A Literature Review Discussing the Value of Early Caregiver Education in the Neonatal Intensive Care Unit.

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I. Introduction

There are approximately half a million premature infants born in the United States each year, affecting one of every ten newborns.[1,2] Among this population of premature infants, about eighty percent require admission into a Neonatal Intensive Care Unit (NICU).[3] The time an infant spends in the NICU varies greatly on numerous factors, but one major factor is the gestational age of the infant at birth,.[3] On average, an infant born at thirty-two weeks gestation stays in the NICU for six weeks.[3] Whereas infants born at twenty-six to twenty-eight weeks gestation, have an average length of stay of about twelve weeks in the NICU.[4]

Even though there have been great advances in technology to improve survival rates of premature infants, emotional and family burdens still remain extremely high.[2,5] In the past, the medical community has under-valued the importance of parent participation in the NICU, and the push for family-centered care (FCC) has only recently accelerated in the United States.[5] In 1993, the Institute for Family-Centered Care was founded, and this style of care was developed and defined in the medical society.[5] One of the founders, Helen Harrison, said "all of us share the belief that parents should be able to participate more fully in caring for and making decisions for their hospitalized newborns." [5] Despite the increasing need for parent participation, hospitals are still slow to adopt FCC as a philosophy of care.[5] Therefore, even though many positive changes have occurred with parent-infant interactions, there is inconsistency in amounts of encouragement from the medical team for parents to participate. This inconsistency can lead to negative outcomes including dissatisfaction with the medical team, parental states of psychological distress, and caregiver insecurity in their abilities to care for their child.[5,6]

In order to ensure a collaborative environment among the family, infant, and medical team, a family-centered care model needs to be implemented in every NICU. To make certain

this occurs, medical professionals should guarantee the family is being educated, making informed decisions, participating with infant care, receiving emotional support, and establishing an adequate transition of care from the NICU to home.[5] In order to implement this demanding task, best-practice recommendations that optimize the outcome of infants and families in the NICU should be established. This review will outline the importance of parent-focused programs and specific evidenced-based interventions to create a family-centered care community.

II. The Neonatal Intensive Care Unit Environment

Infants that are born preterm are at a much higher risk than full term infants to develop neurodevelopmental disabilities, including adverse physical, mental, and behavior problems.[1,2] The NICU presents many challenges and stressors to both the infant and the caregiver.[7] While the NICU environment attempts to control for factors like sound, light, temperature, and infant positioning, it still consists of a plethora of machines, noises, and people, all of which can be stressors to the infant and the caregiver.[7] Along with the physical environment challenges, additional barriers for the family may include limited access to the NICU, transportation barriers, such as access to a car, gas, or driver, financial burden, and family and/or work responsibility.[7] Although many interventions, such as, social work and family support are implemented to reduce the impact of these environmental and social factors, the NICU can be overwhelming and intimidating for caregivers.

III. The Role of a Physical Therapist in the NICU

On a typical day, a hospitalized infant may have upwards of ten different professionals interacting on their medical team.[3] One of the vital professionals on an infant's medical team is the physical therapist. The neonatal specialty requires physical therapists with highly skilled

training in order to meet the complex needs of this population.[8] Along with specialized knowledge in screening, interpreting findings, and creating intervention plans for neonates, a primary role of the therapist is to provide education to other professionals and caregivers.[8] The therapist facilitates proper infant development, while collaborating with the parents to support the need for them to interact with their infant.[9] This type of family-centered care is the gold standard of care in the healthcare field and a fundamental principle in developmental care.[9] Therefore, a mutual understanding between the physical therapist and caregivers is imperative to ensure shared understanding and collaboration.[9] Although many healthcare providers take part in the care of these families and infants, a physical therapist has the unique opportunity to work hands-on with both the infant and caregivers to successfully prepare the family for life in and after the NICU.[1,2]

IV. The Role of the Caregiver of a Premature Infant in the NICU

Caregivers of preterm infants can experience high stress levels and feelings of helplessness when they have infants in the NICU.[1]These caregivers often lack knowledge and confidence in parenting and interacting with their baby, so as a result, have misconceptions about their child.[1,10] Part of these misconceptions come from the physical barriers in the NICU, while others are due to an emotional feeling of separation.[10] Studies have indicated that parents and caregivers of an infant in the NICU are at a greater risk for negative outcomes including depression, anxiety, dysfunctional parenting, and sensitivity to interactions with their infant.[1,10]

In addition, many parents report feeling insecure in their role as a caregiver during their time in the NICU and after the infant is discharged.[1,2,10] Based on the family-centered model of care, parents play a key role in developing and implementing an intervention plan for their baby.[10,11]The caregiver is responsible for the child and should be educated in all areas of their

child's care to ensure informed decisions are made. Ultimately in a family-centered care system, the parents should (i) be encouraged to remain involved in the care of the infant, (ii) choose their level of involvement in decision-making for their child, (iii) be treated with respect, and (iv) have their individual needs addressed and met.[9] One study indicated that autonomy is a key factor in a parent's perception of closeness to their baby.[10] Therefore, facilitating autonomy and reinforcing the parental role is vital for infant and family outcomes.[9,10]

V. Research Supporting Parent Education

Early interventions in the NICU typically target enhancement of the infant's environment to create a positive interactional experience for the child and caregiver.[6] Most of the interventions that involve caregivers are multifactorial and include multiple components.[6] Three main categories of interventions in the NICU have been identified: (i) psychosocial support for the family, (ii) caregiver education, and (iii) developmental support for the child.[6] Many studies have indicated that quality of psychosocial support and caregiver education is what allows for the children to thrive in their developmental support.[6] Therefore, research was reviewed to determine how therapists can address psychosocial factors and caregiver education.

One common intervention studied addresses the psychosocial aspects of the parents or caregivers.[1,6] In a study by Melnyk et al, 260 families with infants in the NICU were randomly assigned to a "Creating Opportunities for Parents Empowerment" (COPE) group and a control group. The COPE program is a four-phase educational-behavioral intervention program.[12] Phase one consisted of information about infant-behavior and the parent's role.[1,12] Phase two provided more information regarding premature infant development and how the parents can stay involved in the child's care. Phase three provided resources for a smooth transition to home.[1] The final phase included activities for parents to perform to develop the infant's cognition.[1] The control

group also got four audiotapes that gave information about hospital services, discharge information, and immunizations.[1]

State-Trait Anxiety Inventory, Beck Depression Inventory, The Parental Stressor Scale-NICU, Parental Beliefs Scale, were some of the outcome measures used to assess the emotional and functional capacity of the caregivers.[1] Length of stay was the primary measure used for the infant outcome.[1] The results of the study indicated that individuals in the COPE program reported significantly less overall parental stress than the control group.[1] The COPE group also had higher parental beliefs about their role in the NICU, had more positive infant interactions, and reported less anxiety and depressive symptoms.[1,12] Also, the mean total length of stay for infants in the COPE group was 3.8 days less than the control group. In conclusion, audio and written interventions that addressed coping and mental health outcomes of parents, significantly improved the health outcome of the parent and infant.[1]

In order to educate patients properly, components of the interventions should be analyzed to determine the underlying effects they have on the outcome of parents and infants.[6] In a systematic review by Benzies et al, the researchers looked at eighteen articles, all using specific interventions to reduce the stress on caregivers to improve the outcome for parents and infants. In this review, it was indicated that all 18 articles reviewed clinically meaning effects for a caregiver's anxiety, depression, and self-efficacy, following particular interventions.[6] These interventions included psychosocial support, parent education, and therapeutic developmental support for the infant.[6] This study also indicated that the key intervention to reduce the parent's anxiety was parental education.[6] It is important to note that parental education alone did not reduce the levels of stress in parents.[6] Instead, a combination of parental support with active involvement education reduced the levels of stress.[6] Lastly, this study also found that active

involvement with the infant improved the parents reported self-efficacy and reduced depressive symptoms.[6] Therefore, it is clear that parental education, through multiple methods, improves many aspects of the parents and infants well-being.

V. Implementing Parental Education in the NICU

NICU physical therapists are in a good position to provide parents with information and resources needed to support their baby.[14,16] As can be seen in research, providing education to these caregivers can improve an infant's developmental skills, reduce time in the NICU, improve the anxiety levels of caregivers, and improve the overall health of the caregiver and infant.[2,14] When deciding what method of education to use, the caregiver's preferences should be taken into account.[13,16] In a study by Dusing et al, the preferred method of education delivery for parents of NICU infants was researched. Three different formats were given to the parents (observation, discussion, and written).[13] Upon completion of the study, parents indicated that a combination of education formats seemed to be the most ideal. In particular, caregivers prefer to observe their child, while simultaneously hearing a therapist describe the expectations for the infant's development. Parents also stated they like additional written materials to take home.[13]

In conclusion, using multiple types of education improved the parent's understanding of motor development and age- appropriate developmental expectations for their infant.[13,16] Furthermore, this increased understanding gives parents more confidence to ask their pediatrician and other health professional questions about their child.[13] Therefore, therapists need to implement parental education with observation, discussion, and written material. Individualizing the education to each parent and infant will allow the parent to feel empowered and become equipped to support their child's needs.[13,16]

Along with multiple educational formats, the timing that this information is provided to the families should be addressed. The quantity of education the parents are receiving in the NICU can be very overwhelming.[13,16] In order to reduce the stress level on parents and promote greater transfer of knowledge, the therapists should slowly introduce their insights to the families.[2] An article by Dusing et al, suggests that therapists send an introductory letter to the family discussing the therapist's role in the NICU. This letter should be followed by parental education during the infant's therapy time, called a bedside program.[2] This incorporation of the parent in the therapy session allows for the parents to observe the therapist and to be engaged in the infants care.[2,14] Parents should also be encouraged to reach out to the therapist on the phone or during in-person meetings to answer questions or concerns.[2] By starting this education early, the parents are able to leave the NICU feeling more confident in their abilities to take care of their baby.[2] Therefore, early interactions with the therapists, and multiple formats for the delivery of education can promote better outcomes in infants and families.[2]

VIII. Conclusion

An expecting parent does not typically imagine the first months of their, and their infant's, life to be in a hospital. This new environment can place great burden on both an infant and their family, causing a lot of psychosocial stress, dysfunctional parenting, and negative outcomes.[1,10] Research makes it clear that in order to optimize the infant's outcome, the caregivers should be encouraged to take a big role in their baby's healthcare. Although interventions vary greatly, and a standard guideline has yet to be established, there are multiple guiding principles to ensure these parents are given every opportunity to learn and interact with their infant.

One guiding principle for therapists to address is psychosocial support for the caregivers. In order to provide this care, every discipline has to understand their role in the outcome of both the caregivers and the infant. Referrals for counseling and cognitive behavioral therapy can be recommended to the caregivers.[17] Also, the introduction of coping skills, relaxation techniques, self-efficacy, and social support can play a role in easing parental distress.[17] The second guiding principle is continuity of care and education for the caregivers. As research show, the best way to educate the parent is to include them in the therapy session.[1,10] The therapy session can be a time to teach parents about their baby's cues and stress signals, improve knowledge of infant development and behavior, and get hands-on interactions with their baby.[17,18] The final guiding principle is to provide developmental support for the infant.[6] This support includes demonstration and education in the NICU, as well as, providing written material and resources as they transition home.[6] The development of an infant does not stop once they leave the hospital, so ensuring the parent and infant have access to information, medical care, and resources is imperative for the infant's development.

In conclusion, although the NICU can be overwhelming, therapists have a large role in ensuring the parents do not get lost or forgotten about. Therapists have the ability to promote a family-centered care system, ensure the parents (i) are encouraged to remain involved in care (ii) can choose their level of involvement, (iii) are treated with respect, and (iv) have their individual needs addressed and met.[9] Providing these for the parents can make all the difference in the outcome of both the caregivers and their infant. With that in mind, every therapist should equip themselves with this knowledge, a plethora of resources, and go into the NICU ready to empower these parents to take care of their wonderful and capable infants.

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