**Final Project:**

**Creation of a NICU Palliative Care Team at Emory Midtown**

**Background**

Over the previous decade, advances in technology have resulted in an overall decline in neonatal mortality. Despite this, in 2013, nearly 16,ooo neonatal deaths occurred in the United States (Matthews, MacDorman, & Thoma, 2015), and virtually all of those deaths occurred within a neonatal intensive care unit (NICU) setting (Wright, Prasun, & Hilgenberg, 2011). The NICU is a specialized inpatient unit that provides complex medical care for critically ill infants. For infants facing life-limiting conditions within the NICU, palliative care may be considered as a treatment methodology. Palliative care is often described as a clinical approach that improves the quality of life of patients and their families who are facing life-threatening conditions (WHO, 2015). Six key roles for palliative care in the NICU include pain management, prenatal palliative care consultation, end-of-life (EOL) care, discharge to hospice, communication and conflict resolution, and collaboration in the care of medically complex infants (Bidegain, & Younge, 2015). Historically, palliative care was offered when curative methods failed, however, contemporary models support the use of palliative interventions concurrently with curative efforts (Bidegain & Younge). Since palliative care in the NICU setting is often a novel service, challenges to integrating palliative care into routine NICU services exist. Barriers may include attitudes and beliefs of healthcare providers, lack of palliative care and bereavement education and training, physical environment, technology, and parental demands (Lisle-Porter & Podruchny, 2009; Wright, et al., 2011). Strategies for improving neonatal palliative care practices, therefore, must be interdisciplinary, requiring working relationships and collaboration at all levels.

**Context**

The Emory University Midtown Special Care Nursery is a 40-bed, level IV nursery in metropolitan Atlanta that treats approximately 300 neonates annually. Infants who are admitted for medical management include those with congenital defects, genetic abnormalities, extreme prematurity, or birth trauma. A multifaceted team consisting of neonatologists, nurse practitioners, clinical nurses, respiratory therapists, pharmacists, and social workers attend to the demographically and socioeconomically diverse patient population.

**Practice Issue**

Despite endorsements from the American Academy of Pediatrics, Institute of Medicine, and National Association of Neonatal Nurses, among others, national standards for neonatal palliative care do not exist and clinical practice continues to be inconsistent (Wright et al., 2011). In order to institute a successful palliative care program, a formal, interdisciplinary, palliative care team should be in place to plan and shape new protocols and guidelines while training additional staff (Catlin & Carter, 2002; Gale & Brooks, 2006).

**Problem Statement**

At present, the NICU at Emory University Hospital Midtown has no established palliative care team. Infants with life-limiting conditions are managed on a case-by-case basis and formal palliative care consultations are rarely made. The use of palliative care teams has been associated with infants receiving fewer unnecessary medical procedures, increases in support available for families, increases in redirection to comfort care, and increases in use of palliative medication (Pierucci, Kirby, & Leuthner, 2001; Samsel, & Lechner, 2015; Bidegain, & Younge, 2015).

**Drivers**

Overall, barriers to providing palliative care may stem from inadequate symptom management, lack of continuity, and unclear prognosis as well as provider deficiencies in education and insufficient communication skills (Pizzo, Walker, & Bomba, 2014; Moro, Kavanaugh, Okuno-Jones, VanKleef, 2006). When applying the CDCs Social-Economic Model to palliative care in the Emory Midtown NICU (Appendix A), individual factors affecting palliative care incorporate the characteristics of individual team members including experience, attitude, and behavior. Nursing experience, both within the NICU and directly with palliative care, has been show to influence the provision of palliative interventions (Engler, et al., 2004; Kain, 2006). While physicians struggle with uncertainties of each situation and an inability to predict patient outcomes, nurses often struggle with perceptions of infant suffering (Davies, et al., 2008; Martin, 2013). Moral distress and internal conflict can result from either situation and influence how palliative care is approached and delivered.

Interpersonal factors to consider when addressing palliative care include interdisciplinary communication as well as communication between healthcare members and patient families. Historically, the fields of nursing and medicine have approached patient care differently. Nursing teaches holistic treatment of the patient and, while evolving, medicine focuses on diagnostic skills and curative efforts (Martin, 2013). Interpersonal relationships in the NICU may therefore be challenged by fundamental differences among these and other interdisciplinary healthcare members (Martin, 2013). Additionally, breakdowns in inter-professional communication may further lead to moral distress (Martin, 2013). Interpersonal relationships with patient families are built on communication. In the NICU, research has shown that families feel there is inadequate communication with the health care team regarding prognosis and unclear delineation of care choices. (Henner & Boss, 2017). Families in one study identified six priorities for pediatric palliative care, two of which focus on healthcare team interaction and team building; honest and complete information, communication, and care coordination (Meyer, Ritholz, Burns, & Truog, 2006). Moreover, cultural differences and language barriers may further confound interpersonal relationships with families (Davies, et al., 2008). Interpersonal relationships, both interdisciplinary and between families, influence neonatal palliative care.

Within the NICU community, lack of a palliative care team, lack of staff grief support, lack of protocols guiding palliative care, and limited education and training in palliative care and bereavement further influence palliative care. The organizational aspects impacting palliative care may include current clinical practices and degree of support from upper levels of management in the unit as well as NICU representation on the hospital-wide Emory Palliative Care Team. Drivers influencing standardized neonatal palliative care (Appendix B) primarily include access to resources and personal beliefs and behavior. Access to resources includes the knowledge and awareness of available resources such as protocols. Personal beliefs and behaviors include perceptions of palliative care, comfort in providing palliative care, self-awareness, and moral standing.

**Stakeholders**

A number of stakeholders, each with varied interest and influence, will be necessary in order to build an Infant Palliative Care Team (InPaCT) for the Emory NICU. For this project, infants and their families represent the primary stakeholders. Additional primary stakeholders are interdisciplinary and consist of physicians, nurse practitioners, clinical nurses, and other healthcare members. Secondary stakeholders include additional healthcare affiliates such as social workers, clergy, and lactation consultants. Furthermore, secondary stakeholders could include physician and practitioner supervisors, NICU nurse managers, unit educators, and those with experience in palliative care, such as the Emory Palliative Care Team as well as the Children’s Healthcare of Atlanta (CHOA) Pediatric Palliative Care Team. Key stakeholders in the NICU (Appendix C) have been identified as the nurse practitioner supervisor, the medical director for the NICU, and a satellite sponsor with significant experience in perinatal and neonatal palliative care.

Infants and their families, along with clinicians and nurses, are primary stakeholders classified as promoters, those with substantial interest and influence. Secondary stakeholders such as the nurse practitioner manager and unit medical director are described as latent members, having large influence with little immediate interest. An expert in perinatal and neonatal palliative care, the satellite sponsor is described as a defender; while interested in the project there is little influence to facilitate change.

**Transformation Team**

Using Belbin’s (1981) defined team roles, the members for this project are presented below (Table 1). The team implementers turn the team's ideas and thoughts into tangible plans. Applying this to the DNP project, the team implementers will act to generate interest and motivate the team toward change. According to Belbin (1981), the shaper role is performed by people who are dynamic and relish challenges. The supervising physicians identified for inclusion in this project will act to push ideas forward and support changes in the unit. Workers with expert knowledge in a particular area comprise the specialist role. This team includes three specialist, two on-sight members with expertise in palliative care, and one satellite member with extensive experience in neonatal palliative care specifically. As the team lead and coordinator, I will act to guide the activities of the team toward the team's goal of establishing NICU based palliative care guidelines.

The team roles, as defined by Belbin (1981), are as follows;

Table 1:

InPaCT Participants and Roles

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Name | Credentials | Team Role | Clinical Role | Affiliation |
| Sonya McLaughlin | MSN, NNP-BC | Project Lead | Nurse Practitioner | Emory University |
| David Carlton\* | MD | Shaper | Medical Director | EUHM NICU |
| Tracy Martin\* | RNC, CN IV | Shaper | Pain Champion | EUHM NICU |
| Karen Kavanaugh\* | DNP, NP-C | Specialist (Satellite) | Palliative Care NP | Wayne State Univ |
| Stephanie Norman | DNP, NNP-BC | Implementer | Nurse Practitioner | Emory University |
| William Sexson | MD | Implementer | Attending Physician | EUHM NICU |
| Kim Cooley | MSN, NNP-BC, CNS | Shaper | Unit Educator | EUHM NICU |
| Karen Wilks | MA, CPNP, RNC | Shaper | Nursing Director | EUHM NICU |
| Mi-Kyung Song | PhD, RN | Specialist (Local) | Director, Center for Nursing Excellence in Palliative Care | Emory University |
| Erin Mullaney | MSN, RN | Specialist (Local) | Pediatric Palliative Care NP | CHOA |

**\*key stakeholder**

**Project Partners**

According to Taylor-Ide & Taylor (2002), change must be facilitated from the top-down, bottom-up, and from the outside-in to ensure sustainability. In order to construct a NICU-based palliative care protocol, input from the top-down would encompass the thoughts and opinions of the Neonatology Medical Director within Emory Midtown Hospital as well as representation from the neonatal nurse practitioner group. Engaging these physicians and advanced practitioners would ensure involvement from the viewpoint of the provider and patient care management. The most intimate forms of patient care are provided by clinical nurses. At the bedside, physicians, nurse practitioners, clinical nurses are educated to implement interventions first-hand. This close contact provides invaluable information regarding the successes and challenges of policy and protocol execution. Incorporation of this information from the bottom-up would be achieved through the nurse manager and the clinical nurse education. Due to the fact that there has been limited research into neonatal palliative care and bereavement there is a need to incorporate the successes of others. For this project, experts in neonatal palliative care and representatives from pediatric palliative care teams would serve as outside-in contributors. A key stakeholder in this project, Dr. Kavanaugh, has extensive experience within the field of pediatric palliative care, specifically in the neonatal population. She has published numerous works speaking to the need for neonatal palliative care, provider perceptions or palliative care, and barriers to delivering community support for bereaved families. As noted by Taylor-Ide & Taylor, 2002), the primary role of experts in the three-way partnership is to provide knowledge and skill and “these commodities can then empower the process of change” (p. 242).

**Recruitment**

The primary objective for InPaCT is to construct evidence based guidelines for the NICU. Potentially better practices (PBPs) are interventions that have been shown (or are believed) to improve outcomes in one location, such as an inpatient unit (Hobar, et al., 2001). These interventions can then be selected, modified, and applied to different environments depending on each unique situation (Hobar, et al., 2001). Widely used in the NICU to address issues such as kangaroo care, accidental extubation, pain management, and central line associated blood stream infections (CLABSIs), PBPs are a well-established method by which quality improvement frequently occurs in the NICU (Brown, Ohlinger, Rusk, Delmore, & Ittmann, 2003). A primary task of InPaCT will be to generate PBPs as a basis for protocol construction. The construction of PBPs requires input from all parties and communication among stakeholders is integral to the team’s success, however communication efforts must consider their varied interests. Communication and recruitment for InPaCT will occur at various impact levels and will target different key stakeholders (Center for Community Health and Development (CCHD), 2017).

In order to recruit bottom-up stakeholder Tracy Martin, initial contact will be made via email. A brief summary of the team goals will be offered and an invitation will be made to further discuss potential involvement with the team in person. As a palliative care champion and a classified promoter, Ms. Martin may offer unique and powerful insights during the formation of a palliative care guideline. During an informal meeting, perhaps over coffee, information regarding palliative care, InPaCT objectives, and potential team role would be discussed. Ms. Martin’s passion for neonatal pain management speaks to potential personal motivations to participate with InPaCT. Additionally, recognition in the NICU as a palliative care champion, as well as potential for further career growth, may aid in maintaining interest.

Gaining support from the top-down may present challenges as the medical director is classified as a latent participant. With a great deal of influence to enact change, efforts will be made foremost, to increase interest level. A NICU palliative care ‘persuasion packet’ consisting of an executive summary and short persuasive video, will be sent to Dr. Carlton by email with a request for an in-person meeting. During the meeting, the importance of palliative care and the need for practice change will again be emphasized. Following this, continued communication through email and in passing will serve to remind Dr. Carlton of the need for improvement. Elevating the standard of care in the NICU may also positively influence Dr. Carlton to participate with InPaCT. Additionally, Emory Midtown does not have Magnet status, the highest recognition for nursing excellence operated by the American Nurses Credentialing Center (ANCC). The Magnet program also allows for the dissemination of successful nursing interventions. This may appeal to the medical directors’ desire to share comprehensive methods for palliative care in the NICU. If the medical director, as a latent participant, can be shifted to a promoter, InPaCT will gain a powerful ally (CCHD, 2017).

Satellite expert Dr. Kavanaugh is identified as a defender in a palliative care team. While there is little ability to enact personal change within Emory specifically, her extensive experience may influence the shaping of palliative care guidelines. Initial contact to this key stakeholder will be through email. Following formal introduction, conversation will include a brief overview of team goals. Formal invitation to meet (in person if possible) will be made, however, geographic challenges may arise and can be addressed by using technology such as Skype or FaceTime. Motivation to share personal work and opportunities for publication may also positively influence this key stakeholder to become involved with InPaCT.

Recruitment of key stakeholders, regardless of influence and interest, requires team members to be cognizant of group activity. Communication strategies described by Taylor-Ide & Taylor (2002) as well as tactics discussed by the CCHD (2017) promote capturing stakeholders’ individual interests, providing support during the process, providing praise for accomplishments, and engaging in team decision-making.

**Engagement**

Shazhan Amed, Pinkney, and Shea (2015) foremost discuss the principles of community based participatory research, defined by the authors as “a collaborative, co-learning and community-partnered approach to addressing complex social problems” which includes “community engagement, program design and planning, evaluation, implementation and sustainability, and governance” (p. 426). This type of collaboration will be integral to the success of a new guideline within the NICU. Engagement must occur across several, diverse groups, each with varied levels of interest and influence. The design and planning of a new protocol must take into account the needs of the entire NICU community and should therefore be a collective product. At its inception, key stakeholders identified for this project will represent the interests of the greater NICU community.

To maximize engagement, a variety of methods will be utilized, varied with respect to the individual stakeholder. Engagement from the bottom-up will be encouraged by requesting nursing-specific data and feedback such as success and challenges presented at the bedside. As InPaCT begins to evolve, leadership and mentoring new participants from the bottom-up will continue to encourage engagement. From the top-down, engagement will be facilitated with open, continued communication. Additionally, this key stakeholder will be asked to provide input from the perspective of the physician group. Expert engagement will rely heavily on internet and telephone interactions due to geographic barriers. One significant engagement strategy for this key stakeholder includes requesting existing frameworks applicable to this team. These materials could act as a springboard during initial project brainstorming, saving valuable time. Sharing personal successes and barriers may provide an emotional connection to the project team. To further foster engagement, continued requests for feedback, using an expert lens, will be made and should data be published, this outside-in stakeholder would be encouraged to participate in manuscript construction, editing, and submission. Encouragement from all stakeholders will be further supported by incorporating suggestions and feedback of members, structured planning and discussion of upcoming meetings, and ongoing requests for feedback to further direct guideline shaping (CCHD, 2017).

The process of change in the NICU to better support palliative care is reflected in the plan-do-study-act (PDSA) cycle. The PDSA cycle involves planning, implementing a change, evaluating responses to that change, and, finally, adapting aspects to further improve response to change (Gillam & Siriwardena, 2013). Within this community, “PDSA cycles build knowledge about the system in the local NICU, help manage the inherent risk of change, and encourage participation in improvement as individuals see initial signs of success in the early cycles” (Horbar, et a., 2001). During planning, key stakeholders will be engaged with monthly web-based and in-person meetings. Meeting agenda will include project goal setting, program strategizing, and creation of PBPs for guideline development. As the team continues to grow, additional members will be brought onboard. Additional participants will be encouraged to join monthly team meetings. Once the full team is constructed and guidelines are finalized, team members will be responsible for various tasks such as data collection and palliative care training during the ‘do’ and ‘study’ phases of the PDSA cycle. Continued use of a protocol and future modification will be the responsibility of InPaCT and evaluation of change will also use the principles of PDSA during the final ‘act’ stage.

**Ensuring Input**

*Divergent Thinking- Nominal Group Technique*

Nominal Group Technique (NGT) has been used since the 1960s as a means by which to facilitate group decision making among experts (Harvey & Holmes, 2012). For initial divergence of thought with this DNP project team, NGT will be used to assist in developing approaches to providing palliative care and establishing priorities related to components of a new protocol. NGT is an appropriate choice to generate concepts and ideas for a number of reasons. Foremost, NGT is time efficient, allowing for the generation of a large number of ideas and suggestions in a relatively short period of time. Additionally, NGT requires little preparation of participants; an important consideration for physicians who are short on time and energy. Harvey and Holmes (2012) maintain that NGT has the “capacity to give equal representation to all group members and to create an environment conducive to initiation of change” and that “the collaborative nature of NGT increases the stakeholders’ ownership of the ensuing research and therefore increases the likelihood of changing clinical practice and policy” (p. 190). For this DNP project, equal representation is necessary to ensure multidisciplinary ownership and responsibility of the project. Equal representation ensures no group becomes dominate or is able to assert ideas on other members (Harvey & Holmes, 2012).

Practical application of NGT will begin when InPaCT key stakeholders are asked to hold a team meeting in an informal and relaxed environment. During the team meeting, members will be invited to participate in NGT in an effort to generate ideas related to what content should be included in a preliminary palliative care protocol. Foremost, the team will be asked to write their ideas on post it notes with an enforced time limit of 5 minutes. These post-it notes will then be further reviewed, categorized, and discussed using convergent thinking strategies.

*Convergent Thinking*

The possibility to generate a large number of ideas and concepts through collaborative, divergent thinking leads to the need to manage and organize a mass of information. Without convergence, “such a huge amount of concept alternatives reduces the clarity. It becomes harder to recognize valuable concept alternatives and also to evaluate and select some of them” (Sell & Pinkwart, 2016, p. 4). This merging of similar ideas and familiar concepts and the subsequent selection of topics by the group are described within the convergent steps of the creative process (Sell & Pinkwart, 2016).

For practical application, post-it notes generated in the team meeting will then be organized under several “themes.” Some themes that may be produced include pain, parental needs, and documentation/paperwork. Once the team is satisfied with the position of post-its under their agreed upon themes, participants will be asked to vote for their preferred selections. Majority winners will then be rank ordered by participants before the selection of key concepts to include in a neonatal palliative care protocol.

**Potential Challenges**

The identified team for this DNP project would fit conceptually into the ‘Storming’ stage of group development. At this stage of maturity, the team is described as having intragroup conflict, characterized by uneven interactions, polarization over key issues, emotion, fighting, and a lack of unity (McMorris, et al., 2005). Neonatal palliative care, as the core focus of this project, is sensitive material for many that presents emotional and ethical arguments, both in support of and in resistance to the defined goals of this team. Uniting persons at varied levels of influence and power may fuel conflicts. Furthermore, the struggle for power can be expected when discussing palliative care plan development, implementation, and monitoring. It is possible that there will be debate among physicians, nurse practitioners, and clinical nurses to determine appropriate leadership and representation and those outside the immediate NICU community will hold different levels of compassion for the project mission and vision. Intragroup conflict may be further amplified by personal feelings and individual morality regarding neonatal palliative care and the need for practice change. This conflict may be most evident when tasks are assigned to team members. Task orientation conflict at this level of development include emotional responses and resistance to task demands and group requests (McMorris, et al., 2005). The three-way partnership as described by Taylor-Ide and Taylor (2002) states that “holism comes from the three-way partnership” (p. 256). Role-reallocation and relinquishment of power by top-down and outside-in members serve as methods by which power is shared with bottom-up community team members (Taylor-Ide & Taylor, 2002). An annual team forum will be held in order to discuss progress and reassess team goals. Participants will also be reminded that decisions will be made on fact rather than personal opinions. Additionally, suggestions not accepted will be documented and kept for future re-evaluation.

**Consensus Building**

Tools to gain consensus among teams are often used to fairly identify the pathway a group will take towards its goals. The Delphi technique has been in use since the 1950s (Foth, et al., 2016). The Delphi technique uses the following steps: identifying the problem, completing a literature review, developing a questionnaire, conducting surveys with developed questionnaires, consensus building, and summary of findings (Foth, et al., 2016). Steps for this DNP project mirror the stages of the Delphi technique. Foremost, the problem has been identified; lack of guidance in delivering neonatal palliative care. An ongoing literature review is being conducted by the project lead to stay current in research and findings. Development of a questionnaire focused on necessary components of a palliative care protocol could be formulated using a consensus tool such as the Winshaw Matrix. One such way to use this tool would be to ask participants to rank-order potential elements of a palliative care protocol. Results would then represent the general opinion of the group and potential best strategies for successful collaboration. Results of a consensus tool such as the Winshaw Matrix, subsequently, would spark conversation and feedback between team members. From results, team strategies can be strengthened and consensus building can begin.

**Conclusions**

The creation of a palliative care team at Emory University Hospital Midtown represents the first of several steps in providing comprehensive palliative care in the neonatal population. Despite endorsement from several medical and nursing bodies, neonatal palliative care across the United States continues to be sporadically practiced (Wright, et al., 2011). Likewise, at present, the NICU at Emory University Midtown has neither an established palliative care team, nor guidelines for governing palliative care. Potential benefits of InPaCT will reach a large pool of stakeholders, most significantly patients and families facing end-of-life in the NICU. With an interdisciplinary emphasis, formal palliative care team members should include physicians and practitioners, unit management, physician and practitioner supervisors. Insights from established palliative care organizations and field experts will contribute additional outside-in input. Creating a NICU-based palliative care protocol by using divergent and convergent thinking methods, employing a consensus model such as the Delphi technique, and anticipating and addressing challenges promotes quality input and ownership from team members.

**References**

Belbin, R. M. (1981). Management teams: Why they succeed or fail. *Oxford, International Journal of New York*.

Bidegain, M., & Younge, N. (2015). Comfort care vs palliative care: Is there a difference in neonates?. *NeoReviews, 16*(6), e333-e339.

Brown, M. K., Ohlinger, J., Rusk, C., Delmore, P., & Ittmann, P. (2003). Implementing potentially better practices for multidisciplinary team building: Creating a neonatal intensive care unit culture of collaboration. *Pediatrics, 111*(4), 482-488.

Catlin, A., Brandon, D., Wool, C., & Mendes, J. (2015). Palliative and End-of-Life Care for Newborns and Infants: From the National Association of Neonatal Nurses*. Advances in Neonatal Care, 15*(4), 239-240.

Center for Community Health and Development, (2017). Chapter 7, section 8: Identifying and analyzing stakeholders and their interests. Lawrence, KS: University of Kansas. Retrieved September 19, 2016 from <http://ctb.ku.edu/en/table-of-contents/assessment/assessing-community-needs-and-resources/conduct-concerns-surveys/main>

Concannon, T. W., Meissner, P., Grunbaum, J. A., McElwee, N., Guise, J. M., Santa, J., ... & Leslie, L. K. (2012). A new taxonomy for stakeholder engagement in patient-centered outcomes research. *Journal of General Internal Medicine*, *27*(8), 985-991.

Cortezzo, D. E., Sanders, M. R., Brownell, E., & Moss, K. (2013). Neonatologists’ perspectives of palliative and end-of-life care in neonatal intensive care units. *Journal of Perinatology, 33*(9), 731-735.

Davies, B., Sehring, S. A., Partridge, J. C., Cooper, B. A., Hughes, A., Philp, J. C., ... & Kramer, R. F. (2008). Barriers to palliative care for children: perceptions of pediatric health care providers. *Pediatrics, 121*(2), 282-288.

Duff, R. S., & Campbell, A. G. (1973). Moral and ethical dilemmas in the special-care nursery. In *Problems of Birth Defects* (pp. 389-393). Springer Netherlands.

Engler, A. J., Cusson, R. M., Brockett, R. T., Cannon-Heinrich, C., Goldberg, M. A., West, M. G., & Petow, W. (2004). Neonatal staff and advanced practice nurses’ perceptions of bereavement/end-of-life care of families of critically ill and/or dying infants. *American Journal of Critical Care, 13*(6), 489-498.

Foth, T., Efstathiou, N., Vanderspank-Wright, B., Ufholz, L. A., Dütthorn, N., Zimansky, M., & Humphrey-Murto, S. (2016). The use of Delphi and Nominal Group Technique in nursing education: A review. *International Journal of Nursing Studies*, *60*, 112-120.

Gillam, S., & Siriwardena, A. N. (2013). Frameworks for improvement: clinical audit, the plan-do-study-act cycle and significant event audit. *Quality in Primary Care*, *21*(2).

Harvey, N., & Holmes, C. A. (2012). Nominal group technique: An effective method for obtaining group consensus. *International Journal of Nursing Practice, 18*(2), 188-194.

Henner, N., & Boss, R. D. (2017, February). Neonatologist training in communication and palliative care. In *Seminars in Perinatology*. WB Saunders.

Horbar, J. D., J. Rogowski, P. Plesk, P. Delmor, W. H. Edwards, J. Hocker, A. D. … Carpenter, (2001). Collaborative quality improvement for neonatal intensive care. *Pediatrics 107*(1) 14-22.

Kain, V. (2006). Palliative care delivery in the NICU: what barriers do neonatal nurses face?. *Neonatal Network*, *25*(6), 387-392.

Lisle-Porter, M. D., & Podruchny, A. M. (2009). The dying neonate: Family-centered end-of-life care. *Neonatal Network, 28*(2), 75-83.

Martin, M. (2013). Missed opportunities: A case study of barriers to the delivery of palliative care on neonatal intensive care units. *International Journal of Palliative Nursing, 19*(5).

Matthews, T. J., MacDorman, M. F., & Thoma, M. E. (2015). Infant mortality statistics from the 2013 period linked birth/infant death data set. *National vital statistics reports: from the Centers for Disease Control and Prevention, National Center for Health Statistics, National Vital Statistics System*, *64*(9), 1-30.

McMorris, L. E., Gottlieb, N. H., & Sneden, G. G. (2005). Developmental stages in public health partnerships: A practical perspective. *Health Promotion Practice*, *6*(2), 219-226.

Meyer, E. C., Ritholz, M. D., Burns, J. P., & Truog, R. D. (2006). Improving the quality of end-of-life care in the pediatric intensive care unit: Parents' priorities and recommendations. *Pediatrics, 117*(3), 649-657.

Moro, T., Kavanaugh, K., Okuno-Jones, S., & VanKleef, J. A. (2006). Neonatal End‐of‐Life Care: A review of the research literature. *The Journal of perinatal & neonatal nursing*, *20*(3), 262-273

Pierucci, R. L., Kirby, R. S., & Leuthner, S. R. (2001). End-of-life care for neonates and infants: The experience and effects of a palliative care consultation service. *Pediatrics, 108*(3), 653-660

Pizzo, P. A., Walker, D. M., & Bomba, P. A. (2014). Dying in America: Improving quality and honoring individual preferences near the end of life. *Washington, DC: Institute of Medicine*.

Rabinowitz, P. (2012). Identifying and analyzing stakeholders and their interests. Retrieved from the University of Kansas Community Tool Box website: http://ctb. ku. edu/en/table-ofcontents/participation/encouraging-involvement/identify-stakeholders/checklist.

Samsel, C., & Lechner, B. E. (2015). End-of-life care in a regional level IV neonatal intensive care unit after implementation of a palliative care initiative. *Journal of Perinatology, 35*(3), 223-228

Sell, J., & Pinkwart, N. (2016, September). Rambla: Supporting collaborative group creativity for the purpose of concept generation. In *CYTED-RITOS International Workshop on Groupware* (pp. 81-97). Springer International Publishing.

Shazhan Amed, M. D., Pinkney, S., & Shea, S. (2015). Creating a collective impact on childhood obesity: Lessons from the SCOPE initiative. *Canadian Journal of Public Health*, *106*(6), E426.

Taylor-Ide, D. C., & Taylor, C. E. (2002). Just and lasting change: When communities own their futures. JHU Press.

Tuckman, B. W., & Jensen, M. A. C. (2010). Stages of small-group development. *Group Facilitation*, (10), 43.

Wright, V., Prasun, M. A., & Hilgenberg, C. (2011). Why is end-of-life care delivery sporadic?: A quantitative look at the barriers to and facilitators of providing end-of-life care in the neonatal intensive care unit. *Advances in Neonatal Care, 11*(1), 17-36.

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| --- | --- | --- | --- | --- | --- | --- | --- |
|  |  | 1  Novice | 2  Beginner | 3  Competent | 4  Proficient | 5  Expert | Comments |
| **Analysis** | **Context** of project summarized |  |  |  |  |  |  |
| **Practice issue/problem** defined |  |  |  |  |  |  |
| **Drivers** of problem/issue analyzed |  |  |  |  |  |  |
| **Stakeholders** broadly identified |  |  |  |  |  |  |
| **Key stakeholders** analyzed (3) |  |  |  |  |  |  |
| **AIIM** for key stakeholders |  |  |  |  |  |  |
| **DNP team** defined |  |  |  |  |  |  |
| **\*\*Collaboration strategies**  defined and clear ***\*\*(Weighted 3 times)*** | X3 | X3 | X3 | X3 | X3 |  |
| **Challenges** identified |  |  |  |  |  |  |
| **Strategies** for challenges created |  |  |  |  |  |  |
| **Gen** | **Literature** cited in support of analysis and background |  |  |  |  |  |  |
| **Summary** as a whole is cohesive, cogent, clear |  |  |  |  |  |  |
| **Written scholarship-structure** APA format, English Grammar-Syntax-Diction-Spelling-Punctuation, Length/page limits, PICOT or Problem Statement included, introduction/conclusions |  |  |  |  |  |  |
|  | Raw Score: | / 45 | | | | | |
|  | Final Dreyfus Score: |  | | | | | |

Appendix A- Ecological Model Emory University NICU

Interaction and communication among care team

Lack of continuity

Interaction with patient families

**Interpersonal**

Appendix B- Drivers Diagram

**Policy- NICU**

**Organizational- NICU**

Lack of staff grief support

Lack of multidisciplinary palliative care team

Presence/access to guidelines for end of life care

Limited palliative care training opportunities

**Community- NICU**

Moral distress- comfort providing end-of-life care

Fear of litigation

Knowledge and attitude

**Individual**

Lack of standardized palliative care guidelines

No palliative care focused continuing education requirement

Cost of associated training

Current Unit Practice

Incentive for certification

Support from unit management

Unit education and awareness

NICU presence within Emory Palliative Care Team

Evidence Based Palliative Care Protocol

#members on palliative care team

Type members represented

Availability of grief support and counseling

Perception of team support

#palliative care nurses

#hours training in palliative care

Presence of palliative care guidelines

Knowledge and awareness

% use of available resources

Types of cases resources used/not used

# cases where protocol used

# cases protocols not used

Types of cases protocols used/not used

Access to Resources

Personal Beliefs & Behavior

Standardized palliative care and bereavement practice among providers at Emory University Midtown

Interdisciplinary Environment of Care

Support and Guidance (grief support, ethical/moral counseling, interdisciplinary collaboration)

Education and Training

Provider perceptions of palliative care

Comfort with providing palliative care

Self-awareness of moral standing

|  |  |  |
| --- | --- | --- |
| **Appendix C- Stakeholder Summaries** | | |
| ***Stake-holder*** | **Stakeholder**  (Individual & Institution) | David Carlton, MD  [Emory University- Division Director of Neonatal-Perinatal Medicine, Department of Pediatrics] |
| **Ecologic Level** | Policy |
| **AIIM** | **AIIM**  (Promoter, Latent, Defender, Apathetic) | Latent |
| **Influence**  (High vs. Low) | High |
| **Interest**  (High vs. Low) | Low |
| **Resource** | **Strengths**  (Capacities-Skills-Resources) | Ability to require education and training for MDs, and NNPs within Emory Midtown NICU  Ability to allow addition of new unit policies for palliative care |
| **Potential role in team** | Liaison between larger physician group  Assistance in development and adoption of unit palliative care guidelines |
| **Engagement** | **Self-interest in team** (i.e., ‘currency’ or values) | Innovation in practice |
| **Strategy to obtain active participation** | Continued communication  Request physician-specific experiences with protocol implementation  **Encourage participation in InPaCT**  **Incorporate suggestions and feedback into formation of new guidelines**  **Discussion of upcoming meetings and agendas**  **Continued request for feedback to further direct guideline shaping** |
| **How to recruit** | Persuasive presentation focused on neonatal palliative care  In-person meeting |
| **Barriers**  (Recruitment - Collaboration ) | Time requirement  Lack of compassion for the cause/belief practice is sufficient |
| **Who will recruit to team** | Project lead |

|  |  |  |
| --- | --- | --- |
| **Stakeholder Summary** | | |
| ***Stake-holder*** | **Stakeholder**  (Individual & Institution) | Tracy Martin, RNC, CN IV, neonatal pain champion  [Emory University Hospital Midtown NICU] |
| **Ecologic Level** | Individual |
| **AIIM** | **AIIM**  (Promoter, Latent, Defender, Apathetic) | Promoter |
| **Influence**  (High vs. Low) | High |
| **Interest**  (High vs. Low) | High |
| **Resource** | **Strengths**  (Capacities-Skills-Resources) | First line providers of palliative care |
| **Potential role in team** | Instrument of change |
| **Engagement** | **Self-interest in team** (i.e., ‘currency’ or values) | Personal beliefs and mental well being |
| **Strategy to obtain active participation** | Request nursing-specific reports regarding protocol successes and challenges  Leadership and mentoring new participants  **Encourage participation in InPaCT**  **Incorporate suggestions and feedback into formation of new guidelines**  **Continued request for feedback to further direct guideline shaping**  **Discussion of upcoming meetings and agendas** |
| **How to recruit** | Initial email correspondence followed by informal face-to-face meeting  Ongoing request for feedback  Open communication |
| **Barriers**  (Recruitment - Collaboration ) | Reluctance to new protocols  Lack of communication between team members  Ideological and cultural concerns |
| **Who will recruit to team** | Project lead |

|  |  |  |
| --- | --- | --- |
| **Stakeholder Summary** | | |
| *Stake-holder* | **Stakeholder**  (Individual & Institution) | Karen Kavanaugh, PhD, RN, FAAN  [Wayne State University] |
| **Ecologic Level** | Organizational |
| AIIM | **AIIM**  (Promoter, Latent, Defender, Apathetic) | Defender |
| **Influence**  (High vs. Low) | Low |
| **Interest**  (High vs. Low) | High |
| Resource | **Strengths**  (Capacities-Skills-Resources) | Experience in neonatal palliative care  Assist in policy creation for palliative care interventions  Numerous publications in neonatal palliative care |
| **Potential role in team** | Outside-In expertise |
| Engagement | **Self-interest in team**  (i.e., ‘currency’ or values) | Dissemination of personal work  Fulfillment of personal goals  Possible publication opportunities |
| **Strategy to obtain active participation** | **Encourage participation in InPaCT**  Request outline/framing for initial project brainstorming  Dialog regarding successes and barriers in previous experiences  Continued involve in project shaping  Publication assistance  Ongoing requests for feedback and guidance  Visit unit if possible to see palliative care teams in practice |
| **How to recruit** | Open communication  Presentation of ideas via Skype or FaceTime  In-person meeting, if possible |
| **Barriers**  (Recruitment - Collaboration ) | Distance from project- residence in Michigan  Communication barriers  Time constraints |
| **Who will recruit to team** | Project lead |