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# HEALTH AND WELLNESS TOOL

Creation of A Health and Wellness and Self Care Tool for Mothers of Infants Requiring a

Neonatal Intensive Care Unit Stay

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### **Abstract**

Purpose: Despite occupational therapy's established role in the neonatal intensive care unit (NICU) in providing family centered intervention, mothers continue to report lack of readiness to discharge home and emotional distress while in the NICU and upon discharge home. Occupational therapists have the unique skillset to promote engagement in meaningful activities and facilitate overall health and wellness for mother's during and after their NICU stay.

Method: A qualitative survey was distributed to a convenience sample of fifteen participants to identify emotional experiences in the NICU, how these experiences impact each mother fulfilling her role as a primary caretaker, and the perception of each mothers' self-care needs being met during the NICU stay. A thematic analysis analytic approach was used to identify themes.

Results: Key themes of supports and barriers were identified, and a health and wellness tool was created to meet the self-care needs of future mothers of infants requiring a NICU stay. Two participants who completed the qualitative survey then evaluated the health and wellness tool through focused interviews and reported the tool is something they would have liked incorporated into their plan of care and that appears to meet their self-care needs.

Conclusion: There is an opportunity for occupational therapists to incorporate this health and wellness self-care tool into future family centered practice in the NICU in order to address the emotional needs of the mother and assist them in fulfilling their role as a primary caretaker.

### **Literature Review**

Previous literature has concluded that the neonatal intensive care unit (NICU) is a stressful environment and parents of infants requiring a NICU stay require supportive emotional care (Turner, Chur-Hansen, Winefield & Stanners, 2015). Many mothers report post-partum health issues, including post-partum depression and post-traumatic stress, (Vanderbilt et al., 2004, Verbiest et al., 2016). A study demonstrated that “women who were not offered counseling during their infant’s NICU stay had a 60% increased risk for post-partum depression (PPD) onset,” (Bergstrom, Wallin, Thomson, Flacking, 2012, p. 148). Many factors contribute to the increase risk of post-partum depression in mothers of preterm infants, such as previous diagnosis of a mental health disorder and experience negative perceptions of self and/or the infant at NICU discharge (Hawes, McGown, O’Donnell & Tucker, 2016). Other maternal health issues include the challenge of parental lived experiences differing from expectations, which contributes to maternal stress, depression, anxiety and low self-esteem (Lazarus & Rossouw, 2015).

Interventions such as incorporation of relaxation techniques to manage parental stress while in the NICU have been shown to decrease anxiety levels (Fotiou, Blastaraskos, Bakoula, Papagaroufalis, Bakoyannis, Darvin & Chrousos, 2016). However, according to a study conducted by McGown, Du, Hawes, Tucker & O’Donnell (2017), this “vulnerable group (mothers with reported mental health disorder during a NICU stay) perceive themselves as less ready for discharge home with the infant, indicating an unmet need for provision of enhance transition services,” (p. 68).

Occupational therapists (OT) have an established role in the NICU , which is supported by the occupational therapy practice framework (OTPF), in providing family

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centered care in regards to feeding, positioning, reaching developmental milestones, primitive reflexes, and parent/caregiver education (Gibbs, 2011). Family centered care includes adopting a social systems perspective, placing the family as a unit of intervention, empowering and promoting growth of families, focusing on family needs, and strengthening the family's social network (DeGrace, 2003). However, despite OT's established role in the NICU, the literature suggests there is an unmet need to address the mothers' health and wellness while in the NICU in order to prepare for a successful discharge plan and transition home, as well as facilitate the mother fulfilling her parental role.

### **OT's role in the NICU/Health and Wellness & Problem Statement**

Occupational therapists' established role in providing family centered services in the NICU is reflective of the occupational therapy practice framework (OTPF). The OTPF discusses the concept of co-occupations as those that implicitly involve two or more individuals (Zemke & Clarke, 1996), and occupations that involve active participation on the part of both the caregiver and the recipient of care," (OTPF Domain and Process, 2014). These "co-occupations" are key for the mother of a NICU infant in order for her to establish and engage in her parental role. These co-occupations include eating/feeding, dressing and toileting (changing diapers, clothes, etc), comforting and soothing the infant, and bonding to create the meaningful parent-child relationship. Furthermore, occupational therapy in the NICU facilitates the IADL of child rearing, which is defined as "providing care and supervision to support the developmental needs of a child," (OTPF, 2014). In the NICU, neonatal therapists facilitate co-occupations between the parent and infant through feeding interventions, positioning, assessing

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primitive reflexes, and providing parent education in order to enable co-occupation participation.

Despite occupational therapy's established role as providing family centered services in the NICU, some mothers still report feeling unready for discharge home and the NICU remains a stressful environment requiring supportive emotional care (Turner, Chur-Hansen, Winefield & Stanners, 2015). Furthermore, according to Podvey (2018), "many women need support to change life roles...and [through the] recovery processes," (p. 17). Occupational therapy's involvement in the perinatal period is vital for maintaining engagement in meaningful occupation, role establishment and overall well-being among new mothers (Podvey, 2018). This need presents an opportunity for occupational therapists to address health and wellness in the NICU environment. The OTPF identifies health and wellness as an intended outcome as the result of the occupational therapy process. The outcomes of the occupational therapy process reflect attainment of goals that relate to engagement in occupation, specifically when clients (in this case the mothers), "realize the effects of engagement in occupation and are able to return to [or establish] desired habits, routines, roles, and rituals." The practice framework cites the definition of health from the World Health Organization (WHO), as a state of physical, mental, and social well-being, and wellness as a state of mental and physical balance and fitness.

### **The Stressful Nature of the NICU Environment**

A study by Turner, Chur-Hansen, Winefield & Stanners, (2015) identified various aspects of the NICU environment that can be unsettling or stressful for parents. These aspects include various sights and sounds such as loud alarms or beeping from the

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monitors, hearing their own or other babies cry during procedures, the multiple lines or tubes connected to the baby, the use of a ventilator for helping the baby breathe, and harsh lighting in the NICU room (Turner, Chur Hansen, Winefield & Stanners, 2015).

Given the stressful environment of the NICU setting, health and wellness needs can be considered key factors in the success of the mother fulfilling her parental role. Furthermore, due to the reported stress and need for emotional care from previous literature, facilitating health and wellness through the mother's own engagement in basic self-care tasks or other meaningful occupations such as leisure, sleep and relaxation, religious or spiritual activities, or social participation needs to be incorporated into the mother's plan of care during the NICU stay, as well as into the discharge plan from the NICU.

### **Purpose and Research Questions**

The purpose of this capstone is to create a tool that encompasses maternal health, wellness, and self-care needs with the intent of incorporating the tool into the plan of care for the mother in future occupational therapy practice. For the purpose of this study, the following research questions were addressed:

1. What are the emotional experiences of mothers of infants requiring NICU stay?
2. How do these emotional experiences impact mothers' ability to fulfill the role of primary care taker?
3. What are the perceptions of mothers in the NICU regarding their own self care needs being addressed/acknowledged during their NICU stay?

### **Methods**

A qualitative approach was used for this capstone, which unfolded in two phases. The purpose of phase one was to collect qualitative data from mothers of NICU babies regarding their emotional experiences in the NICU as well as at discharge from the NICU in order to identify what key information should be incorporated into the tool. Following creation of the health and wellness tool, phase two was implemented and involved evaluation of the tool through semi-structured interviews via video conferencing. Approval to conduct the study was received from the George Washington University IRB.

### **Participants**

The inclusion criteria for participating in the study is an English speaking mother over the age of 18 who have had an infant requiring a neonatal intensive care unit stay within the past five years.

### **Data Collection**

*Phase I.* A qualitative survey (see Appendix A) was created through use of SurveyMonkey and distributed online on platforms including FaceBook and online parenting forums and blogs. Purposive sampling was utilized in order to target the intended audience and snowball sampling was encouraged by participants. The survey consisted of fourteen questions that provided opportunity for open-ended responses to questions that related to their emotional experiences during the NICU stay and at discharge, what supports were helpful, what services they wish had been offered, their perception of their self care needs being met, and reflection about their role of as a



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mother in the NICU. In the survey, participants were provided informed consent and if they consented, they were then able to complete the remainder of the survey. At the end of the survey, participants were requested to leave contact information (email address).

*Phase 2.* Participants who completed the survey and provided their contact information were asked to participate in an in-depth, follow up semi-structured interview to review and evaluate the health and wellness tool created by the researcher. The interviews were conducted using online videoconferencing software. The interviews were conducted separately between the two participants and recorded and transcribed to record their feedback and comments on the tool.

### **Analysis**

A thematic analysis approach (Nowell, Norris, White & Moules, 2016) was utilized to analyze the data from phase 1. The data was reviewed and categorized to reach saturation, and ultimately three major themes were created out of the categories. The results from phase 1 of data analysis were utilized to create the health and wellness tool using the voice of the mothers with NICU experience.

In phase 2 of analysis, the health and wellness tool was evaluated. To evaluate the tool, an approach discussed by Guskey (2013) was utilized. Guskey reports, “we use evaluations to determine the value of something,” (2013, p. 2). Semi-structured interviews were recorded with two of the participants and transcribed for analysis. Using the transcribed script, the direct feedback provided by the participants was used to evaluate and update the health and wellness tool. The participants were asked the following questions to evaluate and determine the value of the health and wellness tool:

1. Discuss your initial thoughts of the health and wellness tool.

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2. Does this tool provide the information and/or resources to address your own health and wellness needs?
3. What would you add to this tool? What would you take away?
4. Do you believe this tool would be helpful for future mothers requiring a NICU stay? Why or why not?

### Results

For phase 1, fifteen mothers responded to the survey questions. All of the fifteen participants reported at least minimal distress with their NICU stay regardless of if the baby in the NICU was the mother's first child, length of stay in the NICU or level of NICU. Seven of the fifteen participants reported moderate emotional distress and five participants reported extreme distress while in the NICU. In regards to discharge, twelve of the fifteen participants reported mixed emotions or only distressful emotions at discharge.

Through thematic analysis, three major themes regarding health and wellness during the NICU stay and at discharge were identified. The themes are identified as follows: needs and/or barriers for NICU mothers, supports and helpful interventions for NICU mothers, and the struggle and complexity of fulfilling the role of a NICU mother.

#### *Needs and/or barriers for NICU mothers*

Needs and barriers for NICU mothers	Supported by the categories: <ul style="list-style-type: none"><li>• General emotional distress</li><li>• Seeking connection and sense of control</li><li>• Fear of unknown or lack of knowledge</li><li>• Need for social support</li></ul>
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The theme of needs and/or barriers was supported by the categories/codes of need for social support, seeking connection and sense of control, fear of the unknown or lack of knowledge, and general emotional distress such as guilt, stress, worries, and anxiety. When discussing the need for social support, one mother (participant 12) emphasized, “[It was] the most difficult time of my life, felt like there was little support for parents. To this day I have a very hard time dealing with the emotions of our stay.” To support the need for connection and sense of control, participant 3 reported, “Having a C section and barely being able to move yet still feeling this unwavering desire to be with my baby took quite a toll on my emotionally.” A shared experience of the participants was also fear of the unknown and a general lack of knowledge for what to expect in the NICU environment or at discharge. For example, one mother (participant 11) reported, “As a mother, you are filled with fear, fear you aren’t doing enough. Fear that your body failed your child and fear that it could do so again should you decide to have more children.” Another participant (participant 1) expressed, “[It’s] hard to have the beeping monitors for all the babies and worrying about our baby and the other babies. Hard to know what was happening or what happened next.” Finally, the last key category identified was general emotional distress. Participant 5 exemplifies this category by reporting, “My emotional health was poor during this time. I was working during the [NICU] stay and I’d have to [go to work] after caring for my baby in the morning. I had a toddler at home; I was pulled in many directions. I felt like I was always at war with the hospital, trying to advocate for my daughter’s development. I felt like I was always fighting someone, over the course of a four month stay, that’s a long time to be in conflict.” In regards to discharging home and feeling emotional distress, one mother (participant 11) expressed

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this by stating, “Upon discharge, you are tasked with the duty that was once bestowed upon an entire healthcare team of doctors, nurses, and support staff with high tech equipment and monitors, which leaves you with a vulnerability and anxiety that never really goes away.”

### *Supports and helpful interventions for NICU mothers*

Supports and helpful interventions for NICU mothers	Supported by the categories: <ul style="list-style-type: none"><li>• Prioritizing self</li><li>• Social Supports</li><li>• Allowing time for bonding and connection</li><li>• Help from professional/NICU staff</li></ul>
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While the participants identified barriers to their health and wellness needs during the NICU stay and at discharge, participants were also able to articulate supports and helpful interventions. In the theme of supports and helpful interventions, the following categories were identified: prioritizing self, social supports, allowing time for bonding and connection, help from professional/NICU staff.

One of the key supports the mothers reported was prioritizing self during the NICU stay and at discharge. For example, participant 5 reported, “It does not get easier the longer you’re in there, so you might as well do what you can to care for yourself. Read books for pleasure, knit, shop for the baby. Be available to the baby as much as you can but also be available to yourself.” Additionally, participant 1 stated, “Prioritize yourself as much as the baby. I felt like I had to visit as much as possible and overdid it after a C-section and rough recovery. I needed to be told to stay in my room to take care of myself.”

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Many of the participants were able to identify positive social supports that they found helpful during the NICU stay. In the category of social support, participant 1 discussed, “That there were a community of moms that reached out to me who had been through something similar because we posted about it on social media. Having that outlet was really valuable. So don’t be afraid to talk about it.”

The participants also discussed that allowing time for bonding and connection was helpful for their health and wellness needs. Several mothers (participant 2, participant 10, participant 11, participant 12) reported that being by their baby’s bedside whenever they wanted, being involved in the baby’s care, as well as technology called “NICU cams” that allowed mothers to see their baby on a monitor when not bedside with the baby were all comforting supports that allowed for increased bonding and connection during their NICU stay.

Participants also identified professional help from the staff as a support to their health and wellness needs. For example, participant 1 reported, “We had nurses who helped walk through everything with us on what was happening, what the next steps were, when we would see the doctor. They always had answers to my questions. They helped us be less fearful about all the wires and monitors and sounds.”

### *Struggle and complexity of fulfilling the role of a NICU mother*

Finally, the third theme identified was the participants struggle and complexity of fulfilling the role of a NICU mother. For example, participant 8 reported, “At times I was too much of a medical mom instead of just a mom. I was worried a lot about milestones and overall health.” Another mom (participant 12) said she “somewhat felt like I wasn’t

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her mom yet because I didn't really know her. I finally got to take home my baby and although I was excited, I wasn't sure if I knew how to be a mother.”

### **Creation of the Health and Wellness and Self Care Tool**

The identified themes and categories were integrated to create a health and wellness and self-care tool for future use with NICU mothers (see Appendix B). The tool educates the mother about physical, emotional and spiritual, and social self care needs, how occupational therapy services can assist in meeting these needs, provides resources for the mothers, and most importantly captures the voice and advice of the NICU mothers that participated in the survey. Rather than a clinical and technical approach to self-care needs, this tool incorporates advice directly from the participants in an attempt to capture the voice of NICU mothers who have been through the NICU experience before, which is emphasized in the introduction of the tool. The voices of the participants are utilized to address and provide guidance regarding physical, emotional/spiritual, and social self-care. The tool also allows the mother to identify her own self-care and health and wellness needs, identify social supports, provide an opportunity to ask for more resources regarding areas of key concern, and how the NICU staff can better assist in meeting those needs. The tool's main intention is to be a collaborative resource between the mother and the NICU team and prioritize the mother's health and wellness needs as part of family centered care provided in the NICU. This is achieved through a portion of the tool allows the mother to reflect on her own needs, what supports she would like to seek, and how the NICU team can collaborate with the mother to need the identified needs. Finally, a list of general resources is provided at the end of the tool such as information on post-partum depression and community and charity organizations.

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### **Phase 2 Results, Evaluating the Health and Wellness Self Care Tool.**

To evaluate the tool, in-depth, semi-structured interviews were completed. Two of the original participants (participant 1 and participant 12) were provided with the health and wellness tool and were requested to provide thoughts, feedback and general comments through a semi-structured interview. The participants were interviewed separately. Overall, the participants both reported the health and wellness tool is a resource they would have liked to have been provided with during their NICU stay and that the tool met their health and wellness needs. For constructive feedback, participant 1 emphasized the importance of incorporating direct quotes from the mothers' as a powerful mechanism to emphasize the importance of self-care. Additionally, in the collaborative portion of the tool, participant 1 reported choices for self-care strategies would be helpful, rather than requesting the mothers to think of self-care strategies that have been effective, as the mother may be too overwhelmed originate self-care strategies independently. Participant 12 appreciated the post-partum depression resources listed on the self-care tool, as this is something that may not occur until weeks or months after the NICU stay. Participant 12 also encouraged emphasizing the "graduation" from the NICU as something for the mother to look forward to as a positive coping mechanism.

### **Discussion**

The research questions (What are the emotional experiences of mothers of infants requiring NICU stay? How do these emotional experiences impact mothers' ability to fulfill the role of primary care taker? What are the perceptions of these mothers regarding their own self care needs being addressed/acknowledged during their NICU stay?) were captured by responses to the qualitative survey. The participants discuss their emotional

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experiences in the theme of needs and barriers. For example, participants discussed lack of social support, not prioritizing their own self care needs, and being pulled in too many directions. These emotional experiences impact the participants' role fulfillment as a caretaker as evidenced by participants 8 and 12 expressing their struggles in regards to fulfilling role as primary care takers. There were mixed responses from the participants in regards to the acknowledgement of their self-care needs being met while in the NICU; seven participants report helpful staff that addressed self-care needs, while five participants reported struggling for support during their time in the NICU. Overall, the qualitative data suggest that there appears to be a lack of follow-up and/or plan to address the mothers health and wellness needs, despite a reporting of emotional distress during and following the NICU stay.

Emotional experiences of NICU mothers were identified through the use of the survey and identification of key themes of supports and barriers to self-care needs of NICU mothers. Mothers report the NICU emotional experience as a "rollercoaster" which impacts their ability to prioritize their own self care needs, but also fulfill their role as a mother/primary caretaker. While mothers report supportive and helpful NICU staff, the participants reported that their own self care needs were unmet as evidenced by themes identified including need for social support, seeking connection and sense of control, fear of unknown and lack of knowledge, and general emotional distress.

The results of this capstone and creation of the tool can be used in future occupational therapy practice to address NICU mothers' barriers to participation in meaningful occupation or self care tasks such as maternal stress, depression, anxiety, and low self esteem as reported by Lazarus & Rossouw, (2015). Additionally, the need for



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transition services from the NICU was identified by authors McGown, et al., (2017). The health and wellness tool sets the mother up for success upon discharge from the NICU by addressing self-care needs while in the NICU and arranging for appropriate resources to be put in place to facilitate a positive transition home. Based on the feedback from participant one in the semi-structured interview regarding choice of activities for self care, there is opportunity for occupational therapists to integrate measures such as the Interest Checklist (Klyczek, Bauer-Yox,& Fiedler, 1997) for mothers who may struggle to identify ways to meet self-care needs. In regards to facilitation of maternal role fulfillment, Podvey, (2018) discussed the importance of supporting mothers to changing life roles through the recovery process. Through the use of the health and wellness tool, mothers are able to collaborate with occupational therapists and other NICU staff members in how to establish tangible ways to fulfill the maternal role, while also balancing and prioritizing her own health and wellness/self care needs.

### **Limitations**

This capstone project has limitations that may have impacted results. The qualitative survey was distributed online, therefore the participants needed access to a computer/smart phone and internet, which may have limited participants without this access or those who do not have the skills to utilize such technology. The survey also did not collect geographical information of the participants, and experiences in the NICU could vary based on location. Additionally, while this is not necessarily a limitation, it is a consideration that the data collected in the qualitative survey (phase 1) were written responses. Collection of data orally (via phone call or video conference) may have resulted in different responses. Furthermore, while fifteen participants was sufficient to

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obtaining consistent themes, it may not be sufficiently representative of all NICU mothers. Only two participants (participant 1 and participant 12) were available for follow up focus interviews for evaluation of the tool. Further evaluation of the tool from a greater number of mothers would be beneficial to ensure it is meeting identified needs. However, the two participants did provide in depth, rich evaluations of the health and wellness tool.

Additionally, this survey only explored the experiences of the mothers, but further insight could be provided from fathers, partners, or other family members directly involved in providing care for the child. This could be incorporated into future development of the tool and future practice could integrate the whole family unit into utilizing the health and wellness tool throughout the NICU stay.

### **Recommendations for the Future**

In order to initiate trialing use of the health and wellness tool, it will be presented to NICU teams in order to establish staff buy-in. It is important to establish staff buy-in for future use of the health and wellness tool, as it will take effort from interdisciplinary teams for optimal carryover of the mother's identified needs (through use of the tool) and staff collaboration to meet those needs. While trialing the health and wellness tool, data logs could be recorded of the mother's overall emotional distress level to determine effectiveness of the tool. Additionally, objective data could be collected to evaluate difference in outcomes between mothers who received the tool while in the NICU compared to mothers who do not receive the tool.

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### **Implications to Occupational Therapy**

The results of the qualitative survey and follow up focused interviews show there is opportunity for occupational therapists to incorporate the health and wellness tool into the plan of care for mothers in the NICU and to elevate the future practice of occupational therapists in the NICU in providing quality, holistic family centered care. Furthermore, the capstone shows there is opportunity educate other NICU health professionals regarding the role of occupational therapists in the NICU, specifically occupational therapy's role in addressing health and wellness of mothers, facilitation of role fulfillment as a new mother, and promoting maternal health through engagement in meaningful occupations and self care.

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### Appendix A

#### Survey:

##### Background questions

1. At how many weeks gestation was your baby born?
2. How long was your baby in the NICU?
3. What level of care NICU was your baby in?
4. Was this baby your first child?
5. Was there a neonatal therapist on your care team?
6. Overall, rate your emotional distress during your NICU stay

##### Open Ended Questions

7. What interventions or education did you find the most helpful in your NICU stay?
8. Describe the challenges you faced during your NICU stay. Reflect on your emotional health during this time
9. What things did you find comforting during your NICU stay? Result on your emotional health during your NICU stay.
10. What things do you wish you had been offered during your NICU stay that you did not receive?
11. What advice would you give to mothers with babies in the NICU in regards to managing their own self care and emotional stress?
12. What services (if any) were you set up with at discharge from the NICU (early intervention, follow up, etc)
13. Describe your emotions at time of discharge from the NICU.
14. Describe any challenges you faced when trying to fulfill your role as a mother after discharge from the NICU

### Appendix B (Health and wellness Tool)

# Health, Wellness & Self Care For NICU Mothers

During your stay in the NICU, you may experience stress, anxiety, guilt, general feelings of being overwhelmed, or difficulty adjusting to your new role as a NICU mother. It is important to take time for yourself during this stressful time. This information is collected from mothers who have been through this experience before, and is meant to help guide you through this time and help manage your own health and wellness. By taking care of your own needs, you will enable yourself to be an even better mother to your little one.

## Types of Self Care

### Physical

- Sleep, stretching, walking, healthy food/nutrition, yoga, rest, leisure activities

### Emotional/Spiritual

- Stress management, meditation, time alone, connection, nature, journaling, sacred/safe place

### Social

- Support system, positive social media, communication with loved ones, asking for help

## Occupational Therapy Services:

You may have noticed an Occupational Therapist (OT) is part of your baby's NICU team (if not, that's ok!). The OT's role in the NICU is to provide family centered care and intervention. The OT provides developmentally appropriate care and a positive sensory environment for your little one, as well parent education for how to care for your baby and meet his or her unique developmental needs. While the OT may work directly with your baby, providing family centered care includes *you* as well. OT's help individuals across the lifespan engage in activities they need to do and want to do, including how to help you meet your self care needs and be the best mom you can be.

# Helpful Hints for Health & Wellness from other NICU mothers

## Prioritize yourself and your needs

- ❖ In order to be a good mother, you need to take care of yourself. You can't pour from an empty cup.
- ❖ While you may want to spend every moment in the hospital with your baby, take time for yourself. Being in the hospital 24/7 is too overwhelming. It is ok if you do not make it in to the hospital everyday. Ask your NICU team about NICU cams that allow you to see your baby from home on a video monitor if that helps you feel more at ease when you are away from your baby.
- ❖ Other mothers in the past took time get a massage, get lunch with a friend, go shopping for the baby, or do something that makes them feel relaxed and manage their stress
- ❖ Engage in one of your favorite hobbies or take up a new one. Learn to knit a blanket for you baby, paint, play an instrument
- ❖ Take a few minutes every day to reflect on your feelings and keep your mind healthy. Journal, meditate, call a loved one

## Physical Activity

- ❖ Many mothers find light exercises as a good way to manage their stress. Try morning walks, yoga, or light stretching.
- ❖ \*\*\*Note: Ensure physical activity is approved by your doctor as you may have precautions following your labor/delivery

## Sleep

- ❖ NICU mothers in the past have reported how importance getting sleep and rest was during their NICU stay. Here are some tips to help you sleep
  - Exercise (if your doctor clears you)
  - *Try* to sleep when baby sleeps
  - Set up your bedroom environment for optimal sleep. Do not use screens (TV, smart phones, or tablets), too close to bedtime. Make sure the room is dark and at a comfortable temperature for you
  - Do not do other activities such as watching TV, or reading, while in bed. Associate your bed with sleeping.

A quote from a mother of a NICU graduate...

*"You are a NICU mom, which requires more strength, more courage and more resilience than you will ever know that you were even capable of. Your best is enough. Try not to let guilt consume you. Find someone you love and trust to spend time with your child also, when you can't be there or need to recharge."*



## Seeking Social Support

- ❖ Talk to other parents on the unit. They are going through the same experience as you. You can support one another through this shared experience.
  - ❖ Ask about community support groups for NICU parents.
  - ❖ Utilize positive social media. There are many Facebook and online parenting forums full of other mothers who have been through similar experiences as you. Many mothers have found having a positive outlet valuable to managing their stress and worries.
  - ❖ Don't bottle up your feelings, talk to your family, friends. They are ready to listen and want to help you.
  - ❖ While social support is so important, some mothers find having too many visitors during this time overwhelming. It is also ok to refuse visitors at this time, as it is important for you to take time for yourself. Your loved ones will understand.
- To sum it up... "Don't be afraid to ask for help! We all try to be Wonder Woman, but we need help," – a NICU mother.

## General Advice from other NICU mothers

- Prioritize yourself as much as the baby, you need to take care of you
  - Take a few minutes each day to focus on yourself
- You have to rest. Sleep as much as you can, trust the care providers, ask questions, attend rounds if available
  - Talk to others about how you're feeling, don't bottle it up
- Don't feel like a horrible mother if you can't make it to the NICU everyday to see your baby
- Day by day, minute by minute. Your health is needed to be able to care for a special baby.
- Reach out to other mothers who have had NICU experiences. If you don't know any, ask your NICU team for information on support groups or peer programs.

# My Self Care Needs

This resource is intended to be a collaborative tool between you and the NICU team in meeting your self care and health and wellness needs. Please complete the following and feel free to discuss any questions or concerns with your NICU team.

I enjoy completing my self-care by:

I would like resources on:

New self care techniques I would like to try:

At discharge, I would find it helpful if I were provided with:

My social supports are:

My NICU team can help meet my self-care needs by:

*Please see more resources on the following  
page*

## Resources for NICU mothers

Below are organizations that along with your NICU team that can assist with your transition home. Please ask your NICU team members questions or seek more information if the organizations below do not meet your unique selfcare and health and wellness needs.

- ❖ March Of Dimes
  - <https://www.marchofdimes.org/index.aspx>
- ❖ Information on Post Partum Depression
  - <https://www.nimh.nih.gov/health/publications/post-partum-depression-facts/index.shtml>
- ❖ National Alliance on Mental Illness (NAMI)
  - <https://www.nami.org/Blogs/NAMI-Blog/January-2018/Postpartum-Depression-Ways-to-Cope-and-Heal>
- ❖ Early Intervention
  - <https://www.cdc.gov/ncbddd/actearly/parents/states.html>
- ❖ Helpful (and free!) apps.
  - ❖ Headspace (Mindfulness app, can be helpful for anxiety)
  - ❖ Mindshift (relaxation skills, develop new thinking, suggests healthy activities)
  - ❖ Calm (another medication app)
  - ❖ BellyBio Interactive Breathing (provides biofeedback and monitors your deep breathing, helpful for anxiety and stress)
  - ❖ Positive Activity Jackpot
  - ❖ Take a Break! Guided Meditations
  - ❖ Relax and Sleep well with Glenn Harold (20 minute guided meditation to help you fall asleep)

