

**PARENT SATISFACTION OF CHOC'S
PALLIATIVE CARE SERVICES IN THE NICU**

A Thesis submitted to the faculty at Stanbridge University in partial fulfillment of the requirements for the degree of Master of Science in Occupational Therapy

by


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Certification of Approval

I certify that I have read Parent Satisfaction of CHOC's Palliative Care Services in the NICU by Ariella Benporat, Megan Hernandez, Gabrielle Thomas, and Morgan Van Ausdal and in my opinion, this work meets the criteria for approving a thesis submitted in partial fulfillment of the requirements for the degree of Master of Science in Occupational Therapy at Stanbridge University.



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Dedication

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Abstract

Within the past 5 years the topic of NICU care and palliation has become prominent in the pediatric occupational therapy profession. However, there is a lack of research specifically related to the improvement in the quality of palliative care for premature and medically fragile infants and their parents who are trying to cope with stressful and unpredictable situations. The presence of various environmental barriers such as infants being in isolettes, healthcare staff, and numerous lifesaving lines hinder a caregiver's participation in parental roles. Therefore, the promotion of parent-infant bonding is of high importance in the NICU. The dynamic between these environmental barriers and caregivers fulfilling meaningful roles in the NICU setting is vital. Due to these interruptions and barriers in bonding, it is essential for developmental therapists, specifically occupational therapists, to encourage and guide parents to engage in various activities and occupations with their infants that they find meaningful.

This thesis delved into why and how occupational therapists play a vital role in promoting and establishing meaningful parental occupations and parent-infant bonding within the NICU setting through numerous therapeutic interventions. The commonality found in the research and upon interviewing seven parents through a phone conducted survey is that the parents value the opportunities the developmental specialist team provides for caregivers to fulfill parental roles, the education they receive from the care team, and being encouraged to bond with their infants. These findings support the need for occupational therapy in the palliative care NICU setting.

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Parent Satisfaction of CHOC's Palliative Care Services in the NICU

In the United States, more than 23,000 infants die each year with 67% of these deaths occurring in Neonatal Intensive Care Units (NICU; Baughcum et al., 2017). Many families who are faced with these challenging times choose palliative care services for their infants. Palliative care in the NICU is a delivery service model that involves providing comfort, relieving pain, and maintaining the quality of life for an infant who is unlikely to recover from disease or other diagnoses. This contrasts with curative care, which focuses on promoting recovery (Winger et al., 2020). A palliative care team primarily consists of physicians, nurses, and other medical staff that can assist in providing for the needs of both the infant and family. However, specific needs that may not fall within the scope of practice of a medical practitioner may require providing additional professional support such as social workers, spiritual care specialists, and developmental therapists.

A team for the Children's Hospital of Orange County (CHOC) NICU Palliative Care Program was established in September 2017 to pilot a cohesive evidence-based program. More specifically, the role of the developmental specialists within the palliative care team—which consists of physical therapists, speech-language pathologists, and occupational therapists—has been to provide positive experiences for infants and their families while in the NICU.

Occupational therapists provide palliative services to nurture bonding between parent and child and to create family opportunities (Winger et al., 2020). Using the Occupational Therapy Practice Framework, it is understood that developing and promoting familial bonding and occupational roles can be crucial in a parent's overall

well-being (American Occupational Therapy Association, 2020). Within the NICU setting, palliative care services delivered by occupational therapists can assist in enhancing feelings of attachment between an infant and their families. Providing palliative care services and breaking down barriers can help to improve overall parental engagement in bonding experiences and occupational roles. Ultimately, fulfilling these occupational and familial roles before and after the passing of one's infant can assist in improving a family's overall satisfaction regarding the palliative services they received.

To improve the quality of care of palliation in the NICU it is necessary to understand the needs and wants of the caregiver. It is also necessary to understand how the healthcare staff can assist and support caregivers during their time receiving palliative care services. While research exists for satisfaction and symptom reduction in the successful utilization of palliative services in adults, there is a lack of sufficient research involving family perspectives of infants in the NICU who received palliative care services (Petteys et al., 2015). Thus, parental and caregiver satisfaction with the services provided is needed to understand the developmental therapists' role in facilitating parent-child bonding, and to improve the care services offered. This study aims to determine the effectiveness of the CHOC NICU's developmental specialist team's treatment strategies in developing parent-bonding moments for families and their infants during end-of-life care. This will be determined by a questionnaire answered by parents whose infants received CHOC NICU palliative care services.

Literature Review

Palliative care is a care delivery model in the management of patients with serious illness, advanced disease, or who have suffered a traumatic injury (Winger et al., 2020).

This specialized care is used in collaboration with health care staff and caregivers to provide patients with the most peaceful, painless, and dignified death. Palliative care is an integral part of providing a treatment plan that optimizes clinical outcomes and improves the quality of life by utilizing accessible healthcare resources. This care delivery model can be especially crucial in the NICU setting, where families may want to maintain the quality of life for an infant with a short life expectancy.

A thorough review of the current literature was conducted to examine the role of occupational therapy in NICU palliative care services. Current literature regarding hospital-based palliative care supports the use of specific clinical guidelines for physicians and nurses to provide the best quality of care for infants and their families in the NICU. These clinical guidelines primarily focus on preventing and treating caregiver burnout, memory-making, and providing patients relief from symptoms and pain associated with their illness (Winger et al., 2020). However, research has yet to address the advantages that occupational therapy services can provide within this setting, particularly within palliative care.

Research by Rubio-Grillo (2019) on occupational therapy within the NICU setting suggests that occupational therapy plays a critical role in the satisfaction and occupational performance of parents and infants. Occupational therapists can promote participation in preferred and meaningful activities for their clients that will improve their quality of life (American Occupational Therapy Association, 2020). Therapists are also able to promote participation in these activities within the client's specific context and environment. For the NICU setting, occupational therapists primarily focus on encouraging social participation for parents and infants and encouraging parents to fulfill their new

occupational roles as mother/father.

To promote social participation and meaningful relationships between families, occupational therapists focus on creating meaningful bonding opportunities. A parental bond grows and adjusts over time, especially as the medical course of the infant changes. Every parent will cope differently with processing exceedingly difficult information surrounding their infant's prognosis. Coping is a process that is flexible, dynamic, and resilient as they adjust to their unexpected parental roles (Abraham et al., 2017).

Developing the opportunities to build bonding relationships can help with coping through memory-making activities, partaking in infant dressing, and creating scent cloths (Petteys et al., 2015). Parents often feel concerned that their infants may be in pain while they are in the NICU. Research has shown that skin-to-skin contact, breastfeeding, rocking, handholding, massage, and reading to their infant can not only alleviate their pain, but also provide avenues for bonding. Mothers are encouraged to partake in these various forms of mother-baby bonding. These experiences are not only beneficial for the infant to reduce pain and promote comfort, but also for the emotional well-being of mothers (Anand & Hall., 2008).

In addition to providing bonding activities for families and their infants, occupational therapists also encourage parents to participate in their role as mother and father regardless of the environment and circumstance. Activities that promote the fulfillment of the parental occupational role include bathing, feeding, holding, soothing, and other comfort care that gives parents a sense of purpose in caring for their infant (Petteys et al., 2015).

Although a substantial amount of current research has outlined the role and utility

of occupational therapy services in the NICU setting, there is an absence of research addressing the need for occupational therapy services in the palliative NICU setting.

Statement of Purpose, Hypothesis, and Research Questions

There is an absence of research and advocacy for occupational therapy services in the palliative NICU setting. The purpose of this study was to measure parent satisfaction regarding their experiences with CHOC's NICU palliative care team's developmental therapists. From these findings, we hope to gain feedback that can help improve the services provided by these palliative team members. The research question examined was: What is the level of satisfaction of parents receiving palliative care services provided by developmental specialists in the NICU at CHOC?

Theoretical Framework

The Model of Human Occupation (MOHO) is a top-down, holistic approach that is applied to many interventions within the scope of occupational therapy (Lee et al., 2008). The MOHO model looks at the individual, occupations that are meaningful to them, and how they are influenced by the environment. Additionally, MOHO is based on an open systems theory, analyzing that an individual is a self-organizing system in constant interaction with their environment (Cole & Tufano, 2020). MOHO posits that individuals interact with their environment through occupations and receive inputs and outputs. An input is when an individual takes part in activities of interest/relevance in their surrounding environment and acts upon them with an output, or also known as occupation. When one interacts with the environment, they receive feedback, or input, which ultimately leads to influenced change. Another part of this model is volition, which is defined as one's motivation, and habituation is defined as one's habits, roles, and

patterns (Cole & Tufano, 2020). These, along with performance patterns, are all key components that make up this occupational model. One vital concept to understand when evaluating MOHO is that all its components are dynamic, meaning when one part of it changes, the entire dynamic has the potential to be altered in either a positive or negative way.

The first aspect of a person's input in MOHO is their volition. Volition is the idea that chosen activities are motivating based on their personal causation, values, and interests (Cole & Tufano, 2020). In the NICU, a parent's volition would be the intrinsic motivator that promotes their desire to engage in parental activities towards their infant such as dressing, bathing, and feeding, despite their infant receiving palliative services. The second important aspect is a person's habituation, which varies among individuals as it is based upon one's culture, spirituality, and career. A NICU caregiver's habituation consists of their expected roles, habits, and routines they identify with as caregivers or parents of their infants.

The last aspect of a person's input, under MOHO, is one's performance capacity. This can be described as an individual's ability to participate in occupations which can be based on one's physical and cognitive abilities, or the physical and social components of their surrounding environment (Cole & Tufano, 2020). In the NICU setting this environment is uncharted for new caregivers, especially with the services that are being provided. Due to this, families and caregivers may be unsure of what activities they are able to engage in with their infants and how they should go about asking to participate in caring for their infant. In the NICU, environmental barriers may include the infant being hooked up to various wires and medical devices, family privacy being limited due to the

presence of medical personnel, an inability to sleep or hold an infant, and the presence of constant noises and lights due to medical machinery. Though these are just a few examples of environmental barriers within the NICU, all of them play a major role in hindering a caregiver's potential in fulfilling their familial roles. These roles that caregivers look forward to participating in may include feeding, dressing, bathing, soothing, and holding their baby. Using MOHO, a caregiver's volition, habituation, and performance capacity in the NICU can be seen as their intense desire or motivation fulfill their new roles as caregivers for their infants (Cole & Tufano, 2020).

Becoming a parent or caregiver is a major life event that is paired with occupational changes in one's roles, routines, and responsibilities (Graham, 2020). Additionally, the ability to engage in meaningful occupations associated with caring for a baby can be impacted when one's infant is in the NICU environment. Using MOHO, occupational therapists in the NICU can better assist with the complex needs of the families' receiving services. This is because the model assists in explaining one's motivation and complex patterns for occupation in relation to the performance capacity required to carry out parental roles (Graham, 2020). This understanding of MOHO can then help to accurately recognize and determine what occupations are important to caregivers so that they can be integrated into intervention plans of the occupational therapists in the NICU environment.

The palliative care services offered in CHOC's NICU provide both life changing care to the infants admitted and comfort and education to caregivers during this life adjustment. Developmental therapists encourage parents to continue their roles as caregivers despite the setting, as by continuing to engage in these roles leads to better

health and developmental outcomes for the infant. The palliative care team provides services that support parent-baby bonding to promote caregiver engagement in meaningful occupations to ultimately foster the caregiver's role as a parent. Through MOHO, occupational therapists in the NICU can evaluate the specific environment to better understand one's volition, habituation, and performance capacity within their surrounding environment (Bigsby, 2020). By doing so an occupational therapist can provide more client focused care for both parents and infant in the NICU setting.

Methodology

Design

This study utilized a cross-sectional study design to collect information on parent satisfaction of the developmental therapy services they received from CHOC's NICU palliative care team (Setia, 2016). The purpose of using this study design was to obtain information about this population during a period in which the palliative care team had been established for a significant period. The study gathered data on parent satisfaction during May 2021 for developmental services received from September 2017 to November 2020 at CHOC's NICU. The descriptive study nature of this cross-sectional study design was utilized to gather quantitative data without manipulating any variables that would influence the results of this study.

Setting

The study took place through a children's pediatric acute care hospital, CHOC, that includes a Level IV NICU located in Orange, CA. This Level IV NICU provides a palliative care team for premature or medically compromised infants.

Institutional Review Board

The Stanbridge University Institutional Review Board #MSOT10-09 and CHOC's IRB #210219 provided research study approval prior to initiation of the study. The lead neonatologist of CHOC's NICU palliative care team also provided support and approval on behalf of the palliative care team. We completed CHOC's HIPAA and cornerstone and credential training for student preceptorship.

Sample

This study consisted of a retrospective review of the intake book in CHOC's NICU by the primary investigator to determine all infants who had passed between September of 2017 through November of 2020. An exempt consent was utilized for retrieving intake book data due to the previous consent from parents and family members of each patient during their time of accepting NICU palliative services during the time of stay. Out of the 70 infants who had passed in this time frame, 41 patients met the initial inclusion criteria and were included in the initial participant list.

Inclusion Criteria

Inclusion criteria for participation in the research study consisted of any individual whose infant received CHOC Palliative Care services from September 2017 to November 2020. This time frame ensured six months between the death of a potential participant's infant and the research survey. Additionally, the infants had to have been admitted into the NICU for 8 days or more. The NICU Palliative Care Team was established in September 2017 and data collection began in April 2021.

Exclusion Criteria

Participants were excluded from the study if the infant had passed away outside of September 2017 to November 2020 window or was still receiving palliative services in the hospital. Additional exclusion criteria consisted of individuals whose infants were discharged from palliative care on home health or hospice, or if they were admitted to the NICU for less than 8 days. However, if the study is performed again, those who have lost their infants more recently will be asked for the same parental satisfaction survey regarding the developmental services they received. Due to the lack of a Spanish Interpreters, only parents who were able to speak and read in English were included in the study.

Sampling Methods

After completing CHOC's HIPAA and intern protocol training, we were granted access to CHOC's Citrix drive. The drive provided patient and developmental service information. From this document, we were able to identify specific patients who had received development therapy services. Out of the 44 infants that received NICU services within the study's qualification period, a subsequent list of 19 patients was identified as receiving developmental services and had directly interacted with developmental therapists. Several of these patients had more than one parental contact. Seven total participants completed the study survey either via telephone or via email. Four of the seven participants were co-parents of the same patient but completed separate surveys.

Study Procedure

CHOC's principal investigator, who is also a research advisor at Stanbridge

University, placed a phone call to parents of infants who met inclusion criteria to ask if they were interested in participating in the research study. If participants agreed to engage in the research, they had the option to complete the survey via telephone or email through CHOC's REDCap Software Program. If participants chose to complete the survey via email, email addresses were collected, and surveys were sent out to each participant. If participants chose to complete the survey via telephone, the principal investigator conducted the survey over the phone with each participant, also through CHOC's REDCap Software Program. During each telephone survey conducted, Stanbridge University students had the option to attend and collect survey responses while remaining on mute. Therefore, the students were able to listen to conversations between study participants and the principal investigator for learning purposes, but not interact with the participants. Participant consent of the student's participation was requested before the students were allowed access to the conversation.

Data Collection

Outcomes of this study included basic demographic information, and the caregiver's overall experience/satisfaction of the services they received when their baby was receiving CHOC NICU's palliative care services. The data instruments used to achieve these outcomes included a questionnaire offered through CHOC's REDCap Software Program. The questionnaire consisted of Likert-scale based responses to statements regarding topics such as comfort, privacy, and activities completed with the therapists. This is the only source that was used in the assessment portion of the study that required consent or training.

Results

To examine patterns within the study's 19 Likert-scale questions a chi-square goodness of fit test was employed. We found a statistically significant relationship within these questions ($\chi^2 [5, N = 132] = 176.55, p < .001$).

Demographics

The study's survey was filled out mostly by mothers ($n = 5; 71\%$) compared to fathers ($n = 2; 29\%$). The most common age group of those who filled out the study's survey was 31–40 years of age ($n = 5; 72\%$). The most common ethnicity of those who filled out the study's survey was White ($n = 3; 43\%$). The most common age of infants admitted to the NICU was 32–33 weeks ($n = 5; 72\%$). The most common length of stay for infants admitted in the NICU was 91 days ($n = 3; 43\%$). Most infants in this study have one sibling ($n = 3; 43\%$). For all study participants, this was their first time in the NICU ($n = 7; 100\%$). Lastly, most participants selected “strongly agree” regarding the statement that the NICU “Provided me written material on the services provided by developmental therapists” ($n = 4; 57\%$; see Table A1).

Parent Responses

Questions 10 through 27 on the study questionnaire included Likert-Scale based responses. Each question was categorized into four categories. These categories include environment, family-oriented care, activities of daily living (ADLs), and positive touch.

Environment

As shown in Figure A1, this section included questions 11, 12, and 27 on the study questionnaire regarding environment. Strongly agree and agree accounted for 95%

of total parental responses, and 95% of these study participants strongly agreed or agreed that CHOC NICU's developmental care team provided factors to facilitate a supportive environment.

Family-Oriented Care

This section included questions 14, 23, 24, 25, and 26 on the study questionnaire regarding family-oriented care. Strongly agree and agree made up for 74% of all parent responses. In other words, 74% of study participants strongly agreed or agreed that CHOC NICU's developmental care team provided factors to facilitate overall family-oriented care (see Figure A2).

ADLs

This section included questions 15 and 16 on the study questionnaire regarding ADLs. 50% of parents strongly agreed or agreed that CHOC NICU's developmental care team provided services to parents that allowed them to engage in meaningful ADLs (see Figure A3).

Positive Touch

This section included questions 17 through 20 on the study questionnaire regarding positive touch. Strongly agree and agree represented 78% of all parental responses. Essentially, 78% of study participants strongly agreed or agreed that CHOC NICU's developmental care team provided factors to facilitate bonding and experiences of positive touch (see Figure A4).

Discussion

Overall Satisfaction

Upon reviewing participant results recorded from the study questionnaire,

overall satisfaction was found from most parents regarding the palliative care services they received. Of the 19 Likert Scale questions included in the study questionnaire, 100% showed “strongly agree” as the most chosen answer following the review of participant results. This indicates the seven parents who participated in this study were highly satisfied with palliative care services provided by CHOC NICU. These overall results of high satisfaction found from this study indicate the positive impact that OT services provided through Palliative Care in the NICU can have on families going through this process. Additionally, these results place an emphasis on the value of promoting parent-infant bonding techniques within the NICU. Results that evidenced high satisfaction were organized into categories that describe the themes intended for each question of the survey.

The category of environment includes questions 11, 12, and 27. In general, the environment facilitated by the development therapists within CHOC's NICU provided families with a relaxing domain where caregivers were able to bond with their infants. The developmental care therapists were able to provide a relaxing and calming environment by manipulating the physical environment and providing family-centered care to the families of infants. Examples to facilitate this environment may have included dimming the lights within the environment, playing soft music, or presenting families with bonding opportunities. These findings support the use of these positive environmental impacts provided by the developmental care team, as our participants report that these environmental adaptations played a major role in their overall NICU experience.

Family-oriented care was another aspect where families reported high satisfaction. The category of family-oriented care includes questions 14, 23, 24, 25, and 26. The family-oriented care within CHOC's NICU was provided by the developmental care team by encouraging caregivers to participate in caring for their infants. Additionally, developmental therapists addressed infant pain and suffering in an effective manner, resulting in a positive impact on caregivers. Developmental therapists also made sure to devote adequate time to infants and their families to fulfill familial needs within the NICU. Providing privacy was also a key factor in facilitating overall family-oriented care. All these family-oriented care strategies provided by developmental therapists resulted in the family's overall trust in NICU clinicians.

The category of ADLs was asked about in questions 15 and 16. The results of this category suggest that at least 50% of the parents were not satisfied with or did not participate in activities of daily living with the therapists. Participating in swaddling, bathing, and dressing their infants are important activities that parents can engage in to fulfill their occupational role as parents. Life-saving equipment such as ventilators and gastrostomy tubes on infants make participating in these activities difficult and seemingly overwhelming for parents. Therefore, it may be beneficial for CHOC's NICU palliative team therapists to focus on creating opportunities for these activities with families.

The category of positive touch was asked about in questions 17, 18, 19, and 20. The results from these questions indicate that parents participated in opportunities to provide gentle and relaxing tactile stimulation to their infants through touch. This,

in turn, benefits both the parents and the infants by creating bonding opportunities and reducing pain/discomfort in the NICU. These positive touch opportunities included activities such as infant massage and hand holding. These are also activities that can be difficult for parents due to life-saving equipment and infant fragility. However, occupational therapists can provide education and support parents to partake in positive touch.

Offer of Developmental Services

Of the 44 infants who received NICU services within the study's qualification period, only 19 of these infants received developmental services. There were a variety of reasons as to why these infants did not receive developmental services, such as not meeting certain qualifications. Qualifications to receive developmental services were influenced by the following: infant fragility, reduced length of stay in CHOC's NICU, and delay of offered services. Due to results from this study showing overall satisfaction from parents, we believe that all infants and their families, no matter the infant's medical status, could benefit from some form of developmental services. Additionally, it could be advantageous to widen the eligibility criteria for those infants that qualify for developmental services to maximize the benefits received from such services when an infant is in the NICU.

Limitations

Though there was no monetary cost for participants to partake in the study, if participants chose to receive a questionnaire via email, an email account and online access was required. Bereaved parents are considered a vulnerable population. To support any difficult memories this survey could potentially bring up, the support of CHOC's

Chaplain, Rob Rexroat, and CHOC's social worker, Karina Ousley, were offered to all surveyed parents.

Another limitation of the study was the inability to have translators. The survey was only able to be conducted in English, and if English was not their primary language, parents were unable to participate in this study. Due to the lack of translators, we were unable to interview 3 families, which could have yielded 6 more surveys if both parents were willing to participate. Another possible limitation of the study is that the questionnaire results yielded high satisfaction results from the services they received in the NICU. A limitation would be that those who had negative experiences were less inclined to answer due to reliving trauma and or fear of being contacted over their critical responses. Compensation was provided to participants in the form of a gift card for \$10, funded by CHOC's Division of Neonatology/PSF.

Due to hospital guidelines, standing orders for rehabilitation services is one-week post-admission date to CHOC's NICU. In this window of time, infants may pass or be deemed by medical personnel as too ill or fragile to receive palliative services. Additionally, after reviewing CHOC's NICU data, some infants who had passed in the NICU did meet the 7-day admission requirement, yet still did not ever receive palliative care services for unknown reasons. The survey was also conducted in a single facility, which therefore narrowed the number of potential study participants.

Ethical and Legal Considerations

Verbal consent was requested so that students could listen to the survey being administered over the phone. If parents disagreed, students were disconnected from the phone conversation, and the interview was conducted with only the principal investigator

on the line. If parents agreed to participate the survey continued with the students listening on another line. When consent was given for us to listen to the call, we were able to note longer answers that were given to survey questions that only had multiple-choice options. These notes were taken outside of the designated survey answers to gain more insight into each parent's individual experience to then aid in reporting satisfaction back to the developmental therapists.

Parents were asked to participate in the research survey and whether they consented to the survey over the phone or opted out. Risk to participants included potentially traumatic thoughts and feelings related to the survey questions. Survey questions may bring up memories of each participant's difficult time in the NICU. The potential risk was minimized by offering contact information to CHOC's chaplain who agreed to accept these phone calls. The only known risk is related to psychosocial issues or resurfacing emotions from past trauma. However, if they chose to explore non-religious options, they were provided contact information from the social worker with the palliative care team.

All known benefits of the study pertain to assisting CHOC NICU staff to provide more standardized and effective care for future families receiving palliative care services. Additionally, results obtained from the study will assist CHOC NICU in improving care for future families in hopes of better comforting them during this difficult time. Parents who participated in the survey were offered \$10 e-gift cards for the completion of the survey. Otherwise, there was no direct benefit for the participating parents. However, the knowledge gained on the satisfaction of the treatments, provided by developmental therapists as part of end-of-life care, will improve the quality and care provided by

CHOC's developmental specialists to NICU families in the future.

There was minimal risk related to breach of confidentiality. Potential risk was minimized with the use of REDCap to remove all identifiable information, and we secured and protected data from improper use or disclosure. Data was stored within encrypted, password-protected files that were managed through REDCap at CHOC. Only study investigators and permitted study personnel had access to CHOC data during and after the research. Only de-identified data was shared and stored outside of CHOC's server.

We were required to complete CHOC HIPAA compliance training before implementing the study. We had no access to the participants' medical records. The participants completed the study's questionnaire via REDCap housed on CHOC's shared drive. REDCap is a password-protected web application used for research by CHOC. REDCap follows HIPAA guidelines. The participants were assigned an identification number to protect identifying information from the researchers after being contacted via phone call and prior to completing the survey. Only the student researchers, the research advisor, the CHOC palliative NICU team, and the statistician had access to the data collected from the questionnaire results. The statistician, a non-CHOC affiliate, did not have any access to any information containing patient identifiers.

Future Implication for Occupational Therapy

The purpose of this study was to analyze the services provided to families during their infant's stay in CHOC's NICU and to assess if caregivers found these services beneficial. From these findings, we hoped to gain feedback for areas of improvement for

the palliative team to improve their care model and the experience for future families and infants receiving services.

After surveying the participants who met the inclusion criteria, we found participant responses to be overwhelmingly positive. This led to the overall conclusion that participants were satisfied with the care and services that their infants had received. Due to most of the caregiver feedback being positive, the original hypothesis was wrong, prior to the study being completed, and was altered. Because three out of the four categories of findings regarding the palliative services provided did not highlight the need for any major improvements, promotion and continuation of these services can be beneficial. Additionally, continuing these services, while raising awareness of the benefits that these services provide, is encouraged not just in CHOC's NICU, but in other facilities as well. Due to the limited research regarding the benefits of palliative services on infants and their families, the hope of this study is to pioneer research and to promote the founding of similar teams in other facilities. This is because these services are shown to improve familial bonding and memory-making between terminally ill infants and their families. Additionally, we also identified areas in which the qualification criteria for infants who are eligible for developmental services could be expanded to the small baby units or to other infants who would benefit from developmental care.

Occupational therapists possess the unique role of bridging the gap between therapeutic interventions and nurturing bonding between caregivers and their infants to create meaningful and fulfilling memories. These highly specialized occupational therapists work to encourage parents to interact with their infant and educate them on

bonding opportunities. By providing this supportive environment, these therapists break down the barriers of fear and promote overall engagement in meaningful occupations.

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Appendix A

Tables and Figures

Table A1

Written Materials Provided by NICU Staff About Development Therapists

Table 1. Likert scale	O	E	%	χ^2	df	p
strongly disagree	3	22	2.27	176.55	5	<.001
disagree	12	22	9.09			
neutral	9	22	6.82			
agree	24	22	18.18			
strongly agree	77	22	58.33			
n/a	7	22	5.30			

Note. O=observed count. E=expected count. df=degrees of freedom. p=p-value.

Figure A1

Environment

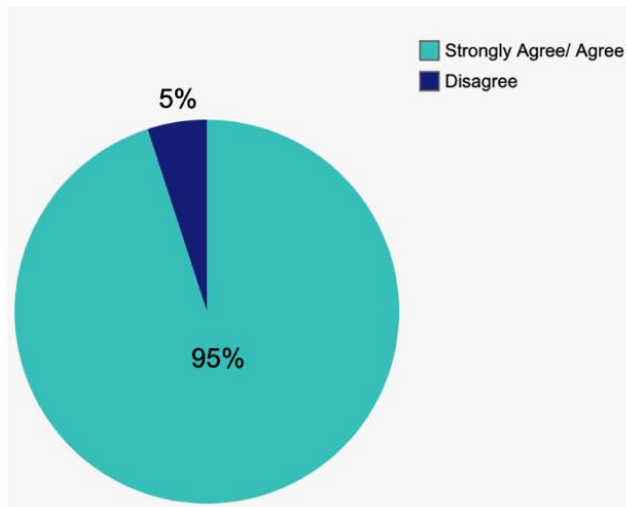


Figure A2

Family Oriented Care

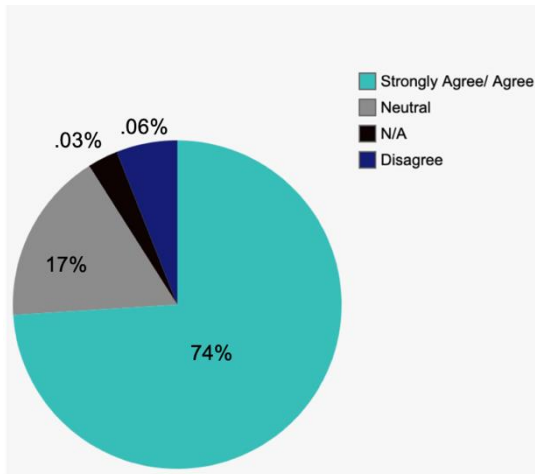


Figure A3

ADLs

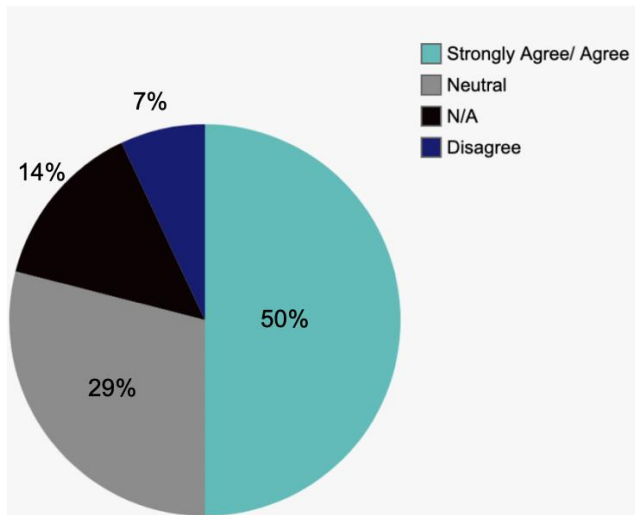
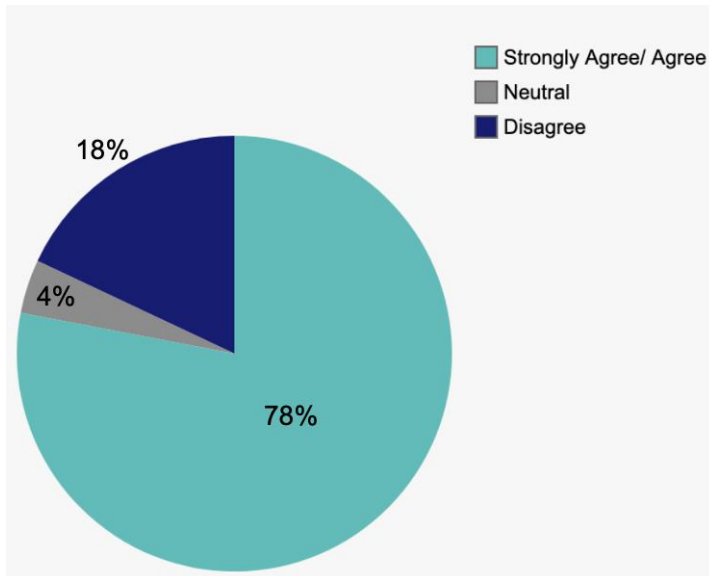


Figure A4

Positive Touch



Appendix B

Institutional Review Board Approval

04/26/2021

Re: IRB Application Number MSOT10-09

Dear Ms. Vu and Research Team,

The Stanbridge University Institutional Review Board has completed a review of your application entitled, "Palliative Care in the NICU." Your research protocol MSOT10-09 is fully approved and categorized as exempt.

Should you wish to make modifications to this approved protocol, please submit a modification form for IRB review and approval. No changes may take place without IRB approval.

Sincerely,

Dominique N. Wascher, Ph.D.

IRB Chair

Appendix C

Survey

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Page 1

NICU Palliative Care Form Update

CHOC Children's is committed to providing our patients and families with the support and resources needed during their care. This survey will take about 10 minutes to complete. Participation in this survey is optional, voluntary, and you may stop at anytime. The survey is intended to collect information about the quality and satisfaction of services that were offered during your child's care in the NICU at CHOC. The survey is anonymous and your responses will be kept confidential. The results of the survey will be used to understand how CHOC can better partner with families to provide the support and resources they need during their care.

We understand that your time at CHOC was difficult and this survey may bring back some painful memories. If you would like to talk, we are here for you. Please call CHOC's chaplain, Rob Rexroat at 714-509-4381 x19336 or email at rob.rexroat@choc.org.

If you agree to participation, please complete the survey below. If you have any trouble completing the survey or a question is confusing, feel free to call Vicky Vu at 714-309-5926 or email at vvu@choc.org.

Thank you for your time.

Please complete the survey below

Today's Date _____

Who is answering this questionnaire?
 Mom
 Dad
 Caregiver

What is age of person responding?
 20-30
 31-40
 41-50
 51-60
 (Years)

Please specify your ethnicity:
 White
 Hispanic or Latino
 Black or African American
 Native American or American Indian
 Asian/Pacific Islander
 Other

Other ethnicity _____

How old was your baby when admitted to the NICU?
 23-28
 29-31
 32-33
 34-36
 37+
 (Listed in Weeks)

What month/year was your baby admitted?
 September 2017- August 2018
 September 2018-November 2020

How long was your baby admitted in the NICU?
 Less than 14
 15-30,
 61-90,
 91+
 (Listed in days)

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Page 2

How many siblings does your baby have?

- None
- 1
- 2
- 3 or more

Was this your first time in the NICU?

- This was my first time in the NICU
- I have been in the NICU before

Confidential

Page 3

My developmental therapist:						
	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree	N/A
Provided me written material on the services provided by developmental therapists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provided me a verbal explanation of the services provided by developmental therapists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provided my baby with a relaxing environment (dim lights, quiet, soft music).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Created an environment that facilitated bonding between my baby and I	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Welcomed my baby's siblings.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Encouraged me to participate in caring for my baby.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Supported me to swaddle bathe my baby.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Supported me to dress by baby.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provided me with helpful infant massage education.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree	N/A
Helped me utilize scent cloths and lovey dolls	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provided me with touching opportunities such as holding hands	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provided me with opportunities to hold my baby	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Listened to my stories	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provided me with memory making opportunities with my baby (such as hand and foot print molds)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Addressed my baby's pain/suffering in an effective way.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Devoted adequate time to my family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Page 4

Provided my family with enough privacy when my baby was passing.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Was a clinician I trusted	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Made a positive impact on my family's overall experience at the NICU	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I would have liked to:

- Have less distractions during one on one time with my baby
- Learn massage techniques sooner
- Have more opportunities to hold my baby despite medical barriers
- Have more legacy building opportunities

What is one way that you/your family personally honored your baby after passing?

Would you be interested in learning ways your feedback could improve the patient and family experience for future NICU families?

If yes, please provide your contact information

If you prefer to leave this survey anonymous but are interested in learning more, please contact: Diana Hurtado at dhurtado@choc.org.
