Navigating complex decisions at the end of life

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Story from the frontlines:
An older man with a history of metastatic cancer was admitted for anemia secondary to hemorrhage from his bladder caused by prior treatment of his cancer. The patient's primary goal was to get the bleeding under control so that he could return home. He underwent multiple procedures in order to control his bleeding. His hospital course was complicated by many issues which limited his capacity to make medical decisions for himself.

We recommended going home with hospice but a family member, also his MDPOA, wanted to pursue further life prolonging treatment options. Ultimately per the wishes of his family the patient was transferred to another hospital to undergo hyperbaric oxygen therapy where he died not long after.

Teachable moments:
There are multiple issues that were challenging about this case.

The first is the medical appropriateness of hyperbaric oxygen therapy (HBOT) as a treatment for hemorrhagic radiation cystitis (HRC) in this patient. Typical management of HRC involves initial emergent stabilization followed by selection of therapy based on the severity and location of the bleeding, as well as pertinent patient factors[1]. There are various therapeutic interventions currently available to treat hemorrhagic cystitis including arterial embolization, formalin injection, cystoscopy with surgical intervention, mesenchymal stromal cell instillation, various intravesical therapies and HBO[2]. However, because of the relative rarity and case-by-case heterogeneity of this condition, high quality studies are lacking to guide clear treatment options. General expert consensus is that intravesical therapies and HBO are reasonable first-line options, while surgical or arterial interventions represent later-stage alternatives[2,3,4]. With regard to HBO specifically, its reported effectiveness varies widely across many small, non-randomized studies. However, in one study of 71 patients it was noted that a lower hematuria grade, indicative of less severe disease, was a statistically significant predictive factor of successful treatment ($p = .027$)[4], which points to HBO as a more effective and appropriate therapy in patients with milder HRC. In our patient's case, he fell into the severe category and had already failed multiple last-line treatments, so HBO was unlikely to be effective.

Given this information, why did we end up transferring such a medically tenuous patient for a therapy that was likely to have little to no benefit? This brings up the second issue surrounding this patient's story; how can we best work with patients and their family members when a challenging decision needs to be made, especially when we think that there is potential to cause harm to the patient? Health literacy is widely considered the largest barrier to equitable and transparent shared-decision making[5], but in this case the patient's POA was well-informed about the patient's medical condition and risks. Ultimately, the most challenging aspect for family members isn't interpreting recommendations, it's separating the medical information

from the emotional components of a complex decision. As members of a healthcare team, we often only see a patient when they are sick and deconditioned, which makes it easier to give objective recommendations. The family members know the patient's personality, passions and life history, which I can imagine could make it difficult to forego a curative – however unlikely - treatment plan. There are many proposed strategies for improved shared decision making[6], but none of them attempt to address this emotional aspect of a challenging decision. I don't pretend to have an answer for this all too common situation in healthcare, but we can start with expressing sympathy and striving to empathize with the family prior to discussing the medical information.

References:

1. Pascoe C, et al. Current management of radiation cystitis: a review and practical guide to clinical management. BJU Int. 2019 Apr; 123(4):585-594. doi: 10:1111/bju.14516. Epub 2018 Nov 28.

2. Dautruche A and Delouya G. A contemporary review about the management of radiation-induced hemorrhagic cystitis. Current Opinion in Supportive and Palliative Care. 12(3):344–350, Sep 2018.

3. Chong V and Rice M. The effectiveness of hyperbaric oxygen therapy (HBOT) in radiation-induced haemorrhagic cystitis. NZ Med J. 2016 Dec 2;129(1446):79-83.

4. Mougin J, Souday V, Martin F, Assouzi AR and Bigot P. Evaluation of Hyperbaric Oxygen Therapy in the Treatment of Radiation-induced Hemorrhagic Cystitis. Urology. 2016 Aug;94:42-6. doi: 10.1016/j.urology.2016.04.015. Epub 2016 Apr 25.

5. Stacey D et al. Shared Decision Making Interventions: Theoretical and Empirical Evidence with Implications for Health Literacy. Stud Health Technol Inform. 2017;240:263-283.

6. Bae JM. Shared decision making: relevant concepts and facilitating strategies. Epidemiol Health. 2017 Oct 30;39:e2017048. doi: 10.4178/epih.e2017048. e Collection 2017.