Quality of life at the end of life for the patient on parenteral nutrition transitioning to hospice: A focus on ethical principles

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Optum

Background

Clinical ethics is grounded in a patient centered approach, focused on patient preferences and balancing benefits of continuation of therapies to inherent burdens or risks. This abstract targets a unique subgroup of patients receiving preexisting parenteral nutrition (PN) due to a non-functioning gastrointestinal (GI) tract who desire continuation of PN with transfer to hospice. Diagnoses include obstructing, metastatic tumors of the GI tract requiring gastric and/or intestinal decompression. PN is an established therapy favorably impacting quality of life (QOL) and functional status. Transfer of care to hospice on PN may lead to unforeseen challenges related to cost considerations and complexity. Patients and/or surrogate decision makers (SDM) may decline hospice and its associated benefits if unable to continue PN fearing expedited death from starvation and dehydration as opposed to disease progression.

Methods

This home infusion provider surveyed 50 hospice agencies nationwide to investigate acceptance of patients on PN. A case study highlights a patient desiring continuation of PN with transition to hospice (Image 1). Literature reviews and a hospice nurse interview (Image 2) provided insight on applying ethical principles into clinical practice.

Image 1. A case study examining a patient on PN and transition to hospice

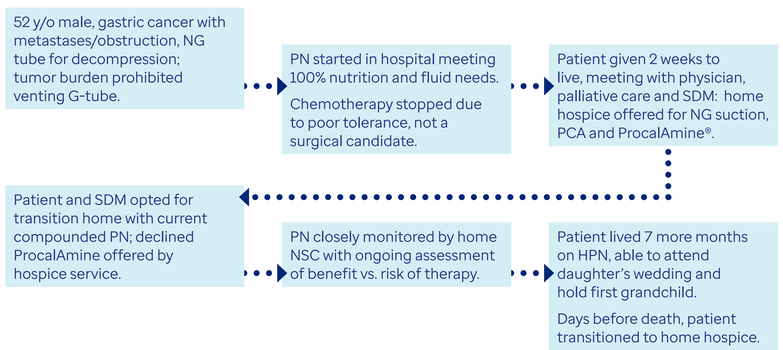


Image 2. Literature review and hospice professional interviews

ASPEN

The four ethical principles of autonomy, beneficence, nonmaleficence and justice should be applied, and that for individuals with cancer, use of a patient-centered communication style incorporates a shared decision-making style.[1]

The American Hospice Foundation

There are situations in which ANH may be more beneficial than harmful, for example when a bowel blockage develops such as in the spread of ovarian cancer, but the person is otherwise fairly functional, TPN has been helpful in allowing that person to live and function longer than without treatment.[2]

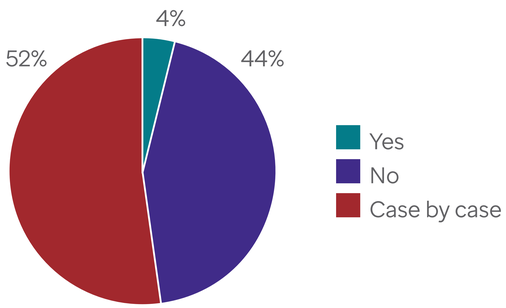
Hospice nurse

- When a patient is faced with forgoing an established therapy, such as PN, emotional distress may compound the already difficult healthcare decisions.
- Is quality of life being preserved by therapy?
- PN modality in the setting of metastatic cancer with obstruction benefits quality of life and comfort issues.

Results

A survey of hospice agencies found 4% accepted patients on PN, 44% didn't accept patients on PN and 52% may accept on a case-by-case basis requiring final review by the hospice medical director (Image 3). Barriers to continuing PN included cost, complexity of infusion and goals not aligning with end-of-life care. Premixed PN, "PN lite" or D5W may be offered to decrease cost, perceived lower complexity and misconception lab monitoring is unnecessary. Internal analysis revealed a 28% cost difference comparing compounded PN to premixed, $120 versus $87/day, possibly driving decision-making.

Image 3. Survey of hospice acceptance of PN patients



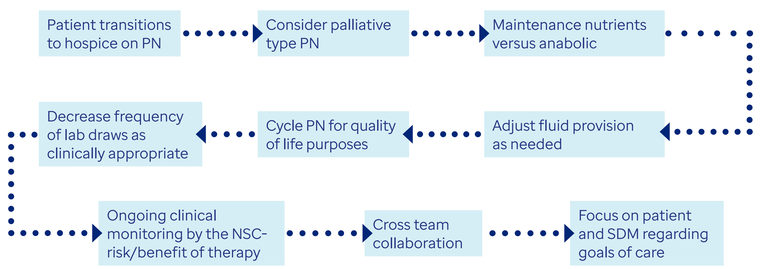
Conclusion

PN patients transitioning to hospice may be presented with various scenarios:

- Scenario I: Patient is accepted by hospice with continuation of PN. Transition to palliative or premixed PN should be assessed and monitored by the nutrition support clinician (NSC) to ensure clinical appropriateness and ongoing safe PN. Formula substitutions must ensure necessary levels of electrolytes and volume with high GI losses. PN is a lab dependent infusion warranting lab surveillance; decrease in lab frequency may be considered once patient equilibrated on desired formulation.
- Scenario II: Patients may decline hospice if unable to continue PN and opt to continue with home healthcare and the addition of palliative care services with ongoing monitoring of PN by the home infusion NSC.
- Scenario III: Transition to hospice and discontinue PN.

Ethical principles must guide clinical decision making to support patient best interests, autonomy and QOL applying continuous risk/benefit analysis and evidence-based medicine as an integral part of the transition process. NSC's are a crucial part of the interdisciplinary team and cross team collaboration with hospice teams is essential to avoid adverse complications associated with PN and provide ongoing clinical monitoring and education consistent with goals of care (Image 4). A patient centered approach amongst a shared decision-making process is essential to reach final informed decisions in the end-of-life setting.

Image 4. Nutrition support clinician pathway for PN and the patient on palliative care or hospice



1. Baird Schwartz D et al. Ethical Aspects of Artificially Administered Nutrition and Hydration: An ASPEN Position Paper. Nutr Clin Pract. 2021; 36: 254-267
2. Artificial Nutrition and Hydration at the End of Life: Beneficial or Harmful? | American Hospice Foundation. Arenella, Cheryl M.D. MPH. Accessed 7.7.22.