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Objectives

- Describe how domains of palliative care can be integrated into the care of high-risk infants in the Neonatal Intensive Care Unit (NICU).
- Delineate the effects of an integrated palliative and neonatal interdisciplinary conference on staff moral distress and neonatal providers' perceptions towards palliative care.

Original Research Background. Despite national recommendations to incorporate palliative care (PC) into the Neonatal Intensive Care Unit (NICU), providers' (MD and APN) perceptions may prevent optimal PC delivery in this setting, leading to moral distress in staff.

Research Objectives. Objectives were to investigate the efficacy of a weekly case-conference to improve moral distress and perceptions of PC in the NICU and to increase consultation rate to specialty PC for newborns at high risk for mortality and/or morbidity.

Methods. An interdisciplinary PC/NICU case-conference served as a platform for educating providers on incorporating palliative care domains into the care of high-risk NICU infants. NICU providers' PC perceptions were measured at baseline and after 12 months of implementation (follow-up) using a published survey. Providers and multidisciplinary NICU staff completed the Moral Distress Scale-Revised at baseline and follow-up. NICU consultation rate to PC at follow-up was compared to baseline.

Results. Surveys were completed by 57 MDs/APNs and 176 NICU staff, mostly RNs. Compared to baseline, providers were significantly more likely to endorse that they provide families with PC options (84% v. 95%; $p < .03$); are comfortable with PC (84% v. 97%; $p = .03$); are satisfied with EOL care (65% v. 79%; $p < .02$); have time to provide PC (42% v. 72%; $p < .02$); and perceive parents are involved in PC decisions (81% v. 95%; $p < .01$). Additionally, moral distress among NICU staff was significantly reduced ($p = .005$) and the number of PC consultations increased by 56%.

Conclusion. Moral distress, provider perceptions of PC, and PC consultation rate can be improved by a weekly case-based interdisciplinary conference that includes PC and NICU stakeholders.

Implications for Research, Policy, or Practice. This study provides direction for overcoming some PC implementation barriers in the NICU. Future studies should assess the effect of improved utilization of PC services on parental perceptions and newborn outcomes.

Availability of Bereavement Support Services for Those Affected by a Pediatric Death: A Literature Review (TH370C)



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Objectives

- Describe the importance of providing bereavement support services to families impacted by the death of a child.
- Describe how to conduct a scoping literature review.
- Discuss the limits of existing research related to the availability of bereavement support services for families impacted by the death of a child.

Research Background. Bereavement support is an essential component of palliative care. Yet little is known about the availability of bereavement support services offered to those affected by a pediatric death.

Research Objectives. To review existing literature related to the availability of bereavement support for families affected by the death of a child (including pre-natal deaths) in the United States (US).

Methods. We searched five databases (PubMed, Embase, PsycINFO, CINAHL, and Cochrane Library) using terms related to three concepts: "child death," "bereavement," and "support." We included articles discussing availability of bereavement support services based in the community, hospital, clinic, or a palliative care organization. We excluded articles that focused on bereavement education, case studies or series, specific program descriptions, healthcare provider support, the impact of a child's death on parents or healthcare providers, adult death, efficacy of bereavement services, activities during the dying period, and programs outside the US. Two people screened articles for those that met our inclusion/exclusion criteria. A third team member resolved discrepancies. Resultant articles were reviewed by two people for content.

Results. Our database search identified 2,067 articles, of which 7 met our inclusion/exclusion criteria. Three articles addressed services for all pediatric populations, 3 focused on pregnancy loss, and 1 focused on cancer patients. 4 articles described the types of services available, two of which highlighted variability in the breadth and depth of services offered. 3 articles described service use and noted that minorities are underrepresented.

Conclusions and Implications for Research, Policy, or Practice. The literature on availability of US bereavement support services for families affected

by pediatric death is sparse. Existing literature raises concerns that certain services might be unavailable to some populations. More research is needed to understand why bereavement support services are not uniformly available and to develop programs for underserved populations.

Embedded Specialty Palliative Care Is Feasible, Acceptable, and Perceived to Be Effective in Cystic Fibrosis: Results of a Pilot Randomized Clinical Trial (TH371A)



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Objectives

- Appraise the challenges in conducting palliative care interventions among individuals with genetic disorders, such as cystic fibrosis (CF).
- Interpret the results of a pilot feasibility trial of an embedded specialty palliative care intervention in cystic fibrosis.

Original Research Background. People with CF experience myriad physical and emotional burdens, all of which degrade quality of life (QoL). Although specialty palliative care (PC) reduces suffering for individuals with serious illness, no evidence exists for its impact in CF.

Research Objectives. Conduct the first randomized pilot trial to evaluate the feasibility, acceptability, and perceived effectiveness of embedded specialty PC for patients with CF.

Methods. Following a needs assessment, we developed a protocolized, patient-centered PC intervention embedding a PC clinician within an adult CF center. Patients receive >4 in-person visits (and follow-up calls as needed) with a PC nurse practitioner, addressing: symptom management, emotional support, advance care planning, and coping. We measured feasibility via enrollment and assessment rates. We conducted semi-structured interviews evaluating acceptability and perceived effectiveness.

Results. We randomized 50 adults to intervention plus usual care, or usual care alone (approach-to-randomize rate, 79%). Fifty-six percent of our sample was male, with a median age of 32 (range: 18-67), and

median FEV1 of 41% predicted (range: 20-82% predicted) at enrollment. Of 50 randomized, two died and one was lost to follow-up. Sixty-seven percent of participants reported the intervention was not burdensome and 100% agreed/strongly agreed that they were satisfied with the PC clinician's care. Sixty-seven percent of participants agreed/strongly agreed that the intervention improved their physical symptoms, 62% their QoL, and 100% felt that all patients with CF should receive specialty PC. Interview themes include: 1) appreciation that PC focuses on more than physical symptoms; 2) appreciation that PC was seamlessly integrated within usual CF care, longer clinic appointments notwithstanding; and 3) a desire to have been exposed to specialty PC earlier in their disease.

Conclusion. Embedded specialty PC is feasible, acceptable, and perceived to be effective among individuals living with CF.

Implications for Research, Policy, or Practice. Given these promising findings, further clinical trials are warranted to establish the efficacy of PC in CF.

Early Palliative Care Consultation in the Medical Intensive Care Unit—A Clustered Randomized Crossover Trial (TH371B)



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Objectives

- Describe patient outcomes with early palliative care consultation in the medical ICU for patients with advanced disease.
- Describe impact of PC utilization on ICU and hospital resource utilization.

Original Research Background. Patients with advanced disease present to intensive care units (ICUs) for management; however, palliative care (PC) consultation is often delayed or not utilized.

Research Objectives. To study the impact of early PC consultation in the medical ICU on patients with advanced disease.

Methods. A PC screening tool was used to identify patients at risk for poor outcomes due to the