Robert was an older man who lived independently and worked full time. He was diagnosed simultaneously with metastatic cancer and myasthenia gravis, an autoimmune neuromuscular disorder that causes muscle weakness in the eyes, face, and throat. Due to his cancer, the only treatment available was high-dose steroids. While his strength improved, he was later hospitalized with steroid-induced psychosis. He was discharged to an assisted living community where he fluctuated between days of psychosis—demanding to leave—with periods of lucidity marked by sincere remorse and understanding of his care needs. He did not have advance directives to guide decision making.

How would you approach Robert when he is demanding to leave the facility?

Caring for residents with fluctuating decision-making capacity due to an underlying mental illness is a difficult ethical dilemma. At its core is a delicate balance between preserving resident autonomy, the right to self-determination, and the principle of beneficence, or the obligation to protect the resident from harm. This dilemma is common and bound to grow as the post-acute and long-term care population continues to have high acuity and complex care needs.

To help PALTTC providers address this dilemma and meet the needs of residents with underlying mental illness, we will provide a framework for the assessment of decision-making capacity.

Defining the Concepts

First, let’s clarify the distinction between two commonly confused concepts: capacity and competency.

Competence is a medical determination made by a medical provider for a specific decision at a specific time. There are four generally accepted criteria to evaluate decision-making capacity:

- The ability to understand relevant information.
- The ability to state a decision.
- The ability to explain how the information applies.
- The ability to reason or compare information and consequences.

Context is important. A physician requires a higher threshold for decision-making capacity if the stakes are high, such as patients who will likely die if they leave the hospital during a massive heart attack, than if the stakes are low, such as a patient with diabetes who wants a scoop of ice cream.

Competency is a legal determination made by a judge and is typically a global evaluation. If a court finds a person lacks the ability to manage his or her affairs, the person will have been found incompetent. Declaring someone as incompetent strips individuals of many of their rights, so this is done through intensive court proceedings. The court will usually name a guardian who is given the responsibility for the care, comfort, and maintenance of the person.

Guardianship comes in two types. Limited guardianship gives a guardian the authority to make specific decisions as spelled out by the letter of guardianship. Full guardianship gives the guardian full, blanket authority. In either situation, guardians must allow individuals to participate in decisions and exercise their rights as much as allowed by their comprehension.

In the absence of guardianship, each state has a hierarchy of decision-making. In our state of North Carolina, for example, decision making falls to (in order) a power of attorney, spouse, majority of reasonably available parents and adult children, majority of adult siblings, an individual who has an established relationship with the patient, or an attending physician with confirmation by a second physician.

The final concept is the difference between consent and assent. Consent is the voluntary agreement of an individual after a discussion of the anticipated risks and potential benefits. This requires that the individual have decision-making ability, as previously discussed. Assent is the willingness to participate without the ability to give consent. For example, a person with severe cognitive impairment may not understand why he is taking an antibiotic for pneumonia and thus cannot consent, but he can assent by agreeing to swallow the pill.

Applying the Framework

Returning to Robert’s case, he has periods of psychosis where he is demanding to leave his assisted living community. The role of the clinician is to first determine whether Robert has decision-making capacity in the moment, understanding a relatively high bar is needed given the potential harm that leaving would pose. If Robert does have capacity, it is his right to leave. If not, a surrogate decision maker should be identified.

In this case, Robert is found not to understand the impact of steroids on his mentality or the consequences of his leaving. Because he does not have a court-appointed guardian or power of attorney, we use the state hierarchy to identify his wife as his surrogate decision maker. After the situation is explained, she decides he should stay at the facility.

The staff working at the assisted living community must be able to safely manage Robert’s behavior. He can be redirected to his favorite snacks, or make use of a wandering garden, or be distracted with another topic of conversation. The risks and benefits of medication management—including decreasing his steroids or adding antipsychotics—as well as repeat hospitalization with a discussion of limits of the facility would be discussed with his spouse and care team.

It is important to note that long-term care facilities, particularly assisted living communities are, with few exceptions, not authorized to use physical restraints or administer medications. If Robert is an imminent danger to himself or the staff, his assisted living community should contact emergency medical services to transfer Robert to a level of care (such as the emergency department or hospital) that can initiate a 72-hour hold, which allows for the administration of psychotropic medications involuntarily. This is justified because of his lack of decision-making capacity, the real risk of serious injury or death if he leaves, and the inability to meet his care needs in the assisted living community.

Fluctuating decision-making capacity due to an underlying mental illness is a challenging ethical dilemma. By following the outline presented here, we hope to have provided a general framework and approach to balancing the ethical principles involved and medicolegal considerations at play.

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