Reconsidering the Language of Serious Illness

To need is to lack something essential. As clinicians, we regularly use the word need to think about and describe the condition of patients with acute serious illness. These patients lack something essential for survival, and clinicians have the technologies and therapies to sustain their lives. So need rolls off our tongues as a shorthand to convey our clinical assessments of patients with acute life-threatening illness:

“if her breathing gets any worse, she will need to be intubated.”

“He needs a central line, a special IV catheter in his neck, so we can give him blood pressure medicines.”

“If she doesn’t make any urine soon, she will need dialysis.”

“If she can’t be extubated soon, she will need a trach.”

Yet, the way we use this term can be misleading, especially when talking with seriously ill patients and their families. For example, the daughter of a woman with advanced cancer who died in the intensive care unit told us she went along with a plan to intubate her mother because the physician called and told her, “Either your mom needs to be on a ventilator or she’s going to die today.”

Despite her mother’s clear assertion that having life sustained by a ventilator was unacceptable, the daughter felt intubation was the right thing to do because the physician was “making the best calls for my mom.” After all, why would a patient’s family member consider withholding intubation when the physician said it was needed?

When clinicians describe patients as needing life-sustaining therapy, especially to seriously ill patients and their worried families, they are conveying more than a clinical assessment about illness severity. Dating back to at least Middle English literature, need creates an imperative and provides justification for action. A literary character named Need in the 14th-century poem Piers Plowman argues that a person who lacks basic necessities is entitled—morally, socially, legally—to whatever is required to sustain life. In our current-day conversations outside of medicine, we use the word need to translate a fact (she doesn’t have water) into a call to action (she needs water). Need is used to describe both what is lacking and the specific required action in response to provide water. When clinicians, from a position of authority, describe patients with respiratory failure as needing intubation, patients and families presume intubation is what should be done. This framing leaves little space to acknowledge the impact of this patient’s change in health or to deliberate about the best course of action.

“If your mother’s breathing gets any worse, she will need to be intubated... What do you think she would say about that?” Sometimes, in our efforts to engage patients and families in decision making, we use a headline about needing life-sustaining therapy to describe the patient’s condition, before transitioning to an explicit discussion of whether the therapy aligns with the patient’s goals and priorities. As clinicians, we can separate our clinical assessment (needing intubation) from the deliberation about whether intubation should be done. We assume that patients and families follow our logic and recognize these distinctions. But after hearing the patient needs to be intubated, patients and families presume intubation is the right thing to do. Clinicians then backtrack, trying to dismantle this unintentional commitment to life-sustaining therapy and create space for transparent deliberation about the patient’s priorities. While using headlines with patients and families is a communication best practice, this pattern of saying the patient needs to be intubated then backtracking into a discussion about whether intubation is best for the patient is a setup for miscommunication and downstream conflict.

We propose a shift in clinicians’ communication and thinking to create space for deliberation about patients’ priorities and the best course of action.

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severe, and the cancer treatment is making it hard for her immune system to control it. We don’t know yet if the antibiotics will help, and I am worried that she could die.”

“What to do next” then frames, separately, an opportunity for deliberation. This open framing, rather than a predetermined need, creates space to consider more than a single course of action and to discuss what is acceptable to the patient. What potential actions and the extent to which these are considered will depend on each individual patient’s case. For many patients with acute critical illness, at least at initial presentation, uncertainty is high, and time to deliberate and discuss is short. With time pressure, the clinician might say, “Let’s talk about what to do next. We can intubate her and provide mechanical ventilation—a form of life support also called a breathing machine. This will give us time to see if the antibiotics are helping. For some patients, though, being on life support like a breathing machine is not okay. Another option is to provide care that focuses exclusively on her comfort, knowing that she may die from this infection.”

When clinicians describe serious illness as a need for life-sustaining therapy, deeply held instincts about what should be done for those in need, for those who are lacking something essential for life, push all of us toward action—life-sustaining therapy. We propose a shift in clinicians’ communication and thinking to create space for deliberation about patients’ priorities and the best course of action. When a patient is facing a life-threatening illness, instead of saying she “needs to be intubated,” we suggest that clinicians say, “Her illness is getting worse. I would like to talk with you about what this means and what to do next.” This shift will take real effort; the way need is used in clinical language is so common that clinicians rarely even notice when doing it.

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REFERENCES