CENTER FOR PRACTICAL BIOETHICS
GUIDANCE AT THE CROSSROADS OF DECISION

February 2024

The Ethics Dispatch

"The object of philosophy is the logical clarification of thoughts. Philosophy is not a theory but an activity."

- Ludwig Wittgenstein

Hot Topic

Autonomy in the Absence of Decisional Capacity

A frequent cause of ethics dilemma is when a patient lacks capacity to make their own medical decisions. A foundational part of modern medical ethics, the principle of respect for patients' autonomy, "is usually associated with allowing or enabling patients to make their own decisions about which health care interventions they will or will not receive" (Entwistle et al., 2010). But what if the patient cannot make decisions?

Patients should be treated with respect and a means of demonstrating that respect is by treating them as capable of making their own medical decisions. But in modern healthcare, many variables can arise that complexify the principle of respect for autonomy for particular patients. These variables could include a patient's lack of medical literacy or negative influence from outside factors like socioeconomic and family stressors. But another frequent disruption to a patient's right to self-determination (autonomy) is when the patient's decision-making capacity is diminished or gone. Does the principle of respect for autonomy then no longer apply?

Appropriate Surrogates

When a patient loses decisional capacity, care providers are still under obligation to the "autonomy" principle. It is, however, additionally challenging to know the patient's medical preferences. We then need to rely on the patient's appointed agent or some other appropriate decisional surrogate. It is their job to make decisions in accordance with the patient's wishes as communicated in advance. Or if there are no advance directives or none with relevance to the decisions at hand, then surrogate healthcare decisions are made as a matter of "substituted judgement"—what the patient probably would have wanted, given who they are and what they value. If nothing is known or can be presumed about what the patient might want in a particular situation, a surrogate needs to make decisions collaboratively with providers in the patient's best interests. In any case, respect can and should be demonstrated towards the patient as the autonomous person they were and possibly might be again in the future.

It is not always easy to ascertain who is the most appropriate surrogate. Advance directives completion rates are only around 36.7% (Yadav et al.). So most patients who lack decisional capacity had not previously named an agent for medical power of attorney. If family or friends are at the bedside, someone typically can function in a surrogate role nonetheless. In most states, but not all, there is family surrogacy law with a statutory order of surrogate decision makers. In other states, like Kansas and Missouri, providers need to discern—with ethics consultation assistance perhaps—who will be the best surrogate of those available and willing to serve. Lack of statutory directive is not necessarily a bad thing as it allows providers to bypass, for example, a spouse who suddenly shows up wanting to make decisions but has been adversarial and estranged from the patient for the past 20 years. A caring and available domestic partner of 15 years might well be a much better surrogate, and one who was likely more trusted by the patient as well.

Questionable Surrogate Behavior

Sometimes we encounter another challenge to respect for a patient's autonomy. Their surrogate might know and state what the patient would decide if they could; yet, the surrogate wants something else for the patient instead. DPOA agents or other surrogate decision-makers should not make decisions in accordance with what they want for themselves. Rather, decisions are to be made as if the surrogate were this patient, hence, acting with integrity on the patient's behalf and at their behest. If the patient is not being respected by the surrogate, then actions should be taken by the healthcare team to do so. In such situations, "it is the duty of the medical team to remind the surrogate that their role is to facilitate the preferences of the patient, irrespective of what the surrogate's personal preference may be. In doing so, the medical team attempts to respect the prior expressed voice of the patient" (Bramstedt).

While the medical team should presumptively trust their patient's surrogate, there are times when a surrogate's behavior calls into question the surrogate's ability to make medical decisions. What should be done then? Clinical ethics consultant Dr Katrina Bramstedt states that "the DMC (decision making capacity) of surrogates should be suspect when care is requested that is in conflict with a patient's prior expressed values and preferences, or, in the absence of such expression, is not in the patient's best interests." But healthcare providers cannot do formal capacity evaluations on people who are not their patients, and competency is a legal process rather than a medical one. Therefore, without the authority to do either a capacity evaluation or declare a surrogate legally incompetent, are we simply stuck with whomever presents themselves as the patient's DPOA or family surrogate?

Calling and facilitating a family meeting is the primary means for resolving a situation of this sort. The meeting is for the purpose of listening, mutual discernment, trust-building, and negotiation. Sometimes a direct and compassionate conversation even with a minimally capacitated surrogate might lead to identification of an alternate surrogate—someone better equipped to comprehend the medical situation and to make decisions in keeping with the patient's wishes or in their best interests.

Family Meetings and Beyond

If a family meeting does not lead to a resolution of surrogacy that is in keeping with respect for the patient and their autonomy, then providers may need to be more proactive and directive in the matter, or even go to court.

> When such negotiation with the surrogate is not successful and the DMC of the surrogate is doubtful and his/her decisions would be potentially harmful to the patient, the medical team must consider switching to the alternative surrogate or seeking appointment of a new one. Even in the absence of projection, other behaviors, such as those influenced by alcohol or drugs, and conflicts of interests can impair a surrogate DMC. Some surrogates are unable to comprehend the patient's clinical situation due to physical or emotional reasons. At this point, an ethics consultation may be helpful. If the ethicist cannot persuade the surrogate to resign in favor of an alternative, it may be necessary to make an application to the courts for assistance.

(Bramstedt)

The principle of “respect for autonomy” is fundamental to the ethically fitting care of patients, even or especially when a patient lacks decisional capacity. Such situations are not always ethically complicated, but they can be. When there is complexity and conflict, ethics consultation may indeed be helpful.

Sources:

Entwistle VA, Carter SM, Cribb A, McCaffery K. Supporting patient autonomy: the importance of clinician-patient relationships. J Gen Intern Med. 2010 Jul;25(7):741-5. doi: 10.1007/s11606-010-1292-2. Epub 2010 Mar 6. PMID: 20213206; PMCID: PMC2881979.

Yadav, K. N., Gabler, N. B., Cooney, E., Kent, S., Kim, J., Herbst, N., ... & Courtright, K. R. (2017). Approximately one in three US adults completes any type of advance directive for end-of-life care. *Health Affairs*, *36*(7), 1244-1251.

Bramstedt, K. A. (2003). Questioning the decision-making capacity of surrogates. *Internal Medicine Journal*, *33*(5-6), 257-259.

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Case Study

“I don’t know, Doc. I don’t get it.”
Decisional Capacity of the Patient's Surrogate

Debra is a 66-year old patient who was admitted to the hospital after suffering a stroke. She was intubated upon admission fifteen days ago and has remained nonresponsive. The medical team believes it is time to have the conversation about whether to:

(a) go forward with a tracheotomy plus insertion of a PEG tube for feeding, or
(b) withdraw life-sustaining treatments and focus on comfort.

Debra’s electronic medical record includes healthcare durable power of attorney documentation (DPOA) naming her spouse of 18 years, Joseph, as surrogate decision maker. However, Debra apparently had not completed a healthcare treatment directive indicating her wishes involving treatment decisions and Joseph says they never talked about things like this.

Joseph is in his late 70s and exhibits signs of mild dementia. As far as is known to Debra’s care providers, Joseph has no specific diagnosis. He just appears confused when information is provided, lacking comprehension of what is meant by a tracheotomy or PEG tube, even when explained over and over again, simply, slowly, and using pictures. He has asked his wife’s physician to repeat the information multiple times. Then Joseph just shakes his head and says, “I don’t know, Doc. I don’t get it.”

Finally, Joseph says, “Okay, just do the operations. That’s what you’re asking, right? I don’t know why you have to put a hole in her neck, but I know that my wife needs to breathe. So do it. And of course she needs food and water so she doesn’t die. She’d probably hate tubes coming out of her; but I can’t live without my wife, so do what you have to do to keep Debbie alive.” Then Joseph stops and looks perplexed again. “I’m sorry. What were we talking about?”

Debra has a 35-year old daughter named Sierra, Joseph’s stepdaughter, who is at her mother’s bedside as well. Sierra seems to have no difficulty comprehending the situation, and she has a different perspective on what should be done. Sierra says that her mother “would *never* have wanted to be like this,” to be kept on a breathing machine or be fed through a tube in her stomach. “If you were to ask my mom, she would definitely say NO to all of this.”

With an adult daughter saying “No” to a trach and PEG and a DPOA spouse of questionable capacity saying, “Do it,” the medical team asks for ethics consultation. What should be done for Debra?

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Ethical Musings

Respecting Autonomy in Practice: Complexities and Guidelines

In the United States, the principle of respect for autonomy, self-rule, holds high value to many people, both patients and providers. It just makes sense that legally competent adult individuals should be able to make their own decisions, particularly their own medical decisions. We who are patients are the ones living our own lives in bodies that belong to us alone. It is reasonable then to claim that each of us, as adults, should be permitted to live the lives that we choose so long as our choices do not infringe on the rights of others to choose for themselves. In particular, we have the right to choose or decline medical interventions for our own bodies. Or mostly so.

The concept of respect for individual bodily autonomy becomes somewhat complicated, ethically and legally, in cases involving a woman's reproductive rights relative to perceived fetal or even embryonic rights. But for all adult patients, the "autonomy" principle is also complexified by the realization that self-rule correlates to one's capacity to do so, to make decisions for oneself. Decisional capacity is on a spectrum from "full" to "lacking". Patients who lack decision-making capacity are those assessed by a physician—any competent physician or psychologist, not just psychiatrists—as unable to sufficiently comprehend information of relevance to a particular decision that needs to be made.

Unaware of Own Preferences

In some cases, an incapacitated patient lacks conscious awareness entirely, comatose or in persistent vegetative state. Other times, a decisionally incapacitated patient is alert and even oriented (to time, place, person, etc.). They have healthcare preferences that are their own, based on previous communications, but also have become cognitively compromised to a point that they are unable to make decisions that are consistent with their own preferences.

It is interesting to ponder this suggestion that a conscious adult either might be unable to know their own preferences or to know them and be unable to make decisions coherent with them. When such persons are patients, we are inclined to name their cognitive state as “decisionally incapacitated” and look for a surrogate decision maker. In such cases, the principle of “respect for autonomy” is not moot relative to “beneficence” and “nonmaleficence”, but it is expressed differently. We respect the patient’s autonomy “such as it is.” Or if decisional capacity is lacking entirely, then our respect is for the patient as a person—which is what that principle was intended to convey anyway when first conceptualized in codes of research ethics.

Disagreement with Caregivers

As ethicists, we have one worry about the assessment of decisional capacity. At least sometimes, it appears that the phrase, “patient lacks capacity,” simply means that the patient is not in agreement with the recommendations of their caregivers. One common scenario is when a patient with diabetes has a foot that has become ulcerated, infected, gangrenous. The recommended intervention, possibly lifesaving, is amputation. But the patient declines. What happens next?

The attending physician may explain to the patient that if they don’t agree to have the foot amputated, they are likely going to die. The patient replies, “I know you think this thing is gonna kill me, Doc, but I don’t want nobody cutting off my body parts. Please don’t cut off my foot!” When the patient is asked to explain their refusal of lifesaving surgery, they say the foot is needed to take care of a grandchild who is an active toddler. “How am I supposed to run after my grandbaby without a foot? And she’s already wanting me to play with the soccer ball. Gotta keep the foot, Doc!” The physician states that the likelihood of ever playing soccer with a foot as bad as this one is extremely low. “Isn’t going to happen.” The patient says, “I know that’s what you think, Doctor, but I’ve got faith. Anyway, I’m gonna hang on to all my body parts, even that foot, just in case God heals it.”

In this sort of scenario, does the patient demonstrate faith, foolishness, “noncompliance”, or “lack of capacity”? It’s not always easy to know, but it may be too easy to assess the patient and their situation as the latter option: “lacks capacity.”

Assessing Decisional Capacity

A patient assessed as having decisional capacity “must be able to: (1) demonstrate understanding of the benefits and risks of, and the alternatives to, a proposed treatment or intervention (including no treatment); (2) demonstrate appreciation of those benefits, risks, and alternatives; (3) show reasoning in making a decision; and (4) communicate their choice” (Barstow, Shahan, & Roberts). In the scenario above, it is reasonable to believe that the patient demonstrates all those aspects of capacity.

The patient appears to understand and appreciate that they could die without the amputation. There is some comprehension despite expressing doubts about the accuracy of the physician's prognosis and despite also having faith that God might just heal that foot. Shouldn't it then be retained, "just in case"? Religious beliefs for healing might seem unreasonable to the physician, even one who shares with the patient some mutual religious commitments. Yet our society provides much accommodation for religion, in healthcare decisions also. The patient also is able to communicate their preference, in this case, against amputation. Is this not capacity?

On the other hand, how sound is the patient's reasoning? Miraculous healing is, at best, rare. In this case, healing seems highly unlikely no matter one's religious belief system. Empirically and by definition, miracles of this sort don't happen often (if at all). And with a gangrenous foot—or a resulting death--there will be no running after a grandchild, much less playing soccer. If the reasons given by a patient are demonstrably unsound, unreasonable, how is that sufficient to count as decisional capacity for or against something as serious as life-saving amputation?

Bottom Line Is Trust

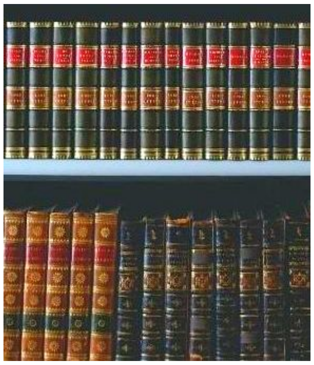
Fundamental to application of the principle of respect for autonomy is the idea of trust, specifically trust between patient and provider. Patients need to trust their providers to do good and minimize harms. Providers need to be trustworthy in that regard. Providers likewise need to trust their patients to collaborate on their own health and healing, to make good choices of options available in any given situation of care. If trust is violated on either side of this covenant relationship, care and caregiving is compromised or at risk. An overly paternalistic/maternalistic approach on the part of healthcare providers reflects lack of trust in patients and can damage their sense of a provider's trustworthiness relative to respect for autonomy.

As with everything in healthcare, situations of compromised decisional capacity, and assessment thereof, remain ethically challenging. We can expect that technological advances in medicine will not resolve the ongoing need for moral thoughtfulness along with clinical ethics consultation and collaboration.

Reference:

Barstow, C., Shahan, B., & Roberts, M. (2018). Evaluating medical decision-making capacity in practice. *American family physician*, *98*(1), 40-46.

Ethics Committee Consortium Resources



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