Legal Corner

Ethics, Decisional Capacity, and Literacy: Protecting Patients, Empowering Practitioners

Dennis A. Robbins PhD, MPH

No doubt, there are many thorny dilemmas involving the assisted living facility resident who has been an integral part of the AL community but who is too impaired to meet the independent living requirements there. Whether this situation arises from an exacerbation of a chronic or acute medical condition, dementia, or other problem, there clearly are times when an individual's mental and/or physical health status deteriorates to the level that he or she must move on to a more care-intensive setting.

Fortunately, there is much that facilities and the clinicians who care for impaired residents can do to protect patients' safety while ensuring that their rights also are honored. This starts with a clear understanding of decisional capacity and health literacy.

What is Decisional Capacity?

"Decisional capacity" essentially refers to the *capacity or ability* of a given person to understand and appreciate the significance of information being afforded to them now. For those residents with mild dementia or fluctuating capacity, there are isolated times where the patient has windows of decisional capacity during which he or she can make informed and responsible decisions. It is critical to document and corroborate those wishes in a timely fashion so that they can be honored when the resident is unable to make decisions personally.

Decisional capacity is more precise than talking about broad issues of competence or incompetence. Decisional capacity speaks to whether someone has the *ability* to understand and appreciate the significance of a specific decision at this moment in time. For example, one may be incompetent to make legal transactions but possess the decisional capacity to make health care decisions. Capacity may be limited to certain kinds of decisions. For example, a resident may not have the capacity to handle complex financial matters such as taxes or managing investments but be able to decide whether he or she wants a flu shot. Even the resident with fluctuating capacity can make certain reliable decisions at some times.

We often confuse decisional capacity with competence and the ability to participate in decision making via our consent when, in fact, decisional capacity is merely an element of—if not a condition for—consent. The legal test for informed consent pivots on the concept of materiality. From a legal standpoint, this is defined as the amount of significance that a reasonable person would attach to specific information. This is closely associated with decisional capacity, that is, the capacity to make a specific decision and understand its significance and importance.

In essence, for consent to be valid, it must portray and embody both cognitive and affective dimensions. When information is shared with resident, it must be delivered in such a way that the person understands its significance. We test or make sure to the best of our ability that the patient understands that information. We do this by asking the patient to explain in his or her own words what we have discussed.

It is important to remember that consent is a process; it is not a form or release. There is a continuity of consent that must occur. At times, we may need to remind the resident about what has been discussed. There is no cookbook way of doing this. Each resident is distinctive in this respect; and good clinical judgment must be exercised in making a determination of whether one understands and appreciates the significance of what is being discussed.

Health Literacy Combines Understanding and Action

"Health literacy" refers to an individual's ability to understand common health care communications and to act on them. According to the Institute of Medicine, 90 million people from all ages, races, and income and education levels have difficulty understanding and using health information.[1] Individuals with low health literacy likely will incur medical expenses that are up to four times greater than costs for those people with adequate literacy skills. This costs the health care system billions of dollars every year. In fact, the National Academy on an Aging Society estimates that additional health care costs due to low health literacy were about $73 billion in 1998 alone, (Health Literacy Fact Sheet, http://www.agingsociety.org/healthlit.htm). The problem is exacerbated by the fact that most patients hide their confusion from their doctors because they are too ashamed and intimidated to ask for help. We must be vigilant in recognizing this. Sometimes just telling the patient, "I'm so glad you came here today" sets the tone for cultivating a shame-free environment.

One technique that can be employed to identify literacy issues is a medication review where the resident is asked to bring out all of his or her medications (both prescription and over-the-counter) and then asked to name each medication, explain why the resident needs to take it, and how often he or she takes it. If the resident opens the bottle and looks inside, rather than reading the instructions directly, this can be red flag and suggest the need to further evaluate the person's health literacy.

Devil in the Details: Other Intricacies of Consent

Besides accounting as best we can for health literacy, it is important to recognize other intricacies of consent. For instance, the flip side of consent is the integrity of the person initiating the consent or evaluating the consent. This is what allows—or disallows—the wishes of the patient to be honored and respected. It is important to speak of "wishes" here rather than "rights," because rights and the language of rights are always adversarial. They demand that someone act in accordance with the resident's right; and, if they do not, there are legal implications and sanctions. Rights only arise when wishes are ignored or not honored.

Obviously, we want to honor the wishes of the resident even if and when their preferences are incongruent with a course of action we would prefer them to choose. While there is no ban against encouraging residents to rethink or reevaluate choice, individuals with decisional capacity have the right to have their decisions honored.

At the same time, clinicians or facility staff can't just "wing it" in the absence of that capacity and no clear sense of the patent's or resident's previous wishes or advance directives. The charge in these circumstances is to make a decision based on what this specific resident likely would have wanted in the same or similar circumstances. It is important to have designated decision makers involved in these situations. The most formidable of these is the durable agent who, in most cases, will have priority even over and superseding the legal guardian. Of course, each state will have established a formal priority of decision makers.

> **When it is no longer safe or feasible for a resident to remain in a given environment, accommodations must be made to meet the need or help transition to a different environment.**

The Ambiguity of Ambiguous Transitions

So how can we fairly and honestly deal with the patient in the throes of an ambiguous transition from being an ALF resident capable of independent living to someone who can no longer remain in this setting safely? Obviously, this does not apply to acute interim episodes where transfer to a hospital or other acute setting is required for a protracted period of time. Instead, it involves situations in which a change requires a permanent or long-term move to a nursing facility or similar setting.

Consistency is a virtue here; and we should be consistently fair in our decisions and determinations. In essence, when it is no longer safe or feasible for a resident to remain in a given environment, accommodations must be made to either meet the need or help transition the resident into an environment that can best meet his or her needs and address the individual's safety and emotional and physical needs. Facilities should have in place policies and procedures that address identifications of when such transitions should occur, how residents will be assessed, what communications—and documentation—must take place, and on what timeline the transition will be made. All staff—including marketing and sales personnel—and clinicians caring for residents in ALFs should be familiar with these policies and required to abide by them consistently.

How to best accommodate such a transition in a gentle yet consistent manner is perhaps the most difficult and agonizing elements of this process. Nonetheless, there are times when such transitions are inevitable; and we owe it to our residents to put their safety and best interests first. ALC

Dennis Robbins (www.DennisRobbins.com) is President of Integrated Decsions, Ethics, Alternatives and Solutions (I.D.E.A.S.) in Phoenix, AZ. He has been instrumental in developing hospice nationally, designing consent-based end-of-life policies/procedures, and consulted with families, clinicians, attorneys, and policymakers on legal liability, ethics, and patient autonomy issues. Dr. Robbins is the author of nine books and numerous articles. He also is a popular national speaker on health care ethics issues.