HPNA Position Statement
Medically Administered Nutrition and Hydration

It is the position of the Hospice and Palliative Nurses Association (HPNA) that it is medically, ethically, and legally acceptable for patients with serious illness or their surrogate decision-makers to choose to initiate, withhold, or withdraw medically administered nutrition and hydration (MANH). [1-6]

Clinical Practice

- Hospice and palliative nurses caring for patients and families deliberating whether to initiate, to withhold, or to withdraw MANH are responsible to ensure:
  - Patient autonomy;
  - Education regarding benefits and burdens of interventions; and
  - Informed decision-making based on the patient's clinical condition, goals, values, beliefs, culture, ethnicity, and religion.6,7,8
- Hospice and palliative nurses must ensure that discussions and decisions regarding initiating, withholding, or withdrawing MANH in advanced illness and end of life are guided by ethical and cultural considerations; patient goals of care, preferences, and beliefs; and evaluation of the benefits and burdens of MANH.9,10
- Hospice and palliative nurses must ensure that patient and surrogate decision- maker wishes regarding MANH are congruent with advance care planning documents, such as advance directives, living wills, in-hospital and out-of-hospital orders for life sustaining treatments, or nursing documentation.4,11-13
- Hospice and palliative nurses must ensure interdisciplinary team support for patients' and families' decision-making related to MANH.

Education

- Hospice and palliative nurses must have education about MANH in the healthcare setting, specifically that MANH is considered a medical intervention.9,14
- Hospice and palliative nurses must affirm that different cultures and religions view MANH as a necessary treatment since administration of food and water is a basic human right.15,16
- Hospice and palliative nurses, patients, families, and other caregivers must be educated about the natural and expected trajectory of advanced illness and the dying process, and their effects on nutrition and fluid status.17

Policy and Advocacy

- Hospice and palliative nurses must understand MANH as an established medical intervention in which common themes include:1-3,6,10
  - Decisions about MANH need to reflect the patient's and family's values, preferences, beliefs, religion, ethnicity, and culture.6

    - MANH is a medical intervention that requires consideration of its benefits and burdens for the patient, family, and care team.
    - MANH may be declined, withheld, or withdrawn based on the patient's clinical condition and goals of care.6,18,19
- Hospice and palliative nurses must ensure the development of policies to guide a decision-making process for resolving disagreements about MANH among patients, families, surrogates, and healthcare team members.5,8
- Hospice and palliative nurses must ensure that patients employ surrogate decision-makers, the legal assignment of a surrogate decision-maker for health care, advance directives, or living wills to document choices and values that guide care, such as MANH, at the end of life in the event decision-making capacity is absent.13,20

Research

- Hospice and palliative nurses must promote more research about MANH along with the benefits and burdens, because the current literature is limited and equivocal in that some patients receive no benefit, whereas others receive benefit from MANH.6,17

Background

Patients with serious illness often experience a decline in appetite, loss of interest in eating and drinking, and weight loss. In addition, patients may experience difficulty with food intake or swallowing, rendering them unable to take food and fluids by mouth or will refuse food. Diminished or cessation of intake of food and fluids raises the topic of MANH.

In a culture where food dominates an individual's daily existence, the lack of nutrition intake evokes emotions steeped in culture, ethnicity, and religion. In many cultures, providing food and fluids is synonymous with caring, hope, and comfort, and the administration of food and fluids is a basic human right and withholding them is prohibited.6,21 Over the years, terminology has changed from *artificial nutrition and hydration* to *medically administered nutrition and hydration* to reflect that it is a procedure and to reduce the judgment about its use.

In most circumstances, the diminished or cessation of food and fluid intake is a major aspect of advanced illness that causes distress for patients, families, and caregivers. There is often concern about malnutrition, which leads to fatigue, lack of energy, hunger, and/or dehydration, resulting in symptoms, such as thirst, dry mouth, headache, delirium, nausea, vomiting, and abdominal cramps.6 Originally developed to provide short-term support for acutely ill patients, MANH is often used to provide a bridge to recovery or to meet therapeutic goals of prolonging life.

Ensuring that patients and families have enough information to make well-informed decisions is difficult. Although the perception is that MANH prolongs life, reduces aspiration, and promotes

quality of life, this is not supported by the literature. In fact, there are few well-designed studies that have examined the physical effectiveness of MANH.11

MANH requires the insertion of a gastrostomy tube, nasogastric tube, or central intravenous line to administer fluids and nutrition. Potential burdens of MANH are contingent on the route of administration and include aspiration, diarrhea (with enteral feeding), sepsis (with total parenteral nutrition), pressure sores, skin breakdown, edema, and complications due to fluid overload.2,6 In addition, it may be necessary to physically restrain patients with cognitive issues, agitation, or delirium who receive MANH to prevent them from removing a gastrostomy tube, nasogastric tube, or central intravenous line.4,6

MANH may offer symptomatic benefits to patients with advanced illness in the setting of reversible or acute condition, such as the reversal of myoclonus, opioid toxicity, electrolyte imbalances, or mechanical obstruction. For patients experiencing temporary symptoms of nausea, vomiting, or diarrhea, a short-term trial of hydration can assist with electrolyte imbalances and symptoms. Finally, there may be psychological and spiritual benefit to patients and families, if they believe that food and fluids are a basic human right or religious necessity.14,21

A patient's prognosis and perception of quality of life may determine the use of MANH. If a patient has a long prognosis and still has quality of life, MANH may be appropriate. In hospice, when a patient must have a prognosis of 6 months or less and forgo extraordinary measures, MANH may not be appropriate. If there is uncertainty about whether a patient will benefit from MANH, a time-limited trial, with specific goals of therapy may be useful.6 The caregiving team should support the patient and family in creating goals for treatment, as MANH can be withdrawn if it is not achieving its desired purpose.

The focus of hospice and palliative care is to minimize suffering and discomfort. MANH interventions should be evaluated for each individual, utilizing evidence-based practices that reflect the benefits and burdens, the clinical circumstances, and the overall goals of care. MANH decisions are complex and must be guided by the ethical principles of autonomy, beneficence, and nonmaleficence. The right of competent adults to decide whether to accept or decline specific medical treatments, such as MANH, is now well established through legal precedent.

Competent adults may express their decision about MANH and other therapies through advance directives, which should guide surrogate decision-makers in the event the patient no longer has decision-making capacity. The right of parents to forego or withdraw MANH for children who are unlikely to benefit from the therapy also needs to be honored.18 When patients are incapable of understanding their prognosis and treatment choices or are unable to express their wishes, advance directives and surrogate decision-makers must be invoked.

Hospice and palliative nurses are instrumental in initiating and facilitating discussions and decisions regarding the use of MANH in patients experiencing serious illness. As with any palliative care intervention, the hospice and palliative nurse seeks to understand the patient's illness trajectory, as well as patient and family goals of care, which can be influenced by a person's education, health literacy, culture, ethnicity, or religion. Such views should be assessed in a culturally sensitive setting with respect to patient and family wishes.2,13

No matter the circumstance, hospice and palliative nurses must be aware of the social and cultural perceptions of MANH that may conflict with their bias about the use of this intervention. This allows the nurse to ensure the patient and family identify an intervention congruent with their values, preferences, and beliefs. In addition, interdisciplinary team involvement is imperative to assist with patient-centered goals of therapy in relation to sociocultural, financial, and spiritual needs.6,13 Chaplains, spiritual leaders, ethicists, and other resources to assist with the understanding of pertinent cultural values should be consulted, enabling the hospice and palliative nurse to ensure that patients' spiritual needs are addressed by those qualified to do so.10

Conclusion

Caring for patients with serious illness requires familiarity with the trajectory of the advancing condition, particularly as an individual loses interest or ability to eat. MANH is a frequent issue that arises for patients and families. Hospice and palliative nurses must ensure that decisions regarding initiating or withholding MANH are guided by patient autonomy; informed decision-making through knowledge of its benefits and burdens; and adherence to ethical principles based on the patient's clinical condition, goals, values, beliefs, ethnicity, culture, and religion.4,6

Definition of Terms

Decision-making capacity: The ability of a person to make decisions. Adults are presumed capable unless declared incompetent by a court of law or judge. Some states require two physicians to determine decisional capacity of an individual. Decisional capacity is specific to a point in time and a specific decision. A clinical evaluation of capacity centers on a person's ability to take in information, understand the relevant information and apply it to their own condition, have insight into the condition and consequences of treatment options, and be able to communicate the decision and reasoning for choices.13,22

Forgoing life-sustaining treatment: To do without a medical intervention that would be expected to extend the patient's life. Forgoing includes withholding (non-initiation) and withdrawing (stopping) any therapy that will prolong life.18,19

Life-sustaining therapy: The use of any medical treatment, intervention, technology, procedure, or medication that averts death, whether or not the treatment affects the underlying life-threatening diseases or biological processes. Examples include cardiopulmonary resuscitation, antibiotics, invasive or noninvasive mechanical ventilation, all types of dialysis, blood transfusions, and medically administered nutrition and hydration.18,19

Medically administered nutrition and hydration (MANH): Receiving nutrition in any form other than the taking in of food and fluid through the mouth (orally). This can be achieved through a nasogastric tube (NG tube), a gastrostomy tube (G tube or PEG tube), an intravenous tube (IV), subcutaneous access, or through total or peripheral parenteral nutrition (TPN/PPN).

Palliative care: "Patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice."23

References

1. American Nurses Association. *Position Statement: Nutrition and Hydration at the End of Life.* Silver Spring, MD: ANA. 2017. https://www.nursingworld.org/~4af0ed/globalassets/docs/ana/ethics/ps_nutrition-and-hydration-at- the-end-of-life_2017june7.pdf. Accessed December 19, 2019.

2. American Academy of Hospice and Palliative Medicine. *Statement on Artificial Nutrition and Hydration Near the End of Life*. Chicago, IL: AAHPM. September 13, 2013. http://aahpm.org/positions/anh. Accessed August 17, 2019.

3. National Hospice and Palliative Care Organization. *Hospice and Palliative Care: Ethical Marketing Practices.* Alexandria, VA: NHPCO. June 3, 2011. https://www.nhpco.org/wp-content/uploads/2019/04/NHPCO_Ethical_Marketing_Statement_June11.pdf. Accessed December 19, 2019.

4. American Geriatrics Society Ethics Committee and Clinical Practice and Models of Care Committee. American Geriatrics Society feeding tubes in advanced dementia position statement. *J Am Geriatr Soc*. 2014;62(8):1590-1593. doi:10.1111/jgs.12924

5. Brody H, Hermer L, Scott L, Gumbles LL, Kutac JE, McCammon S. Artificial nutrition and hydration: the evolution of ethics, evidence, and policy. *J Gen Intern Med.* 2011;26(9):1053-1058. doi:10.1007/s11606-011-1659-z

6. Borrocas A, Geppert C, Durfee SM, et al. A.S.P.E.N. ethics position paper. *Nutr Clin Pract.* 2010;25(6):672-679. doi:10.1177/0884533610385429

7. Danis M. *Stopping Nutrition and Hydration at the End of Life*. 2018. Waltham, MA:Up-To-Date. https://www.uptodate.com/contents/stopping-nutrition-and-hydration-at-the-end-of- life?search=stopping-nutrition-and-hydration-at-the-end-of-life.&source=search_result&selectedTitle=1~150&usage_type=default&display_rank=1 Accessed December 19, 2019.

8. Coyle N, Kirk T. Navigating ethical discussions in palliative care. In: Dahlin. C, Coyne P, Ferrell B, eds. *Advanced Practice Palliative Nursing.* New York, NY: Oxford University Press; 2016:405-413.

9. Geppert CM, Andrews MR, Druyan ME. Ethical issues in artificial nutrition and hydration: A review. *JPEN J Parenter Enteral Nutr.* 2010;34(1):79-88. doi:10.1177/0148607109347209.

10. Druml C, Ballmer PE, Druml W, et al. ESPEN guideline on ethical aspects of artificial nutrition and hydration. *Clin Nutr.* 2016;35(3):545-556. doi:10.1016/j.clnu.2016.02.006.

11. Bukki J, Unterpaul T, Nubling G, Jox RJ, Lorenzl S. Decision making at the end of life—cancer patients' and their caregivers' views on artificial nutrition and hydration. *Support Care Cancer.* 2014;22(12):3287-3299. doi:10.1007/s00520-014-2337-6
12. Arenella C. Artificial nutrition and hydration: having the conversation. *Today's Geriatric Medicine.* 2013;7(5):24. https://www.todaysgeriatricmedicine.com/archive/0914p24.shtml. Accessed December 19, 2019.

13. Palmer BW, Harmell AL. Assessment of healthcare decision-making capacity. *Arch Clin Neuropsychol.* 2016;31(6):530–540. doi:10.1093/arclin/acw051

14. Gent MJ, Fradsham S, Whyte GM, Mayland CR. What influences attitudes towards clinically assisted hydration in the care of dying patients? A review of the literature. *BMJ Support Palliat Care.* 2015;5(3):223-231. doi:10.1136/bmjspcare-2013-000562

15. Alsolamy S. Islamic views on artificial nutrition and hydration in terminally ill patients. *Bioethics.* 2014;28(2):96-99. doi:10.1111/j.1467-8519.2012.01996.x

16. Rapoport A, Shaheed J, Newman C, Rugg M, Steele R. Parental perceptions of forgoing artificial nutrition and hydration during end-of-life care. *Pediatrics.* 2013;131(5):861-869. doi:10.1542/peds.2012-1916.

17. Good P, Richard R, Syrmis W, Jenkins-Marsh S, Stephens J. Medically assisted hydration for adult palliative care patients. *Cochrane Database Syst Rev.* 2014;4. doi:10.1002/14651858.CD006273.pub3.

18. Ko D, Blinderman C. Withholding and withdrawing life-sustaining treatment (including artificial nutrition and hydration. In: Cherny N, Fallon M, Kaasa S, Portenoy RK, Currow D, eds. *Oxford Textbook of Palliative Medicine.* 5th ed. New York, NY: Oxford University Press; 2015:323-334.

19. Plakovic K. Discontinuation of life-sustaining therapies. In: Dahlin C, Coyne P, Ferrell B, eds. *Advanced Practice Palliative Nursing.* New York, NY: Oxford University Press; 2016:479-486.

20. Hellmann J, Williams C, Ives-Baine L, Shah PS. Withdrawal of artificial nutrition and hydration in the neonatal intensive care unit: parental perspectives. *Arch Dis Child Fetal Neonatal Ed.* 2013;98(1):F21-F25. doi:10.1136/fetalneonatal-2012-301658.

21. Cohen MZ, Torres-Vigil I, Burbach BE, de la Rosa A, Bruera E. The meaning of parenteral hydration to family caregivers and patients with advanced cancer receiving hospice care. *J Pain Symptom Manage.* 2012;24(5):855-865. doi:10.1016/j.jpainsymman.2011.06.016.

22. Barstow C, Shahan B, Roberts M. Evaluating Medical Decision-Making Capacity in Practice. *Am Fam Physician.* 2018;98(1):40-46. https://www.aafp.org/afp/2018/0701/p40.html. Accessed December 19, 2019.

23. Centers for Medicare and Medicaid Services. Medicare benefit policy manual chapter 9 - coverage of hospice services under hospital insurance. *CMS Publication 100-02, Chp 9, 10, 20.1, 40.1.3.* September 14, 2018. http://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Downloads/bp102c09.pdf. Accessed December 19, 2019.

This statement reflects the best available evidence at the time of writing or revisions.

Approved by the HPNA Board of Directors January 2020

Copyright © 2020, 2011 by the Hospice and Palliative Nurses Association
To obtain copies of this statement please visit www.hpna.org