	*-All the baby needs to do is be well.* *-Because [my] baby does well, [I'm] thankful to her… that's enough.*
Good son	*-He's a good son. I don't know what other babies are like so I can't compare, so I don't know for sure, but I think it's unusual our baby hasn't made it hard on me, he's steadily endured [everything]. So, he's a good son.*

Table 4-4. Mothers' Perception of the Role of their Family Members in the NICU	
Role Description	**Exemplar Quotes**
People I have to take care of at home	*- I think my husband is also an assistant, who has to help me and the baby… and [I wish the older] children would help me a bit, even if [the older children] don't do anything, I hope they stay healthy and do well…* *- I wish my family were assistants who help me a bit.*
Production staff	*-… if the mother and family together [are able to] act the role of [production] staff, I'm satisfied.* *- Family members [are] also dependable/trustworthy assistants for the baby.*
Safe support	*- When I talk with my younger sister and complain about my mother-in-law, my sister also says things like, she must be a crazy old woman. It comforts me a lot.* *-My family believes in me… so that helps a lot. In a way… there isn't a single person who says things like, 'How can there be a disease like this, if it weren't for you the baby would be healthy.' I guess, more than I thought… it was just me who thought that way. Since my family comforts me, especially my mother and husband, and cares for me by my side, that helps a lot.* *- My husband and mom take care [of me] well, so… I don't think I could've endured it without [them]. My husband… for example, in this situation, if my husband didn't talk to me, and didn't answer even when I tried to talk to him, then I'd think… he must be upset and angry because of the situation with the baby, because of me… because [the baby] was born so early… he's angry because the baby's [so sick]… One mother said there are people [husbands] like that, too. But thankfully my husband isn't like that, [he's good to me] so I'm grateful and I also feel bad for him.* *-Yes, for me, my family members are people who are by my side during difficult times.*

If the mother had dependent family members, then the family was identified as people whom they have to take care of at home, but the family members were still identified by the mothers as 'assistants' for the mother as well as for the baby. Some mothers were satisfied with their family's supporting role with active manner as shown in the exemplar quotes of the 'safe support' in Table 4-4.

However, the mothers' expectations of the family role depended on what the mother considered to be 'the family.' If the mothers considered in-laws to be family, they wished their family members would act the part of production 'staff.' This means that the mothers wanted the family members to provide a supporting role with passive manner, meaning basically listen to the mothers without blaming them, and let the mothers do what they want with the infant in the NICU. The mothers commonly worried about whether they might feel that their role was usurped because of the uneven power balance between themselves and their parents (in-laws) in raising their children. The following narrative exemplifies the mother's perception:

- *In the NICU, the role of the baby is to grow well, the medical staff have to provide services as necessary, I have to do kangaroo [care] and hold [the baby] and let her feel she's loved and give her breastmilk and so on… And the family… [the role I'd like for them] depends on what you consider the family… If [my] in-laws are also family, [I'd] like them to keep some distance and just watch… But to tell the truth, [their] affection for the baby is really strong. When [I] show [them] pictures [I've taken here], [they] mention my husband's family name and say [things like] members of this family all have this characteristic… [they] read a lot of meaning into [things]. When in my opinion, what our baby does, all babies do… So, if our baby does anything here, [I] have to show pictures to my father-in-law… My in-laws say it's the*

high point of their day, to look at pictures of the baby, so [I'm] a bit worried about that, the future. [Because, my in-laws] and I would probably have different ideas on how to raise a child, [I] think they'd insist on their ideas a lot…

The mothers' perceptions of the role of the NICU staff were ambiguous (Table 4-5). The mothers considered the NICU staff to be people whom they trusted, relied upon, and were grateful to, but also people who made the NICU experience difficult for the mothers.

Table 4-5. Mothers' Perception of the Role of the NICU Staff in the NICU

Role Description	Exemplar Quotes
Supporter	*-Well, first, the baby is the main person/center at the NICU, and the medical staff are supporters of the baby as well as… general managers… [because] my family and I don't know how the baby has to be treated [medically], so we have to trust and follow the medical staff… so I think [the medical staff] have the role of assistants…*
People I feel grateful to **Source of information**	*- The nurses are really friendly, and they know a lot of things well and [they've] helped a whole lot, so [I'm] grateful.* *-When I feel anxious the nurses say a lot of positive things about the baby⋯ so I always feel grateful towards the medical staff.*
People I trust/ rely on	*-I just trust this hospital. The hospital is the best in our country, and according to the doctor, there are a lot of children worse off than our child, [and] our baby's surgery is nothing (not difficult/dangerous) so⋯ I was really very worried⋯ but I relaxed after hearing the professor's explanation.* *-The only ones I trust are the doctors and nurses. Because one word from them can make me laugh or cry, so there is no one other than [the doctors and nurses]⋯* *-I tend to depend [on others], and maybe it's because this child was born really early/prematurely, but I depended a lot on the medical staff [for support?]⋯ [I] went to a lot of hospitals, but this [hospital] was the largest and the one [I felt I] could trust the most⋯ But there are so many children here, so on the other hand I worry a bit that [they] might not be able to focus on our child, but [I] can still depend on [them] a lot.*

Table 4-5. Mothers' Perception of the Role of the NICU Staff in the NICU (cont.)	
People who give hope	*-What I really liked was, I think the [medical staff] who took care of our baby were the friendliest of all… Everyone in the ward I was in was kind, but I thought the [NICU] medical staff were particularly warm. Their words, their expressions… Because, in a way, I thought they would have the hardest time, have a lot of stress from being with the sick babies and so on … but the staff treated [my baby and me so kindly], I think [my] stress was reduced by about half. I felt [things could be reversed], that [I] still have some hope…*
Center	*-The medical staff are the most important [people]. They help the baby.*
Director (the professor doctor)	*- I think for treatment, it's really important that [The medical staff] make a good plan and carry it out. Because, for example, if there's another problem with the baby, should [we maybe] not use medication… like a diuretic… but wait a while and see… I think the timing is also important. The reason [I think] that is because when I got surgery at this hospital, I really resisted the surgery, but if [they] had said, "Then let's wait a bit more and see" at that time, the situation could've turned bad. But [I] think I'm alive now because [they] did surgery on me at a suitable time, so… I think the medical staff, particularly the professors, have the most important role [in the NICU]. It's not I who can decide the best time for treatment, nor the child…*
Instrument/ tools needed by the baby	*- The baby is the most important [person] so he's the main character, and [I] think it's me who's at his side, playing the role of assistant, and the medical staff are tools. So, the medical staff would be like [tools] that just help? …Tools or means that help the baby grow well, that's what [I] think, and [I'm] not sure about the family's role.*
People who make it hard for me	*- I have to depend a lot on the medical professionals, but the doctors and nurses aren't consistent, so it's really hard [on me]. One nurse tells [me] to stop bringing breast milk, in a slightly annoyed tone, like "Did not you hear?"… but then the next time, if I don't take breast milk, another nurse asks why I didn't bring breast milk… [I] get really angry at times like that, but I have to just keep it in, what can you do, there's nothing you can do… you can mention it several times and it won't work/change, so I've let it go … [I] said to [my husband] too, let's wait until the baby grows up, I think I'll go mad… and [he said], we can't do anything for [the baby], so let's just wait and [let] the medical staff do what they do… [they] should tell us something (if we wait)… there's nothing we can do except wait [for the baby to grow healthy here] and for you to get healthy…* *- The nurses' actions… some nurses are really friendly, and then some are a bit cold so… I think they're all a bit different…sometimes difficult…*

Table 4-5. Mothers' Perception of the Role of the NICU Staff in the NICU (cont.)	
People who make it hard for me	*- The medical treatment differs from person to person (The medical staff all have different ideas for treatment), and as a mother [I] want to do certain things [for the baby] but [I'm] not allowed to, so [I] get hurt and stressed. For example, the doctor says, now the mother and child should have physical contact even when the baby is feeding from a bottle, but the nurse says, come with a gown on too… how can you have physical contact if you're wearing a gown…* *- When I'm doing kangaroo care, the doctors [say] hello in a friendly way, and say things like, the baby's grown a lot, hasn't she… she's feeding how many cc now, and they think x percent is being absorbed by the baby's body, and the baby still has some apnea, so [we're] doing CPAP care but [we'll] start taking the CPAP away gradually… And a few days later, another doctor came and asked, how do you feel now that [we've] taken the CPAP off… so actually, the doctors talked [to me] a bit more when [I] was doing kangaroo care. When [before] I didn't know anything about the baby's condition and really needed [the doctor's explanations], it was hard to meet [them]…* *- It's a bit frustrating because [they] don't tell you [about the baby] if you don't ask. The hospital sends text messages, but you only get two, the weight and how much [she] is feeding… If I don't ask, for example, did you do something yesterday… [I found they] didn't tell [us]… I just come to see the child so I often forget… My husband says, "Did you ask about this?" and I say "No, I didn't."… Sometimes I remember [and ask], "Did [the baby] get tested for something yesterday?", and [then the nurse] tells me, "We did one [test] yesterday…" It would've been nice if [they] had told me when I came yesterday… But it's nothing out of the ordinary, so if [I] don't hear from them, I think, [they] probably didn't say anything because it was not a big deal, but still… you only learn later, 'Oh! They did such and such a thing.'* *- The medical staff are supporters, but [I] wish they would think the baby was their own and be more friendly, rather than being too professional (overbearing). [I] wish the medical staff would carry out the role of the baby's mother in a [more] definite manner.*

According to the mothers, the mothers experienced stress when there was a gap between the expectations for the NICU staff's role and the reality in the NICU. The mothers desired the

NICU staff's *active manner* in their directing role and/or supporting role. The mothers classified the NICU staff into professor doctor, resident doctor, and nurses, and described their perceptions of each role. The mothers were aware of uneven and/or unfair power balance, not only between the NICU staff and themselves, but also among the NICU staff members (Table 4-5).

Discussion

This study described the participants' perceptions of the role of mother, child, family, and NICU staff, with regard to the maternal stress experiences in the NICU in South Korea. The findings reveal that mothers with an infant in the NICU are likely to experience stress because of the gaps between the ideal and reality in three areas. First, there is a gap between the mothers' expectations of the mother role in the NICU and the reality. The mothers want to participate in their infant's care and to support the baby actively, but in reality they often experience their roles as passive or not important. Second, there is a gap between expectations the mother has for the family in the NICU and the reality. The mothers want to be gently supported and totally understood by the family with regard to the NICU experience. However, if family support is directive rather than supportive, and/or if the mothers feel an uneven/unfair power balance between a family member and themselves, the mothers are more likely to experience stress in the NCIU. Finally, there is a gap between expectations the mother has for the NICU staff and the reality. Although the mothers want a supportive role with the NICU staff, some mothers also want the NICU staff's directing role with active manner. The mothers recognize the uneven power balance between the NICU staff and themselves, such as in staff knowledge or time spent on care of the infant. Moreover, some mothers are even apt to prefer the NICU staff's active directions with authority, and trust their decisions. Regardless of the directive or supportive role, mothers were sensitive to the NICU staff attitudes. They often used the term 'Gahp' and 'Eul' to

describe how they experienced the NICU staff's passive manner (e.g. lack of communication between mother and doctor) as well as their arrogant and bossy attitudes.

Limitations

Despite the significant findings regarding NICU mothers' perceptions, there are several limitations to this study. First, the participants in this study are culturally homogeneous, so it would be difficult to generalize the findings internationally. The themes in this study are based on very recent Korean culture. In particular, the general usage of the terms 'Gahp' and 'Eul' among Koreans is relatively new. In addition, this study was a part of a large mixed methods research project, and the questions for this study were asked almost at the end of the last interview session. Thus, the interview time (3 -10 minutes) might not have been enough to explore the mothers' perceptions comprehensively. These limitations should be addressed in future studies.

Clinical Implications

'Seeking safe support' and 'adapting' are critical strategies for the NICU mothers in handling their stress in the NICU (Kim, 2017). Furthermore, the roles of the family and the NICU staff are also critical as the mothers seek safe support and adapt in the NICU. The findings of this study reveal why the NICU mothers are hesitant about using the family and the NICU staff as their safe support. Thus, the findings of this study would support the need for more effective nursing practices, the development of nursing interventions, and NICU policy, in order to reduce the gap between the ideal for each role in the NICU and the reality.

Conclusion

The mothers' various ideal perceptions of the roles in the NICU reveals not only the mothers' wishes but also a possible solution for filling the gaps. These findings can provide

NICU staff with a better understanding of NICU mothers' perceptions. In order to improve NICU care in South Korea, it is imperative that NICU staff members start by eliminating the '*Gahp-Eul' relation*.

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CHAPTER 5

Summary and Conclusion

The purpose of this dissertation was to distinguish remediable interpersonal and socio-cultural factors by building a tentative theory that comprehensively explains the NICU mothers' stress response process in South Korea, in order to support the development of effective nursing interventions facilitating mothers' management of their stress level and symptoms.

The NICU mothers' stress level and four major frequent stress symptoms, as well as the significant positive correlation between the stress level and the symptoms of stress, were described in the cross-sectional exploratory study (Chapter 2). This is the first study to explore stress level and symptoms of stress using PSS 10 and SOS inventory among NICU mothers in South Korea.

In Chapter 3, the theoretical model of NICU mothers' stress response process: *struggling with stigma*, delineated why stress response occurred among the NICU mothers and how they dealt with their stress. Also, the grounded theory methods study revealed how socio-cultural factors influence the whole process of stress responses of mothers who have infants in the NICU.

In Chapter 4, the sequential qualitative descriptive study explained that the NICU mothers' negative experience of roles, such as *uneven/unfair power balance* and *ranking the roles*, can prevent the mothers from using the NICU staff or their family members as safe support resources in the NICU.

In order to provide effective nursing care that prevents psychological problems among NICU mothers in South Korea, it is important to manage their high stress. To this end, it is critical to have an understanding of the key remediable variables that influence their stress

response process. It is extremely difficult to change fixed variables; thus, it would be more effective for the NICU staff to focus on remediable variables. If nurses have a good understanding of significant remediable variables such as a patient's socio-cultural factors, they can offer more effective nursing care. For example, if a NICU nurse is well aware that a mother's loneliness and emotional irritability are typical symptoms of stress in the NICU, the nurse will be able to provide more effective care to manage the mother's stress. Likewise, if all NICU staff members work to eliminate, or at least lessen, the 'Gahp-Eul' relation (uneven/unfair power balance), it would be possible to reduce the NICU mothers' stress level.

In conclusion, these findings can provide NICU staff with a better understanding of the stress response process of NICU mothers in South Korea. Also, to my knowledge, this is the first published socio-cultural study of the process of maternal stress response in the NICU in South Korea using this approach; as such, these findings can play an important and unique role in the identification of key concepts that influence the stress response process of NICU mothers in South Korea.

Appendix 1. Recruitment Flyer (English Version)

RECRUITMENT FLYER (FOR IRB REVIEW)

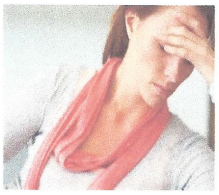
Are You Stressed Out?

Are you a mother?

Is your baby in the NICU?

Then please help me learn about you!

I am looking for NICU mothers who are interested in my study to find out the stress response process and the influences of interpersonal and socio-cultural factors regarding the NICU experience on the stress response.



If you

(1) have a perception of experiencing stress regarding NICU experience;

(2) have an infant in the NICU;

(3) don't have multiple gestations (e.g., twins, triples); and

(4) don't have severe mental illness

Please come to me when I visit here every _____ **day (:00 - :00).**

To determine if this study is good fit for you, or to find out more, contact me, Jungeun Kim, a former NICU nurse with 12 years experience, and a current doctoral student, in the Psychosocial and Community Health Department of the School of Nursing at University of Washington, at **kim0526@uw.edu** or **010-_____-_____.**

Once eligibility criteria are satisfied, you may participate in the study. All participants will take part in **three 40-60 minute interviews at a convenient time and location for you**. You will be asked to answer a set of 4 questionnaires including stress level and stress symptoms during the first interview. It will take about 20-30 minutes to complete. During the second interview, **you will have the results of your stress level and symptoms as well as an in-depth interview**. After the second interview, another set of 4 questionnaires will be distributed to you. It will take about 10-15 minutes to complete at a location convenient for you, and you will bring the 2nd questionnaires to the last, 3rd interview.

Every time you will be given a gift certificate to thank you for your time.

Appendix 2. Recruitment Flyer (Korean Version)

RECRUITMENT FLYER (연구선단지)

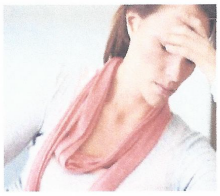
스트레스를 받고 계십니까?

어머니,

아이가 지금 신생아중환자실에 있습니까?

그렇다면 함께 이야기를 나누고 싶습니다!

2014 년 여름, NICU 경험과 관련된 스트레스와 그에 미치는 개인, 사회, 문화적 요인에 대한 연구에 관심이 있으신 어머님과 함께하고 싶습니다(**선착순 20 명**).



만약 어머님께서
(1) NICU 경험과 관련된 그 어떤 스트레스를 겪으신 적이 있으시고
(2) 현재 아이가 NICU 에 입원 중이고
(3) 쌍둥이나 세 쌍둥이의 부모가 아니시고
(4) 이 연구에 관심이 있으시다면

NICU 간호사 선생님께 "연락처를 알려주셔도 된다"고 말씀해 주시거나 아래의 이 메일 이나 **전화로 연락주세요**. 저는 약 12 년간 삼성의료원과 서울아산병원 NICU 간호사였고, 현재는 미국, 워싱턴 대에서 정신사회 지역건강분야, 간호학 박사과정 생, 김정은입니다. kim0526@uw.edu 또는 **010- 5577- 7349**.

연구에 참여하신 어머님과는 어머님께서 편하신 곳에서 편하신 시간에 총 3 단계의 **인터뷰**가 있을 것 입니다. 첫 번째 단계 인터뷰 때, 연구에 관한 설명을 듣게 되시고 동의서 작성 후 스트레스 정도와 증상을 포함한 질문지를 (약 5-10 분 소요예정) 받게 되실 것 입니다. **어머님의 스트레스 정도와 증상 결과는,** 두 번째 단계 인터뷰 때 **아시게 되실 것입니다**. 두 번째 단계 인터뷰가 끝날 때 또 다른 질문지를 (3-5 분 소요 예정) 받게 되시고, 인터뷰 마무리를 끝으로 모든 단계가 종료됩니다.

인터뷰 종료 후에는 어머님의 소중한 시간에 대한 감사의 표시로 총 50,000 원의 상품권이 지급됩니다.

Appendix 3. Recruitment Guide Protocol (English Version)

RECRUITMENT GUIDE PROTOCOL (FOR IRB REVIEW)

"MIXED METHODS SOCIO-CULTURAL STUDY OF THE PROCESS OF MATERNAL STRESS RESPONSE IN THE NEONATAL INTENSIVE CARE UNIT (NICU) IN SOUTH KOREA"

WHAT & WHY: The main purpose of this study is to generate a theory that explains the process of stress response among mothers of infants in NICUs in South Korea, relevant to their social and cultural context in particular.

WHO: Korean NICU Mothers, who have a perception of experiencing stress regarding their NICU experience, as shown in the ***inclusion and exclusion criteria*** below.

To be included in the study, a mother has to:	***Exclusion criteria*** include mothers:
(1) have **a perception of experiencing stress*** regarding the NICU experience; (2) have an infant in the NICU; (3) speak Korean; and (4) live in South Korea.	(1) with severe cognitive impairment; (2) those who have known severe mental illness; (3) those who have multiple gestations (e.g., twins, triples); (4) those who would not expect follow-up due to her loss of her infant in the NICU.

*The perception of experiencing stress will be open to the participants' definition

HOW: If there is a mother identified specifically by you (NICU staff) as individuals who would be suited to this study, please introduce this study, using this Recruitment Guide Protocol for you and the flyer for the potential participant as follows:

"You may be interested in participating in this research study (show them the flyer). Your participation will not in any way affect the care your baby is receiving at this NICU OR from me. If you would like to learn more about it I can either give you this flyer and you can call the researcher directly, or I can forward your contact information to her and she will call you. ***Are you interested?***"

- ⇨ If the answer is "***Yes***", give her a flyer and ask "How would you like to make contact with the researcher? Is it OK the researcher contact you regarding this study? Or you may call her and her number is on the flyer."
- ⇨ If the is "***No***", say "Thanks and let me know if you change your mind."

WHEN & WHERE: Research interviews will be conducted starting June 2014. During the infant's hospitalization period, the interviews and surveys will be conducted at a convenient time and location for each mother, and the interviews may be held at weekly intervals. If an infant is discharged from the NICU after the first or second interview, the researcher will conduct the next interview at a convenient time and location for each mother and the infant, such as at an outpatient clinic on the infant's follow-up day because every infant is supposed to see his/her neonatologist within a week after discharge.

Principal Investigator: **Jungeun Kim**, RN, MSN
Title and Credentials: Doctoral Candidate, School of Nursing, University of Washington
Telephone # & Email Address: **010-_____-_____, kim0526@uw.edu**

Appendix 4. Recruitment Guide Protocol (Korean Version)

RECRUITMENT GUIDE PROTOCOL (FOR NICU STAFF)

"MIXED METHODS SOCIO-CULTURAL STUDY OF THE PROCESS OF MATERNAL STRESS RESPONSE IN THE NEONATAL INTENSIVE CARE UNIT (NICU) IN SOUTH KOREA"

WHAT & WHY: 이 연구의 주된 목적은 한국의 NICU 에 입원한 아기들의 어머니들이 겪게 되는 스트레스 반응 과정을 설명하는 이론을 개발하기 위함입니다.

WHO: Korean NICU Mothers, who have a perception of experiencing stress regarding their NICU experience, as shown in the ***inclusion and exclusion criteria*** below.

연구에 참여하기 위해서, 참여자는	다음의 경우에는 연구대상에서 배제 됩니다.
(1) NICU 경험과 관련된 스트레스를 인지하고, (2) NICU 에 아이가 입원 중이며, (3) 한국말을 하고, (4) 한국에 사는 어머니여야 합니다.	(1) 심각한 인지장애가 있는 경우, (2) 심각한 정신 질환이 있는 경우, (3) 다 태아 (쌍둥이, 세 쌍둥이) 어머니, (4) Those who would not expect follow-up due to her loss of her infant in the NICU.

*The perception of experiencing stress will be open to the participants' definition

How: 만약 선생님께서 보시기에 이 연구에 적합하다고 여겨지시는 어머니가 계시면,

"(연구 전단지를 보여주시며) 어머님은 어쩌면 이 연구에 관심이 있으실지도 모르겠습니다. 어머님의 연구참여 여부는 저나 저희 NICU 에서 아이가 받게 되는 치료와 아무런 상관이 없을 것입니다. 만약 이 연구에 대해 더 알고 싶으시거나 관심이 있으시면 말씀해 주세요. 이 전단지에 나와 있는 연구자 연락처로 직접 연락하셔도 좋고, 아니면 제가 연구자더러 어머님께 연락하라고 할 수도 있습니다. 어떻게... 연구에 관심이 있으십니까?"

- ⇨ 만약 어머님이 "*그렇다*"고 하시면, 부디 전단지를 어머님께 드리시며 향후 연락은 어떻게 하는 것이 좋을 지, (연구자가 어머님께? 아니면 어머님이 연구자에게?) 여쭈어 주시고 제게도 부디 알려 주십시오.

- ⇨ 만약 어머님이 "*아니다*"라시면, "알겠습니다. 만약 생각이 바뀌시면 알려주십시오" 라고 말씀해 주시면 감사하겠습니다.

WHEN & WHERE: 연구 인터뷰와 설문 시작은 2014 년 6 월부터, 아기가 NICU 에 있는 동안에 시행될 것이며 그 구체적인 장소와 시간은 연구 참여자의 편의에 따라 정해질 것입니다. 만약 첫 번째 또는 두 번째 인터뷰 후 아기가 퇴원한 경우, 추후 인터뷰 역시 연구 참여자의 편의에 따라 시간과 장소가 결정 될 것입니다 (e.g., at an outpatient clinic on the infant's first follow-up day).

연구자: 김정은, RN, MSN
Title and Credentials: Doctoral Candidate, School of Nursing, University of Washington
Telephone # & Email Address: **010-_____-_____, kim0526@uw.edu**

Appendix 5. Consent Form (Korean Version)

연구제목: NICU 산모들의 스트레스 연구

안녕하십니까?
본 연구는 신생아중환자실(NICU)에 입원한 아기의 어머니가 겪게 되는 스트레스와 그 반응과정을 설명하는 이론을 개발하기 위한 연구입니다. 본 연구를 통해 NICU 에 아이를 둔 어머니는 왜 무엇 때문에 스트레스를 경험하게 되는지, 그리고 스트레스 수준은 어느 정도이며 그로 인한 스트레스 증상은 무엇인지를 파악하는 것은 추후 NICU 산모들의 스트레스관리와 정신건강 증진에 도움이 되리라 생각합니다. 본 연구의 목적을 달성하기 위해서는 어머님의 솔직한 답변이 무엇보다 중요합니다.

총 3 단계의 인터뷰는 (1) 기초 인터뷰, (2) 심층 인터뷰, (3) 마무리 인터뷰이며 각각 어머니의 편의에 맞춘 시간과 장소에서 이루어질 것 입니다.
(1) 먼저, 기초 인터뷰 시에는 어머님의 스트레스 수준과 그 증상들을 조사하기 위해 4 부분으로 이루어진 한 세트의 설문지가 배포될 것입니다. 설문지 작성의 예상 소요시간은 최대 5-10 분이며 완성된 설문지는 바로 수거하여 다음 인터뷰 때 어머님의 스트레스 수준과 유의한 증상들을 알려드릴 것입니다.
(2) 다음, 심층 인터뷰 시에는 그전의 설문에 대한 분석결과를 토대로 최근의 출산과 NICU 의 입원과 관련된 스트레스 경험 이야기를 나눌 것 입니다. 인터뷰 시 NICU 경험과 관련하여 가족간의 관계변화가 있는지 (예, 시부모님과의 관계변화) 등에 대한 개인적인 질문이 있습니다. 인터뷰가 끝나고 두 번째이자 마지막 설문지가 배포될 것이며 예상 소요 시간은 최대 3-5 분 정도이고 마지막, 세 번째 인터뷰 때까지 돌려주시면 됩니다.
(3) 끝으로 마무리 인터뷰 시에는 본 연구자와 어머니가 함께 기존의 인터뷰와 설문에 대한 확인, 질의 응답시간을 갖고 인터뷰를 마무리 할 것입니다.

이 연구에 참여하는 대상자는 NICU 에 아이가 있는 어머님이며 약 30 여명이 참여하시게 될 예정입니다. 본 연구자는 관련 학술지에 연구 결과를 발표할 계획이며 연구대상자의 익명성은 철저히 보장될 것입니다. 일부 인터뷰는 자료의 분석을 위해

어머니 동의 하에 녹음될 것입니다. 수집된 모든 자료의 모든 실명 등 개인정보는 제거 될 것이며 비밀번호가 설치된 컴퓨터에 저장될 것입니다. 연구의 진행을 위해 따로 연락정보를 (예, 이름, 전화번호, 이 메일 주소) 여쭈어 볼 수 있습니다. 그러나 이러한 모든 연락정보는 수집된 자료와는 철저히 분리되고 자료 분석이 끝나는 대로 분쇄 폐기 처리될 것입니다. 자료분석기간에도 연구실행자 1 인만이 접근가능 할 것입니다.
어머니께서 연구 참여를 원하지 않으실 경우에는 언제든지 연락 주시면 즉시 중단하도록 하겠습니다. 연구 참여는 언제든지 도중에 그만 두실 수 있습니다. 만일 그만 두고 싶으시다면 본 연구자에게 즉시 말씀해 주십시오. 참여를 중단한다고 해서 발생되는 불이익은 전혀 없습니다. 본 연구는 자발적으로 참여하는 것으로 연구 참여 동의서는 참여자, 연구자 서명 후 사본을 제공해 드릴 것입니다.

모든 정보의 비밀은 보장 되지만 만약 연구자가 참여자의 자해나 참여자가 타인을 해할 의도가 있다는 것을 알았을 때에는 연구자는 임상연구심의위원회의 관계 법령에 따라 이를 보고할 의무가 있습니다. 관련 임상연구심의위원회는 임상연구가 안전하고 적합하게 실시되고 있는지를 검증하기 위하여 귀하의 기록을 열람할 수 있습니다. 검증자는 비밀 보장의 의무가 있으며 이 연구의 기록은 법적으로 귀하에게 해가 되도록 사용 될 수 없음을 알려드립니다.

이 연구를 통해서 얻게 되는 직접적인 이득은 가시적이지 않을 수 있으나, NICU 와 관련된 어머님의 스트레스 경험을 어머님께서 원하시는 만큼 이야기 하는 것은 스트레스해소에 도움이 될 수 있습니다.
이 연구에 참여함으로써 예측되는 위험성으로는 개인적 경험을 이야기함으로써 정신적으로 불편함이나 스트레스를 느낄 수 있습니다. 불편한 질문에는 답변을 하지 않으실 수 있으며 본 연구로 인해 피해가 발생한 경우에는 바로 연구자에게 연락하여 주시기 바랍니다.
매 번의 인터뷰 후에는 어머님의 소중한 시간에 대한 감사의 표시로 소정의 상품권이 (첫 인터뷰 후 15,000 원, 두 번째 인터뷰 후 15,000 원, 마지막 인터뷰 후에는 20,000 원, 총 50000 원의 상품권) 지급될 것입니다.

본 연구에 참여하는 동안 연구 참여자로서 귀하의 권리에 대한 질문이 있는 경우, 연구와 관련된 의문 사항이 있는 경우에는 연락하여 주십시오.

피험자보호센터 전화: 02-3010-7161

서울 아산병원 임상연구 심의위원회(IRB) 전화: 02-3010-7166

어머님께서 응답해주신 자료는 NICU 에 아이를 둔 어머님들의 스트레스관리를 위한 자료로 소중히 사용될 것입니다. 또한 이 연구의 결과는 NICU 의료진들이 추후에 NICU 에 입원한 아기뿐 아니라 그 어머니에게도 관심을 갖게 하고, NICU 산모들의 정신건강을 위한 중재프로그램을 개발하는 것에도 도움이 될 것입니다. 연구하는 동안 궁금한 점이 있으시거나 연구와 관련하여 문제가 생겼을 경우, 질문이 있을 경우에는 언제든지 연락해 주시기 바랍니다. 연구에 참여해 주셔서 감사합니다.

연구기관/ 연구자:

University of Washington, School of Nursing / 김정은 (010-8875-7349)

서울 아산병원, 간호부 / 김연희 (02-3010-5320)

동의서에 서명하기 전에 다음 사항을 다시 한번 확인하시고 해당 칸에 V 표기하여 주시기 바랍니다.

1	**이 임상연구는 연구 목적으로 수행된다는 사실을 알고 계십니까?**	
2	**이 임상연구의 목적 및 방법에 대해서 충분히 알고 계십니까?**	
3	**이 임상연구에 참여하지 않아도 불이익을 받지 않으며, 참여하더라도 언제든지 중도에 참여를 거부하거나 중단할 수 있습니다. 또한 이에 따른 어떠한 불이익도 없다는 사실을 알고 계십니까?**	
4	**이 임상연구에 참여함으로써 예측되는 이득에 대해 알고 계십니까?**	
5	**이 임상연구에 참여함으로써 예측되는 부작용 및 위험성에 대해 알고 계십니까?**	
6	**이 임상시험과 관련된 피해가 발생할 경우에는 보상과 치료를 받을 수 있으며 또한 누구에게 연락을 해야 하는지를 알고 계십니까?**	

본인은 본 임상연구와 관련된 모든 설명을 듣고 이해하였으며, 모든 궁금한 사항에 대하여 충분한 답변을 들었습니다. 충분한 시간을 갖고 생각한 이후에 본인은 상기 연구에 참여하기를 자발적인 의사에 의하여 동의합니다. 또한 본인은 본 연구가

진행되는 동안 본인에게 연락하는 것을 허락하며, 동의서 사본 1 부를 받게 될 것임을 알고 있습니다.

피험자 성명 _____ 서명_____

동의서 서명일 _____년 _____월 _____일

본인은 임상연구에 대하여 피험자 또는 피험자의 대리인에게 임상연구에 관하여 충분히 설명하였음을 확인합니다.

연구자 성명 _____ 서명_____

동의서 서명일 _____년 _____월 _____일