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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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 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: A focus on ethical principles

Image 1. A case study examining a patient on PN and transition to hospice
52 y/o male, gastric cancer with metastases/obstruction. NG tube for decompression; tumor burden prohibited venting GI tube
PN started in hospital meeting 2000cal/kg nutrition and fluid needs
Chemotherapy stopped due to poor tolerance, not a surgical candidate
Patient given 2 weeks to live, meeting with physician
PN modality in the setting of metastatic cancer with obstruction benefits quality of life and comfort issues
Patient and SDM opted for transition home with current compounded PN; declined ProcalAmine® offered by hospice service
Patient lived 7 more months on HPN, able to attend daughter's wedding and hold first grandchild
Patient transitions to home hospice

Conclusion
PN patients transitioning to hospice may be presented with various scenarios:
• Scenario I: Patient is accepted by hospice with continuation of PN.
• Scenario II: Patient may decline hospice and 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 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.

The American Hospice Foundation
There are situations in which ANH may be more beneficial than harmful, for example when a bowel obstruction 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.

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

Image 3. Survey of hospice acceptance of PN patients

Yes
No
Case by case

52%
4%
44%

52%
4%
44%

Patient transitions to hospice on PN
Maintenance nutrients versus anabolic
Consider palliative type PN
Decrease frequency of lab draws as clinically appropriate
Cycle PN for quality of life purposes
Focus on patient and SDM regarding goals of care
Ongoing clinical monitoring by the NSC
Cross team collaboration
Adjust fluid provision as needed