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Neonatal Palliative Care

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INFANT MODE OF DEATH

Lin M, Deming R, Wolfe J, Cummings C. **Infant mode of death in the neonatal intensive care unit: A systematic scoping review.** *Journal of Perinatology* 2022; published online 20 January 2022.

Summary

In spite of the many advances that have been made in resuscitation and stabilization, infant deaths account for the majority of deaths in pediatric institutions. Many occur in neonatal intensive care units following the withholding or withdrawing of life-sustaining therapy (WWLST), yet rates, definitions, and clinical decision-making regarding this practice vary. This scoping review followed the Preferred Reporting Items for Systematic Reviews (PRISMA-ScR) and included 58 articles published over the last two decades that were peer-reviewed, written in English, and that reported number of infant deaths by mode (withholding, withdrawing, code) in order to identify, summarize, and characterize several factors associated with the limitation of life-sustaining therapies (LST). How these infant deaths were defined and rationalized in North American and European institutions was described. Outcomes and clinical processes associated with WWLST such as infant/family characteristics, clinical practices, and characteristics of infant deaths were also identified. There were notable differences in how mode of death was reported and how WWLST was defined. Rate of death following limitation of LST has increased over time. Five themes around rationales for WWLST emerged, including medical diagnoses, low predicted survival, low predicted quality of life, futility, and suffering.

Comments

1. LST was defined both broadly (e.g. treatment needed for survival) and more specifically (e.g. intubation and mechanical ventilation).

2. Wide variations in definitions and categorization of LST may lead to over- or under-reporting of infant deaths following WWLST.
3. Quality of life, futility and suffering are key concepts associated with limitations of LST that also remain poorly understood or defined and may be problematic.
4. Recognition of longitudinal patterns in end-of-life outcomes and clinical processes associated with WWLST such as infant and family characteristics (e.g., parental race and/or ethnicity), clinical practices (e.g., shared decision-making) or features of infant deaths (e.g., mode of death) may help to create a minimum standard for EOL care best practices around decisions to limit LST.
5. Further research is needed to standardize definitions and application of these concepts in the clinical setting to continue to advance the field and improve care for infants and families in the NICU.

GOALS OF CARE DISCUSSIONS AND STAFF MORAL DISTRESS

Guttman K, Flibotte J, Seitz H, Huber M, DeMauro SB. **Goals of care discussions and moral distress among neonatal intensive care staff.** *Journal of Pain and Symptom Management* 2021; 62(3):529-536

Summary

A prospective cohort study of neonatal physicians (n=43), nurses (n=178), and social workers (n=10) were enrolled to better understand levels of moral distress in providers in the neonatal intensive care unit (NICU), changes to moral distress related to (GOC) discussions, and specific elements of GOC discussions associated with changes in levels of moral distress. 79 GOC discussions that occurred in the neonatal intensive care unit (NICU) were analyzed. Prior to GOC discussions, provider-reported data was collected: demographics, religiosity and spirituality, experience level, baseline

levels (Moral Distress Thermometer [MDT]) and sources of moral distress (Moral Distress Scale [MDS]). Post-discussion surveys were administered within 10 days: MDT, MDS, presence of key elements of GOC discussions (Williams Instrument), satisfaction with conversation, and agreement of others. Providers experienced an average increase in moral distress of 0.84 ($P=0.002$) following a GOC discussion. 62% of providers reported a high level of satisfaction with the conversations they had. Providers who were dissatisfied with the conversation or perceived disagreement among participating clinicians had a greater increase in moral distress. Key GOC discussion elements included respecting parent preferences, balancing pain and suffering with long-term outcomes, and supporting parents to come to a decision, regardless of the decision.

Comments

1. Best practices for high-quality GOC discussions in the NICU have not been established due to a paucity of literature and difficulty in defining and measuring quality.
2. GOC discussions are associated with an average increase in moral distress in NICU providers.
3. When providers include parents in discussions and seek to understand their goals it may lead to decreased moral distress even when parents make a choice that challenges their perceptions of acceptable outcomes.
4. Providers might consider increased feelings of moral distress following GOC discussions as an internal trigger to reflect on their biases and explore parents' views further.
5. Findings are useful for both researchers and clinicians to continue work toward improving communication with families.

COMPASSIONATE EXTUBATION PROTOCOL TO IMPROVE TEAM COMMUNICATION

Donoho K, Fossa M, Dabagh S, Caliboso M, Lotstein D, Nair S. **Compassionate extubation protocol to improve team communication and support in the neonatal intensive care unit.** *Journal of Perinatology* 2021; 41:2355-2362.

Summary

A quality improvement initiative to aid medical management and communication between staff members during compassionate extubation (CE) in a large, pediatric academic medical center with a level IV, 58 bed neonatal intensive care unit (NICU). An interprofessional team completed institutional data review and a needs assessment of nurses ($n=43$) before creating the checklist and debrief protocol to be used by the medical team prior to, during, and after a CE. Outcomes included nursing perception of good communication with the medical team, nursing assessment of patient comfort after CE, and frequency of post-event debriefing. Within 1 week after the CE event, participating medical providers, nurses, and respiratory therapists ($n=85$) were invited to participate in a survey to determine efficacy of the protocol. Three Plan-Do-Study-Act cycles were conducted to implement changes. Nurses ($n=11$) repeated the needs assessment survey 6 months post-implementation. 18 CE events occurred during the 6-month intervention period. 66 of 85 post-event responses were received. Improvements were noted in ratings of "good" communication with the medical team (60%) and participation in post-event debrief (96%). Subjective nursing assessment of patient comfort during and after CE was high in both the baseline and post-intervention groups.

Comments

1. CE frequently occurs in the NICU and is a stressful event for both families and staff.
2. There is no published consensus guideline, model, or CE-specific checklist to aid medical management and communication during CE in the NICU.
3. Use of a checklist and post-event team debriefing sheet was associated with improved assessment of team communication and increased rate of post-event team debriefs.
4. The most common barrier to use of the protocol was lack of awareness or inability to locate the checklist and debriefing sheet.
5. Future research should measure parent experiences during CE as associations between nurse comfort and improved parent experience during end-of-life care have been noted and would help advance knowledge toward providing the best care to every patient and family in the NICU.

PARENT PERCEPTIONS AND DISTRESS

Clark OE, Fortney CA, Dunnells ZDO, Gerhardt CA, Baughcum AE. **Parent perceptions of infant symptoms and suffering and associations with distress among bereaved parents in the NICU.** *Journal of Pain and Symptom Management* 2021; 62(3):e20-e27.

Summary

A retrospective, cross-sectional pilot study of 40 mothers and 27 fathers (27 dyads; 13 only mothers) of 40 infants who died within the previous five years at a large, Midwestern, level IV NICU. Parents reported demographics, perceptions of infant symptom burden and suffering during the last week of life, and their adjustment following infant death through the Impact of Events Scale-Revised (IES-R) and the Prolonged Grief-13 (PG-13). Infant medical chart data was also collected: dates of birth/death, diagnoses, medical interventions, and symptoms observed in the last week of life. Paired t-tests were conducted to examine differences between partnered mothers and fathers. For those demographic and medical variables that were significantly correlated with post-traumatic stress symptoms (PTSS) and prolonged grief (PG), four hierarchical linear regressions were conducted to predict continuous IES-R and PG-13 scores among mothers and fathers. Clinical levels of PTSS (mothers=18%; fathers = 11%) and PG (mothers and fathers = 3%) were low. Mother report of higher infant symptom burden was associated with greater PTSS $R^2=0.46$, $P=0.001$, and PG, $R^2=0.47$, $P<0.01$. Father report of greater infant suffering was associated with greater PTSS $R^2=0.48$, $P=0.001$, and PG, $R^2=0.38$, $P<0.01$. Less education and lower family income were also predictive of outcomes.

Comments

1. For partnered parents there was no significant difference between average mother and father IES-R or PG-13 scores or average report of infant total symptoms.
2. While few bereaved parents reported clinically elevated levels of distress, recall of their infant's symptoms and suffering at the end of life was associated with great levels of PTSS and PG.
3. Perceptions of infant symptoms and suffering at the end of life may heighten parent distress with

mothers and fathers having different determinants for their distress.

4. Because parent perceptions of symptoms and suffering at the end of life are strongly associated with parent outcomes, NICUs should provide psychological support, education, and anticipatory guidance regarding typical symptoms experienced by infants at the end of life.
5. Further research is needed regarding management of infant symptom burden, provider and parent education, and promotion of resilience following infant death.

NEUROPALLIATIVE CARE

Rent S, Bidegain M, Bost MH, Hornik C, Lemmon ME. **Neuropalliative care for neonates.** *Journal of Child Neurology* 2021; 36(12):1120-1127.

Summary

Neonatal neuropalliative care is an emerging field that focuses on the specific needs of infants with neurologic illness and their families. Advances in technology now allow for the early detection of serious conditions in the fetal, perinatal, and immediate postnatal period making the initiation of a tailored palliative care approach appropriate as soon as a diagnosis is made, even if the prognosis is uncertain. There are four core domains of neuropalliative care: family-centered communication, prognostication, decision-making, and pain and symptom management. Regular communication with the family is important, as is approaching conversations from a place of collaboration to enable families to be open about their wishes. Normalizing prognostic uncertainty, being open about the limitations of diagnostic tests, and helping families to manage the effects of uncertainty on their ability to live in the present can provide a more holistic care approach. A shared decision-making approach with a multidisciplinary team is helpful to ensure that family values and preferences are honored in every decision that is made. Control of infant pain and irritability is a top priority as management of these symptoms can be complicated but can be addressed with several pharmacologic and nonpharmacologic strategies.

Comments

1. It is possible and even encouraged for neuropalliative care to be initiated prior to birth, and then continued while in the NICU, as discharge to home approaches, and at the end of life in patients diagnosed with neurological conditions.
2. Families of infants with neurologic illness are diverse and may be unique in how they approach difficult conversations and decision-making.
3. Clinicians can ease distress about prognostic uncertainty by discussing possible outcomes using a best case, worst case, and most likely approach.
4. Decisions to withdraw life-sustaining interventions may differ from similar decisions made for older children and adults, such as parents and clinicians being more likely to transition to care focused on comfort for infants at risk of life-long disability than they are for children with a preexisting disability.
5. Infants with neurologic conditions are at risk for under-recognition of pain and irritability because scales that assess infant pain rely on changes in behavior that may not be visible in infants with significant impairment and the belief by some clinicians that these infants experience less pain than infants without neurologic conditions.

Other Articles of Interest

Maher-Griffiths C. **Perinatal palliative care in the neonatal intensive care unit.** *Critical Care Nursing Clinics of North America* 2022; 34:103-119.

Chin A, Paraszczuk AM, Eckardt P, Bressler T. **Neonatal nurses' perceptions of palliative care in the neonatal intensive care unit.** *Maternal Child Nursing* 2021; 46(5):250-257.

Allen JD, Shukla R, Baker R, Slaven JE, Moody K. **Improving neonatal intensive care unit providers' perceptions of palliative care through a weekly case-based discussion.** *Palliative Medicine Reports* 2021;2:1:93-100.

Darlington A-S, Randall D, Leppard L, Koh, M. **Palliative and end of life care for a child: Understanding parents' coping strategies.** *Acta Paediatrica* 2021; 110:673-681.

Trottier A, Maitre G, Hébert A, Weiss MJ. **Potential heart, liver, and kidney donation after circulatory determination of death in a neonatal intensive care unit.** *Neonatology* 2021;118:546-552.

Symptom Management Strategies in Palliative Care

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MANAGING PAIN AT END OF LIFE

Cardinale M, Kumapley GK, Wong C, Kuc ME, Beagin M. **Impact of a Nurse-Driven Opioid Titration Protocol on Quality of Orders at End-of-Life.** *J Hosp Palliat Nurs.* 2021;23(1):78-83.

Summary

Achieving comfort is a paramount goal for end-of-life (EOL) care, and opioids play a key role in high-quality, evidence-based treatment to address pain and dyspnea. Nonetheless, there are multiple barriers to the effective administration of opioids at EOL including inadequate knowledge about ordering and titrating opioids, as well as fear of hastening death. In addition, non-pain symptoms are frequently unaddressed. This single-arm, pre-post study evaluated the impact of a comprehensive comfort care orders set, which included a nurse-driven opioid titration protocol, in combination with interprofessional staff education about opioid administration at EOL on the quality of EOL care orders. Pre/post-implementation evaluation of orders entered for terminally ill patients (n=69) receiving morphine infusions showed a greater percentage of post-implementation orders contained an initial bolus dose and titration guidance (94/6% vs. 18/8%, $P < .0001$); as-needed bolus doses, ($P < .0001$); and a maximum dose ($P < .041$). In addition to improved opioid orders, patients post-implementation were more likely to have orders for medications to treat nausea/vomiting, constipation, and anxiety—as well as non-opioid analgesics ($P < .005$).

Comments

1. Management of opioid infusions at EOL by acute care and ICU nurses is an important primary palliative care skill.
2. Research demonstrates nurses often lack knowledge about symptom management at EOL and titration of opioid infusions to manage pain and dyspnea.

3. This well-designed program that aligned institutional policy, evidence-based order sets, and comprehensive staff education facilitated effective implementation of a nurse-driven opioid titration protocol.

MANAGING DYSPNEA

Campbell ML, Donesky D, Sarkozy A; Reinke LF. **Treatment of dyspnea in advanced disease and at end-of-life.** *J Hosp Palliat Nurs.* 2021; 23(5):409-420

Summary

Dyspnea—the subjective experience of uncomfortable breathing—is pervasive at end-of-life (EOL), highly distressing, and impacts patients across a range of conditions from cardiopulmonary to oncologic. The ability to assess and treat dyspnea is an important primary and specialty palliative care skill, and evidence-based knowledge is essential to delivering expert care. This systematic review aimed to gather and critique the evidence about treating dyspnea, including that of smaller studies, to generate up-to-date guidance that is inclusive of knowledge gathered from across the field. Results showed definitive evidence for the effectiveness of: immediate-release opioids; oxygen to correct hypoxemia; a fan directed at the face; long-acting bronchodilators for chronic obstructive pulmonary disease (COPD); and pulmonary rehabilitation for COPD. Although the evidence was not definitive, several other strategies were likely effective (including sustained-release/subcutaneous opioids, short-acting bronchodilators for COPD, breathing management techniques, home-based exercise, and acupressure). In addition, some interventions such as non-invasive ventilation and high-flow nasal oxygen were possibly effective but posed some potential harms. Effectiveness has not been established for multiple commonly used strategies, including benzodiazepines, mindfulness techniques, music therapy, and vaporized cannabis, as

well as more novel strategies. Finally, numerous strategies were shown to be likely or definitively ineffective.

Comments

1. The results of this study provide nurses in a variety of practice settings with evidence-based strategies to treat acute and chronic episodes of dyspnea.
2. Nurses can choose from among a range of options, including pharmacological and non-pharmacological treatments, as well as those delivered by professional providers and by family caregivers.
3. Nurses can trial different dyspnea treatments to develop a suite of strategies tailored to the individual patient.
4. Additional research is needed regarding common dyspnea treatments for which effectiveness has not been established.

MANAGING DELIRIUM

Burry LD, Chen W, Williamson DR, Adhikari NK, Egerod I, Kanji S, Martin CM, Hutton B, Rose L. **Pharmacological and non-pharmacological interventions to prevent delirium in critically ill patients: A systematic review and network meta-analysis.** *Intensive Care Med.* 2021; 47:943-960.

Summary

Delirium is an acute change in cognition marked by inattention, disorganized thinking, and changes in the level of consciousness. Delirium is highly prevalent in the intensive care setting, affecting up to 80% of ICU patients, and is associated with increased mortality, cognitive impairment, functional decline, and increased long-term care placement post-hospitalization. Non-pharmacological interventions that focus on patient orientation have been shown to reduce the occurrence of delirium among hospitalized patients, but have not been effective among ICU patients. The purpose of this systematic review and network meta-analysis was to evaluate various prevention mechanisms on the occurrence and duration of delirium, duration of mechanical ventilation, length of stay, mortality, and adverse effects. Results showed that when compared with benzodiazepines or placebo, dexmedetomidine likely reduced the occurrence of delirium, and possibly reduced ICU length of stay, but had no impact on other

outcomes. Results showed protocolized sedation to reduce sedative exposure and daily sedation interruption were possibly associated with reduced delirium occurrence, but the evidence was tenuous. Antipsychotics were not associated with reduced delirium occurrence.

Comments

1. This rigorous study demonstrated that only dexmedetomidine use was associated with a likely reduction in the occurrence of delirium in the ICU setting, although reduced sedation exposure was associated with a possible reduction in delirium occurrence.
2. Vigilant efforts to reduce sedative exposure may be the best nursing strategy to reduce ICU delirium.
3. Additional research is needed to adapt effective acute care delirium prevention interventions for the ICU setting.

Other Articles of Interest

Management of Dyspnea

Brackett H, Forma A, Foster LA, Fischer SM. **Compassionate removal of heated high-flow nasal cannula for end of life: Care series and protocol development.** *J Hosp Palliat Nurs.* 2021;23(4):360-366.

Hui D, Mahler DA, Larsson L, Thomas S, Harrison CA, Hess K, Lopez-Mattei J, Thompson K, Gomez D, Jeter M, Lin S, Basen-Engquist K, Bruera E. **High-flow nasal cannula therapy for exertional dyspnea in patients with cancer: A pilot randomized clinical trial.** *Oncologist.* 2021;26(8):e1470–e1479.

Delirium Prevention

Duprey MS, Dijkstra-Kersten SMA, Zaal IJ, Briesacher BA, Saczynski JS, Griffith JL, Devlin JW, Slooter AJC. **Opioid use increases the risk of delirium in critically ill adults independently of pain.** *Am J Respir Crit Care Med.* 2021;204(5):556-572.

Khaing K, Nair BR. **Melatonin for delirium prevention in hospitalized patients: a systematic review and meta-analysis.** *J Psychiatr Res.* 2021;133:181–190.

Palliative Care in the ICU

Metaxa V, Anagnostou D, Vlachos S, et al. **Palliative care interventions in intensive care unit patients.** *Intensive Care Med.* 2021;47:1425-1425.

Simeone IM, Berning JN, Hua M, Happ MB, Balwin MR. **Training chaplains to provide communication-board-guided spiritual care for intensive care unit patients.** *J Palliat Med* 2021;24(2):218-225.

Advances in Symptom Management in Acute and Critical Illness

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ANIMAL-ASSISTED ACTIVITY

Kowalski MO, Smith C, Cole DA, Bersick E, Keleekai-Brapoh N, Panfile P, Abate SV. **A multicenter study of animal-assisted activity and anxiety among older adults hospitalized in acute care settings.** *Appl Nurs Res* 2021; 60: 151-447.

Summary

This multicenter study investigated the effect of animal-assisted activity (visitation of handler-animal team) on anxiety for older adults during hospitalization. Dogs were the only animal included in this study. Anxiety was measured using the Spielberger State-Trait Inventory 6-item (STAI-6). Participants (n = 141) had a median age of 75 and were primarily white (90%). Sixty nine percent of participants were dog owners. Visits lasted a median of 12 minutes (range 9 to 15 minutes). There was a significant reduction in anxiety pre/post visit (median difference -3; p <.001). Gender (identified as female) and dog ownership were associated with a slightly greater reduction in anxiety.

Comments

1. Animal Assisted Activity did result in short term reduction in anxiety for hospitalized older adults, however, this study did not evaluate anxiety beyond the immediate post intervention period.
2. Participants in the study had mild baseline levels of anxiety, the impact of animal-assisted activity in moderate or severe anxiety was not able to be evaluated.

GUIDED IMAGERY

Cole L. **The impact of guided imagery on pain and anxiety in hospitalized adults.** *Pain Manag Nurs* 2021; 22: 465-469.

Summary

This small (n = 36) quality improvement study evaluated the impact of a 30-minute guided imagery intervention

on pain and anxiety of hospitalized adults. Patients 18 years of age or older, English speaking, and referred to the APRN led pain management program were eligible for the study. Outcomes were measured pre-intervention and at 24 and 48 hours and included pain score, anxiety (Beck Anxiety Inventory Score) and analgesic usage (morphine equivalent daily dose). The intervention, a recorded 30-minute guided imagery soundtrack, was delivered twice daily. Anxiety scores decreased by 25% at 24 hours (p< .001) and by 50% at 48 hours (p <.001). Analgesia decreased over time (p = .043). There was no statistically significant change in pain scores.

Comments

1. This small quality improvement study identifies guided imagery as a potential intervention to decrease anxiety and pain medication that can be easily integrated into practice.
2. Limitations include convenience sampling and lack of a control group; however similar results have been found in previous studies.
3. A significant number (n=46) of eligible patients declined to participate, in part due to lack of interest in using guided imagery.

BREATHING TRAINING

Srimookda N, Saensom D, Mistungnern T, Kotruchin P, Ruaisungnoen W. **The effects of training on dyspnea and anxiety among patients with acute heart failure at emergency department.** *Int Emerg Nurse* 2021; 56:1-6.

Summary

Conducted in a university hospital emergency department (ED) in Thailand, this two-group (n = 96) pre-post intervention study evaluated the effectiveness of breathing training on dyspnea and anxiety of acute heart failure patients. The intervention incorporated coaching on pursed-lip breathing, mindfulness

breathing (controlled with counting technique), and muscle relaxation techniques plus usual care. The intervention was initiated 30 minutes after admission to the ED and continued for four hours with patients encouraged to utilize the technique when feeling anxious or breathless. The control group received usual care (Fowlers position, HOB > 60 degrees, oxygen, diuretics). Patients in the experimental group had higher levels of education and more severe symptoms (Killip Class) with no other differences between groups reported at baseline. Dyspnea and anxiety were measured on a 10-point visual analog scale at time of consent and then every hour. While dyspnea and anxiety improved for both groups over the four-hour period, the reduction in dyspnea and anxiety was significantly greater for the intervention group.

Comments

1. Despite higher baseline symptoms, patients in the intervention group had a greater decrease in anxiety and dyspnea of patients admitted to the ED with acute heart failure.
2. Preliminary testing of the intervention established patient comprehension of instruction and materials across education levels including for patients with only a primary school education.

VIRTUAL REALITY

Ridout B, Kelson J, Campbell A, Steinbeck K.

Effectiveness of virtual reality Interventions for adolescent patients in hospital settings: Systematic review. *J Med Internet Res* 2021; 23: e24967.

Summary

This review aimed to identify available evidence for virtual reality interventions for hospitalized adolescent patients. Databases searched included PubMed, PsychINFO, Medline, and Scopus and over 1500 abstracts were reviewed. Studies in the review met the following criteria: adolescents as the target population (ages 10 to 19); immersive VR (passive or active), and a hospital setting but could be inpatient or outpatient. Eight articles met inclusion criteria: four RCTs and 4 single case reports. Control group conditions for RCTs included: standard care or distraction (music, TV,

books). VR was used for distraction from burn pain, pain and anxiety during chemotherapy, pain and anxiety during venipuncture, preoperative anxiety, and well-being during palliative care. Most studies reported significant reductions in pain or anxiety with VR compared to control. Adolescents were positive about use of VR finding it fun and engaging.

Comments

1. There are limited studies of VR that are focused only on adolescents, this review excluded any VR studies that included younger children or adults.
2. Despite limitations, VR is a promising intervention to decrease symptoms and support well-being of hospitalized adolescents.

Other Articles of Interest

Clark J, Archer SK. **Thirst interventions in adult acute care-What are recommended management options and how effective are they?: A systematic review.** *Dimens Crit Care Nurs* 2022; 41: 91-102

Dusek JA, Rivard RL, Griffin KH, Finch MD. **Significant pain reduction in hospitalized patients receiving integrative medicine interventions by clinical population and accounting for pain medication.** *J Altern Complement Med* 2021; 27: S28-S36. (data collected in 2012-2014).

Hagstrom S, Hall J, Sakhitab-Kerestes A, Tracy MF. **Pediatric critical care nurses' practices related to sedation and analgesia.** *Dimens Crit Care Nurs* 2021; 40:280-287.

Joseph AE, Moman RN, Barman RA, Kleppel DJ, Eberhart ND, Gerber DJ, Murad MH, Hooten WM. **Effects of slow deep breathing on acute clinical pain in adults: A systematic review and meta-analysis of randomized controlled trials.** *J Evid Based Integr Med* 2022; 27: 1-10.

Kusi-Appiah E, Karanikola M, Pant U, Meghani S, Kennedy M, Papathanassoglou E. **Tools for assessment of acute psychological distress in critical illness: A scoping review.** *Aust Crit Care* 2021; 34:460-472.

Caregiver Palliative Interventions

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PALLIATIVE INTERVENTIONS FOR CANCER CAREGIVERS

Applebaum AJ, Roberts KE, Lynch K, Gebert R, Loschiavo M, Behrens M, et al. **A qualitative exploration of the feasibility and acceptability of Meaning-Centered Psychotherapy for Cancer Caregivers.** *Palliative and Supportive Care* 2022 Jan 26;1–7.

Summary

The purpose of this study was to refine the manual for the intervention Meaning-Centered Psychotherapy for Cancer Caregivers (MCP-C). MCP-C was developed from Meaning-Centered Psychotherapy (MCP), an intervention designed for patients with advanced cancer that has been shown to decrease existential distress and increase spiritual well-being. MCP-C is a unique intervention that addresses the caregiver existential distress by helping them connect and reconnect with meaning and purpose in their life. In this seven session intervention, caregivers are educated about four sources of meaning (historical, attitudinal, creative, and experiential) and how to use these sources of meaning as resources that can buffer their burden and distress during their caregiving journey and beyond. In this feasibility and acceptability study a random selection of 10 caregivers who were part of a randomized controlled trial testing MCP-C with caregivers of patients with glioblastoma multiforme (n = 60), were interviewed about their experiences with the intervention. Four themes were uncovered: MCP-C validated caregivers experiences; it helped them reframe their caregiving identity as part of their larger self-identity; it enabled caregivers to find ways to assert agency through caregiving; and the structure and sequence of MCP-C was feasible and accessible.

Comments

1. MCP-C is one of few caregiver interventions that addresses the existential distress of caregivers.

2. Some caregivers in this intervention would have liked to have received MCP-C earlier in their caregiving journey.
3. MCP-C was initially delivered in person for 18 months and then was pivoted to video conferencing for the remainder of the trial – there were no differences in attrition for caregivers based on mode of delivery; however, recruitment efforts improved when in-person contact was not required.
4. Caregivers shared that MCP-C helped them focus on themselves and validated their caregiving challenges.
5. MCP-C participants also shared that the intervention helped them feel more connected to their loved one and address their anticipatory grief.

PALLIATIVE INTERVENTIONS FOR CANCER CAREGIVERS

Aubin M, Vézina L, Verreault R, Simard S, Desbiens J-F, Tremblay L, et al. **A randomized clinical trial assessing a pragmatic intervention to improve supportive care for family caregivers of patients with lung cancer.** *Palliative and Supportive Care* 2021; 19(2):146–53.

Summary

Family caregivers of patients with lung cancer may experience extreme distress and burden due to their loved one's rapid cancer progression and functional decline; however, caregivers' needs are not often addressed in routine oncology practice. A pragmatic intervention for caregivers of lung cancer patients was developed in which caregivers receive: (1) routine distress screening; (2) one-on-one contact with an oncology nurse to discuss their distress screening and empower the caregiver to develop problem-solving and self-care strategies; (3) the oncology nurse served as a liaison between the caregiver and family physician to share the distress screening and involve them in caregiver supportive care. This study reports the results of a randomized clinical trial including the relevance

and acceptability of the intervention for family caregivers of lung cancer patients. A total of 109 caregivers participated (n = 54 for intervention and n = 55 usual care). Caregiver distress, anxiety, and depression significantly decreased, and quality of life increased over time in both intervention and control groups. Caregivers in the intervention were significantly more prepared than those in the control group. Caregivers appreciated the intervention and found it reassuring but recommended that distress screening occur during transition points (diagnosis, progression, or new symptoms).

Comments

1. This is a pragmatic intervention that integrates the care team into the care of the caregivers. It holds potential as a scalable intervention that can address caregiver needs as it was integrated into routine patient visits; however, the intervention requires further refinement.
2. Caregivers reported mixed preferences for sharing their distress screening with their family physician; while some thought it would help the provider understand what they were going through, others shared that the family physician was not well positioned to help them.
3. This intervention demonstrated improvement in caregiver preparedness but not the primary outcome measure. The researchers surmise this may be attributed to underuse of the intervention by the caregivers in the study, the timing of the primary outcome measure (every two months) and a fixed 3-month interval between data collection (non-differential information bias).
4. Many of the enrolled caregivers had high levels of distress throughout the study emphasizing the need for attention to these caregivers. Attrition was high (40%) primarily due to death of the patient.
5. Working with the family physician did not yield the expected results; it was dependent on the caregivers relationship with the family physician. It may also speak to challenges in collaboration between oncology and primary care.

PALLIATIVE INTERVENTIONS FOR CANCER CAREGIVERS

Dionne-Odom JN, Wells RD, Guastaferrero K, Azuero A, Hendricks BA, Currie ER, et al. **An early palliative care telehealth coaching intervention to enhance advanced cancer family caregivers' decision support skills: The CASCADE Pilot Factorial Trial.** *Journal of Pain and Symptom Management.* 2022 Jan;63(1):11–22.

Summary

Limited interventions address the decision-support skills of family caregivers. This pilot study used a single blind randomized factorial trial (2x2x2) to determine the feasibility of CASCADE (Care Supporters Coached to be Adept Decision Partners). The intervention was delivered via telehealth by palliative care coaches (nurse and lay navigator). The components of CASCADE include: (1) social support effectiveness psychoeducation (1 session or 3 sessions); (2) decision support communication training; and (3) Ottawa decision guide training. Participants were randomized to 1 of 8 experimental conditions and received calls lasting up to 30 minutes with a trained palliative care coach (one to five weekly calls and one monthly follow-up call). Primary outcomes were feasibility and acceptability and a secondary outcome was the preliminary efficacy of the intervention (patient positive decision influence and patient and caregiver distress). There were 132 patients and 83 caregivers approached, and 59 patients and 59 caregivers (46 dyads) enrolled in the study. At least 80% of data collection points were completed by patients and caregivers; caregivers completed 78% of intervention sessions. Acceptability as assessed by whether caregivers would recommend the intervention was rated 9.9/10 (10 extremely likely to recommend) and individual intervention components were rated as 7.7 to 9.5/10.

Comments

1. The intervention is theoretically based on Social Support Effectiveness Theory and the Ottawa Decision Support Framework.
2. Some participants shared that CASCADE came later in their cancer caregiving journal than they would have liked as topics focused on decisions they already made. This supports the immense need for such an intervention early on after a cancer diagnosis.

3. This research design (and also following MOST framework) allowed for determination of the intervention components that may be most helpful for caregivers. This is notably one of few factorial trial designs in the palliative care intervention literature. Preliminary efficacy data suggested that the training for decision-making support and the Ottawa Decision Guide were most beneficial.
4. The participants were recruited 30 to 90 days after diagnosis and yet, a few participants wished the intervention was delivered sooner – this may speak to rapid progression of some cancers.
5. The overall enrollment rate of 55.4% is higher than that reported in other recent cancer caregiver trials (33%). There was a more diverse sample in this study (30.4% African American/Black). These successes were attributed to a verbal consent process that occurred in the participant's homes via phone versus in the busy health care setting and a racially diverse recruitment team.

PALLIATIVE INTERVENTIONS FOR CANCER CAREGIVERS

Wang C, Chen J, Wang Y, Xu W, Xie M, Wu Y, et al. **Effects of family participatory dignity therapy on the psychological well-being and family function of patients with haematologic malignancies and their family caregivers: A randomised controlled trial.** *International Journal of Nursing Studies* 2021 Jun;118:103922.

Summary

Patients diagnosed with hematological malignancies undergo high risk treatments and depend on their family caregivers for support. Caregivers experience distress and burden; however, most only receive informational support. The purpose of this single blind, two-arm group, randomized trial was to determine the effects of family participatory dignity therapy. The intervention is based on dignity therapy in which a legacy document is created to decrease patient distress and promote dignity. The family dignity intervention extends dignity therapy benefits to caregivers, and includes an additional ten questions specifically for family caregivers to promote conversation between the patient and caregiver regarding their true feelings. Based on the words of participants and their selected photos and music, the end result is a vivid e-product that can be shared in whatever way the patient and

caregiver choose. The intervention was delivered by a trained nurse or physician. A total of 68 dyads out of 112 approached participated in the study and were randomized to intervention (n=33) or control (n=33) groups. Patients in the intervention group experienced greater hope, spiritual well-being, and family cohesion and family adaptability. Caregivers in the intervention experienced lower anxiety and depression scores initially, and higher family cohesion and adaptability versus control.

Comments

1. Family caregivers (88.9%) and patients (85.2%) who participated in the intervention had positive evaluations of the intervention and were willing to recommend the intervention to other patient-caregiver dyads.
2. Dignity therapy is theoretically based on an empirical dignity model. Authors of this study suggest that enhancement of family communication through dignity therapy can buffer both patient and caregiver distress.
3. Recruiting dyads is challenging as indicated by 39.3% rate of decline among patients and caregivers approached.
4. Intervention effect assessment occurred in this study at one-week (T1), four-weeks (T2), and eight weeks (T3). The decrease in anxiety and depression for caregivers was not sustained. This could be explained by new caregiving challenges or other changes in the lives of caregivers.
5. Dignity therapy overall showed positive effects on both the patient and caregiver; however, dyads must be willing to accept and commit to engaging in the intervention activities.

PALLIATIVE INTERVENTIONS FOR CAREGIVERS OF PATIENTS WITH LUNG DISEASES

Lindell KO, Klein SJ, Veatch MS, Gibson KF, Kass DJ, Nouraie M, et al. **Nurse-led palliative care clinical trial improves Knowledge and preparedness in caregivers of patients with idiopathic pulmonary fibrosis.** *Annals ATS* 2021 Nov;18(11):1811–21.

Summary

Patients with Idiopathic pulmonary fibrosis (IPF) and their caregivers are not well prepared for the symptom

burden and distress that occurs during this life-limiting disease. The purpose of this randomized controlled trial was to determine the feasibility, acceptability and efficacy of an early, nurse-led palliative care intervention – A Program of SUPPORT (Symptom management; Understanding the disease, Pulmonary rehabilitation; Palliative care; Oxygen therapy; Research Participation, and Transplantation) for patients with IPF and their caregivers. Patient and family caregiver dyads were recruited within 1 month of the patient's IPF diagnosis. The intervention was delivered during routine clinic visits (3 visits with interventionist). A SUPPORT booklet was provided and the following were addressed at the preferred pace of the dyad: (1) education about disease course and prognosis, (2) self-management, (3) caring for the caregiver, and (4) planning for the future and shared end of life goals. A total of 76 out of 136 eligible dyads participated in the study (intervention = 50 and control = 26). There were 35 dyads that completed the intervention (70%). Patients and caregivers were satisfied with the intervention booklet (median = 9/10) and rated the nurse interventionist as 10/10. Caregivers had significant improvements in knowledge, preparedness, and confidence.

Comments

1. This is the first study to test a nurse-led early palliative intervention for IPF patients and caregivers.
2. For advance care planning 66% of patients completed documents in the intervention group versus 33% in the control arm. For caregivers 58% completed an advance directive versus 46% in the control group.
3. There was a high intervention completion rate (70%).
4. The intervention was tailored to the preferred pace of the patient and caregiver, and all requested that the nurse interventionist read the SUPPORT booklet in entirety to them at the first visit with questions at follow-up visits.
5. Although caregiver outcomes of knowledge, preparedness and confidence improved, patient quality of life and symptom burden did not improve. This may speak to the challenges of managing this progressive disease and patient

fatigue that can impact participation in an intervention. The authors suggest that use of telemedicine may better address the needs of patients who may be too exhausted to participate after a clinic visit.

PALLIATIVE INTERVENTIONS FOR CAREGIVERS IN THE INTENSIVE CARE UNIT

Cox CE, Riley IL, Ashana DC, Haines K, Olsen MK, Gu J, et al. **Improving racial disparities in unmet palliative care needs among intensive care unit family members with a needs-targeted app intervention: The ICUconnect randomized clinical trial.** *Contemporary Clinical Trials* 2021 Apr;103:106319.

Summary

There is documented variability in the quality of care delivered to Black patients and their family members in the ICU. Poor communication, inadequate support from the health care team, and inadequate patient symptom management are identified gaps in palliative care for this population. To address this, the intervention ICUconnect was developed to improve the quality of communication and palliative care in the ICU. ICUconnect is an app that guides the interaction between family members and clinicians and encourages family engagement through a question coaching feature. The app also links families to information on ICU practices and therapies. This protocol paper describes the two-arm, parallel group mixed methods clustered RCT with three month follow-up. The study also includes an exploratory aim to understand Black patients and family members perceptions and experiences with the app, and their palliative care needs. The primary outcome is The Needs; Existential concerns; Symptoms; and Therapeutic intervention (NEST) scale completed by family members. Secondary outcomes include psychological distress among family members (anxiety, depression, and post-traumatic stress), goal concordant care, and patient-centeredness of care (3 domains of Interpersonal Processes of Care Instrument). The trial started in April 2019 and 83 family members have been enrolled.

Comments

1. This trial is one of three that are occurring within the Duke University Center Research to Advance Healthcare Equity – the goal is to test interventions

that reduce racial and ethnic disparities. The app is innovative in that it is tailored to family identified needs.

2. The intervention aims to improve the quality of care and address unmet needs for both Black and White patients and families in the ICU. The team identified four gaps in care that require rapid improvement: (1) infrastructure for primary palliative care; (2) family engagement, (3) addressing unmet palliative care needs, and (4) improving clinician communication.
3. A usability pilot was conducted with the app before developing the RCT to further refine the app with all stakeholders.
4. Randomization occurs at the level of the ICU attending (patients clustered at this level).
5. Due to COVID-19, changes were made to overcome in-person informed consent in collaboration with ICU teams. The team worked with the ICU team to reach families via phone introductions and developed a study 'infomercial' so potential participants could get a sense of the trial. Consent was also shifted to REDCap for electronic capture.

Other Articles of Interest

Bonner GJ, Freels S, Ferrans C, Steffen A, Suarez ML, Dancy BL, et al. **Advance care planning for African American caregivers of relatives with dementias: Cluster randomized controlled trial.** *American Journal of Hospice and Palliative Care* 2021 Jun;38(6):547–56.

Bužgová R, Kozáková R, Bar M. **Satisfaction of patients with severe multiple sclerosis and their family members with palliative care: Interventional study.** *American Journal of Hospice and Palliative Care* 2021 Nov;38(11):1348–55.

Kashimura M, Rapaport P, Nomura T, Ishiwata A, Tateno A, Nogami A, et al. **Acceptability and feasibility of a Japanese version of STRategies for Relatives (START-J): A manualized coping strategy program for family caregivers of relatives living with dementia.** *Dementia* 2021 Apr;20(3):985–1004.

Lund L, Ross L, Petersen MA, Rosted E, Bollig G, Juhl GI, et al. **Process, content, and experiences of delivering the Carer Support Needs Assessment Tool Intervention (CSNAT-I) in the Danish specialised palliative care setting.** *Supportive Care in Cancer*. 2022 Jan;30(1):377–87.

Oliver DP, Rolbiecki AJ, Washington K, Kruse RL, Popejoy L, Smith JB, et al. **A pilot study of an intervention to increase family member involvement in nursing home care plan meetings.** *J Applied Gerontology* 2021 Sep;40(9):1080–6.

Porter LS, Steel JL, Fairclough DL, LeBlanc TW, Bull J, Hanson LC, et al. **Caregiver-guided pain coping skills training for patients with advanced cancer: Results from a randomized clinical trial.** *Palliative Medicine* 2021 May;35(5):952–61.

Rosenberg AR, Zhou C, Bradford MC, Barton K, Junkins CC, Taylor M, et al. **Parent perspectives after the PRISM-P randomized trial: A Mixed-Methods Analysis.** *Journal of Palliative Medicine* 2021 Sep 1;24(10):1505–15.

Thompkins JD, Needle J, Baker JN, Briggs L, Cheng YI, Wang J, et al. **Pediatric advance care planning and families' positive caregiving appraisals: An RCT.** *Pediatrics* 2021 Jun 1;147(6):e2020029330.

Walker H, Miller MC, Cowfer B, Akard T, Gilmer MJ. **The effects of animal-assisted interactions on quality of life in children with life-threatening conditions and their parents.** *International Journal of Palliative Nursing*. 2021 Dec 2;27(10):524–30.