



PALLIATIVE CARE CASE OF THE MONTH

“The Voice not Heard: Striving for Patient-Centered Care among Patients Lacking Decision-making-Capacity”

by

Vasilii Bushunow, MD; Joseph Bertino, PhD, HEC-C; Jane Schell, MD

Volume 24, No. 140

Case: Mr. A is a 78-year-old man with schizophrenia. He was admitted with pneumonia and over several weeks required intubation multiple times. He was finally transferred to a medical ward but developed significant anemia from a spontaneous hematoma. His Medicine team recommended a blood transfusion, but Mr. A declined, stating that “The Spirit of Christ” told him not to accept blood products, prompting the team to consult Psychiatry. On Psychiatry’s assessment, Mr. A could demonstrate an understanding of his medical situation, including the risk of death from anemia. Still, he could not describe the rationale for refusing blood products besides invoking “The Spirit of Christ.” Given these factors and the risk/benefit ratio of transfusion, Psychiatry felt that Mr. A could not decline blood, and he was transfused.

Several days later, Mr. A had respiratory distress and was transferred to the ICU. The ICU team told Mr. A that should he be intubated again, he would likely require a tracheostomy, to which he indicated, “I don’t want that.” The ICU team changed the patient’s code status to CMO and transferred him back to the medical floor. The following day, the patient expressed concern that “nobody was coming to see him” and requested that the Medicine team revoke his CMO status. The Medicine team consulted palliative care to discuss Mr. A's goals of care.

Introduction: “Goals of Care” (GOC) consults are typically requests for palliative care to guide patients, families, and medical teams through medical decision-making in times of serious illness. Hospitalized patients, especially those with serious illness, are at high risk for having impaired decision-making capacity ¹. A patient’s inability to make decisions complicates their involvement in GOC, especially in discussions about withdrawal or withholding of treatment, code status, or enrollment in hospice care. Thus, assessing decision-making capacity is a particularly important skill for palliative care clinicians.

What is decision-making capacity and how is it assessed?

The capacity to make medical decisions is generally defined as “the ability of a patient to understand the benefits and risks of, and the alternatives to, a proposed treatment or intervention” ². Established criteria considered necessary for capacity are a patient’s ability to 1) appreciate the situation and its consequences; 2) understand relevant information; 3) explain the reason for treatment options; and 4) communicate a choice ³. It is a common misconception that only mental health experts can assess capacity; any clinician can and should assess the capacity of their patients.

Furthermore, capacity is both time-specific and decision-specific, meaning that capacity must be assessed in the moment a decision is being made, and that patients may have capacity for some decisions and not others and at some times and not others ⁴.

How can palliative care provide patient-centered care to patients lacking decision-making capacity?

Mr. A's case explores a situation in which a patient with limited capacity still expresses preferences regarding their care. It highlights the palliative care skills of mapping goals and values to structure treatment recommendations.

Mr. A was shown to lack decision-making capacity regarding blood transfusions but still has some insight into his situation and can express preferences about his care. The standard approach to patients lacking decision-making capacity is to relegate decisions to a surrogate who is expected to act beneficently. Surrogates are often forced to make difficult decisions on their loved one's behalf, which may result in choices different than what the patient would have made ^{5,6}. Palliative care can assist in these conversations to help surrogates consider treatment decisions in the context of the patient's values. Researchers in this field have proposed frameworks, such as the Facilitated Values History, to guide surrogates through making authentic choices for their loved ones (Table) ⁷. This strategy requires that a surrogate willing to accept this responsibility is readily available.

The Facilitated Values History

Behaviors	Specific Actions
Attend to surrogates’ emotions	NURSE mnemonic Enlist interdisciplinary support
Help surrogates understand their contribution to decision making	Explain that decisions are value laden Reduce projection biases
Understand the patient as a person	
Explore specific values and value conflicts	Discuss the range of relevant values Explore value conflicts
Summarize the values relevant to the decision	
Bridge between values and treatments	Demonstrate bridges
Give “permission” to follow the patient’s wishes	Express empathy Address moral concerns Share social norms

(Adopted from Scheunemann et al 2012)

Personal details in the case published have been altered to protect patient privacy.

For palliative care consultations please contact the Supportive and Palliative Care programs at PUH/MUH, 412-647-7243, pager # 8511, Shadyside, 412-647-7243, pager # 8513, Perioperative/ Trauma Pain, 412-647-7243, pager # 7246, UPCI Cancer Pain Service, pager 412-644-1724, Magee Women’s Hospital, pager 412-647-7243 pager # 8510, VA Palliative Care Program, 412-688-6178, pager # 296. Hillman Outpatient: 412-692-4724. For ethics consultations at UPMC Presbyterian-Montefiore and Children’s pager 412-456-1518

With comments about “Case of the Month” call Dr. Robert Arnold at (412) 692-4834.



Introduction (Continued)

Other ethicists distinguish between complete decision-making capacity and the capacity to express a preference, and argue that there is an intrinsic moral value to respecting preferences⁸. They reason that expressing a preference is a necessary but not sufficient criterion for decision-making capacity - along with the ability to appreciate the situation, understand relevant information, and reason about treatment options³ - and should be considered separately. Patient preferences play a crucial role in decision-making even in fully capable patients. Practically, patients are not offered unlimited options but are asked to express a preference between available, restricted choices. Furthermore, preferences are respected even when patients express preferences that are not in their best interest. In select patient populations that lack full decision-making capacity, such as pediatrics or patients with profound intellectual disabilities, respecting preferences as an expression of personhood and liberty is the foundation for treatment with assent⁸.

Palliative care clinicians can draw on their communications skills for challenging patient encounters when meeting with a patient lacking decision-making capacity. For example, the approach to a patient unable to communicate a choice may be similar to that for a capable patient who is extremely ambivalent or resisting the discussion. Techniques drawing from motivational interviewing, such as complex reflection, allow the patient to identify the values and meaning underlying their preferences. Other techniques such as naming and rolling with resistance demonstrate empathy and allow the patient to continue guiding the conversation⁹. The patient's clinical history and other collateral information provides further context to the patient's preferences.

Following patient preferences should not be simplified to "do whatever the patient wants" - it still requires time, effort, and attention to ensure the preferences are consistent with the patient's options. Nor does following preferences guarantee that the "best" clinical course will be obvious and simple. It can be expected that challenges will arise, and the palliative care consultant has further resources in such situations. The interdisciplinary team conference (IDT) can provide a comprehensive and fresh perspective incorporating disciplines such as Psychiatry, Ethics, Chaplaincy and Social work. Consultation with Psychiatry is helpful if a patient's mental health is contributing to their inability to make decisions or communicate with the team. The Ethics Consultation Service can assist if disagreements occur within or without the team regarding ethically supportable care.

Return to the case:

When seen by the palliative care team, Mr. A shared his fear of getting sicker and of being on machines. He expressed a desire for medical treatment geared toward "getting strong again" that would aid him in "moving forward in the Spirit of Christ."

He described hearing "The Spirit of Christ" over decades as a voice that guided his life choices. He did not have any family and shared that he is "not close with anyone," but when asked who he trusts, he was able to identify people who could act as his surrogates for medical affairs. Considering these preferences, the palliative care and Medicine teams agreed that the patient should continue treatments with a DNR/DNI code status. He continued to improve and was discharged to a nursing facility for rehabilitation.

Conclusion: Palliative care clinicians must be prepared to assess patients' capacity to make medical decisions. When caring for patients who do not have full decision-making capacity, clinicians should still explore patient's preferences, using the same tools as when mapping patient goals in family meetings. The IDT, Psychiatry liaison services, and Ethics Consultation Services are all resources that palliative care can use to address challenging scenarios.

References:

1. Raymont V, Bingley W, Buchanan A, et al. Prevalence of mental incapacity in medical inpatients and associated risk factors: cross-sectional study. *Lancet* 2004;364: 1421-7.
2. Barstow C, Shahan B, Roberts M. Evaluating Medical Decision-Making Capacity in Practice. *Am Fam Physician*. 2018 Jul 1;98(1):40-46.
3. Appelbaum PS. Clinical practice. Assessment of patients' competence to consent to treatment. *N Engl J Med*. 2007 Nov 1;357(18):1834-40.
4. Ganzini L, Volicer L, Nelson WA, Fox E, Derse AR. Ten myths about decision-making capacity. *J Am Med Dir Assoc*. 2004 Jul-Aug;5(4):263-7.
5. Wendler D, Rid A. Systematic review: the effect on surrogates of making treatment decisions for others. *Ann Intern Med* 2011;154: 336-346.
6. Shalowitz D, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision makers: a systematic review. *Arch Intern Med* 2006;166:493-497.
7. Scheunemann LP, Arnold RM, White DB. The facilitated values history: helping surrogates make authentic decisions for incapacitated patients with advanced illness. *Am J Respir Crit Care Med*. 2012 Sep 15;186(6):480-6.
8. Wasserman JA, Navin MC. Capacity for Preferences: Respecting Patients with Compromised Decision-Making. *Hastings Cent Rep*. 2018 May;48(3):31-39
9. Pollak KI, Childers JW, Arnold RM. Applying motivational interviewing techniques to palliative care communication. *J Palliat Med*. 2011 May;14(5):587-92.

Personal details in the case published have been altered to protect patient privacy.

For palliative care consultations please contact the Supportive and Palliative Care programs at PUH/MUH, 412-647-7243, pager # 8511, Shadyside, 412-647-7243, pager # 8513, Perioperative/ Trauma Pain, 412-647-7243, pager # 7246, UPCI Cancer Pain Service, pager 412-644-1724, Magee Women's Hospital, pager 412-647-7243 pager # 8510, VA Palliative Care Program, 412-688-6178, pager # 296. Hillman Outpatient: 412-692-4724. For ethics consultations at UPMC Presbyterian-Montefiore and Children's pager 412-456-1518

With comments about "Case of the Month" call Dr. Robert Arnold at (412) 692-4834.