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

Ludwig Wittgenstein

# **Hot Topic**

## Challenges of Surrogate Decision Making

The principle of Respect for Autonomy is an essential part of ethical patient interactions, with the patient always maintaining the right to the principle. When a patient lacks decision making capacity, the patient does not forfeit their right to the principle of Respect for Autonomy. The lack of capacity only implies that the typical means for accessing that patient's autonomy and medical preferences is not available, and other means are required.

This is a large difference from the patient not having the right to autonomy. But how do you access a patient's medical preference when a patient is unable to express themself even when assisted? There are three different models typically accepted for the protection of decisionally incapacitated patients: pure autonomy, substituted judgement, and the best interest standard (Beauchamp & Childress, p. 226).

### Models for Protecting Autonomy

The pure autonomy, sometimes called "precedent autonomy" model, calls for applying formerly autonomous decisions of a patient who is now incapacitated or declared (by the courts) legally incompetent. This typically takes the form of an advance directive, or advance care planning. "Substituted judgement" is when a surrogate decision maker dons "the mental mantle of the incompetent" (p. 227), as stated in a classic court case. The surrogate's decision substitutes for that of the incapacitated or incompetent patient, but with at least some knowledge of the patient and their values so as optimally to make a decision that coheres with those values. The third model, the "best interest standard," is decision making without benefit either of advance directives or the patient's values of relevance to a decision that must be made. So a surrogate does the best they can by using "reasonableness" to make a decision coherent with what seems best for the patient. A determination is made of the most probable net benefit among options, using a risk/benefit analysis.

One of the difficulties with all three of these models, in comparison to a fully informed and capacitated or competent patient, is that they require a surrogate decision maker. This is a person or persons with the responsibility to make medical decisions on behalf of someone else. But they are also tasked with upholding the patient's right to autonomy.

With average advance directive completion rates at ~36.7% (Health Affairs), it is far more likely that a surrogate decision maker would have to utilize substituted judgement or the best interest standard rather than pure autonomy/precedent autonomy. Both of these are seen as far weaker ways of properly upholding patient autonomy, with advance directives typically seen as the best evidence of the patient's wishes (Childress). But lacking either a capacitated patient or their advance directives, what remains—substituted judgement or the best interest standard—are the only methods that remain for surrogate decision making. It is the best we can do.

This presents multiple issues and complications. This is especially true for the best interest standard, by which decisions are made "as a reasonable person" might do in similar circumstances. There is much room for error in this method. But even when something is known about the patient and their values, allowing for substituted judgment, there is still latitude for mistaken judgements. Our expectation is that the surrogate decision maker will make decisions in the same manner as if the patient were to become miraculously capacitated in that moment (Superintendent of Belchertown v Saikewicz 1977). Another way of thinking about this is that the surrogate

decision maker should not make decisions *for* the patient, but rather make decisions as if they *are* the patient. Surrogate decision makers should not be determining what they think are the best options or what their preferences are for the patient, but rather need to "don the mental mantle" of the patient and make decisions that are in line with what the patient would say and with the patient's values and preferences.

#### Managing Cases Involving a Surrogate

Needless to say, this can be a challenging task for many surrogate decision makers and can lead to a number of ethical problems. These can include, but are not limited to: emotional barriers, decisions inconsistent with the patient's preferences or values, conflicts of interest, and disagreements among potential surrogates (Lo, p. 103-104). Each of these situations or issues can impact a surrogate decision maker's ability to act as a proper surrogate.

Surrogates might be conflicted in their decision making, either through emotional distress or personal conflicts and interpersonal disagreement. Such conflicts could negatively impact the surrogate's ability to "don the mental mantle" of the patient, much less to act in their "best interest." Identifying conflicts as they arise can be helpful, and is accomplished through engaged discussion. If a patient's surrogate is making statements like, "I do not want to give up on them," that is potentially the surrogate making a decision *for* the patient, not as if they *are* the patient. Intentions may be good, and yet that sort of surrogacy remains inadequate.

This creates an additionally challenging situation, both ethically and legally. How do you manage a situation with a surrogate not acting as with adequacy for the task? Removing a patient's surrogate is not, and should not be, a simple matter. Is there objective proof that the surrogate is not properly reflecting the patient's known values and preferences? Are they making surrogate decisions overtly in conflict with what will benefit and not harm the patient, i.e., contrary to what is in the patient's best interests? Without an advance directive or some form of advance care planning, errors of reasoning and even surrogate maleficence (unintended harms) is made more likely. We all ought to do and encourage advance care planning. And lacking such, ethics help may be especially needed. We can provide intentional support for well-intended surrogates, engaging them for conversation and careful listening while offering ethics guidance. Three ways that this achieved is through discussion regarding ethical surrogate decision making process, offering ethics recommendations, and soliciting help as needed from other health care workers (Lo, p. 104-105).

There is no easy solution for engaging with and being a surrogate decision maker. It is a tremendous amount of responsibility and can result in stress and even signs of PTSD (<u>Wendlandt et al., 2018</u>). This further emphasizes the importance and value of engaging in advance care planning and completing an advance directive.

#### Bioethics in the News

- Berkeley Public Health announces plans to rename, repurpose former eugenics fund
- A Bioethicist on Trump's COVID-19 Treatment Plan
- What factors can undermine our autonomy?
- Vaccines, euthanasia, organ donation, and much more, today, with Fr. Tad.
- Philosophers On Access to Medicine
- Are COVID-19 Vaccine Trials Ethical?

# Case Study

The patient is an 82-year-old male, admitted for shortness of breath and complications from his diabetes. This patient has been diabetic for over 10 years and has not been following the treatment plan outlined by his physicians. He says that he has had sores on his right foot for several months, but he had just hoped they would go away naturally. Likely due in part to the patient's nonadherence and avoidance, his foot has worsened and now has become gangrenous.

The surgical team has been consulted and recommends amputation. During a family meeting involving the attending physician, consulting surgeon, a nurse, a social worker, the patient and the patient's adult son, all of the medical team and the patient's son agree with the recommendation for surgery and amputation of the patient's right foot. The patient is assessed to have decisional capacity in general, although not fully so. He has begun to exhibit confusion about some things when asked. He seems clear, however, when asked by the surgeon if he will consent to amputation surgery. The patient refuses. He also demands to remain Full Code status. He wants to live, and also wants to retain bodily integrity. "Don't take my foot!"

After the family meeting with providers, the patient's son says to the medical team that after his father's mental status worsens due to gangrene and sepsis, his capacity for making decisions will also be lost, surely. "When Dad needs me to make his decisions, I will consent to the surgery for him," the son states.

While this is the decision the medical team wants for their elderly patient, the son's anticipated surrogacy also makes them a bit uncomfortable. They are requesting an ethics consult.

# **Ethical Musings**

## Ignorance Is Not Bliss

Imagine this scenario: A shipowner is about to send his ship on a voyage across the ocean. The ship itself is pretty old and worn and, to be honest, was not the highest quality ship even when brand new, which now it is not. The shipowner has doubts that the old ship may be seaworthy. He thinks to himself that he should have the vessel fully and thoroughly inspected, which would come at a great cost to himself. The tickets for the voyage are already sold, and it will be a full ship. The shipowner decides to not have the inspection and will put his trust in fate. He fully convinces himself that there is nothing more powerful than fate and who is he to think otherwise. He satisfies his conscience, collects his insurance money when the ship subsequently sinks on its journey, and never tells anyone about his prescient concerns.

What would we say about this shipowner? Clearly, we would say that he is responsible for the deaths of the passengers, and that his failure to have the ship inspected and convincing himself of its worthiness was an immoral act. Even though he was fully convinced that the ship should sail based on his trust in fate, that does not change the immorality of his failure to have an inspection. Why? Because *he had no right to believe* in "fate" given the evidence of actual risk and unwillingness to seek further evidence needed to prove otherwise.

### Right or Wrong Forever

But let us change the situation a little bit. Say that the ship ultimately proved to be sufficiently seaworthy as *not* to sink on its journey. Does that change the guilt of the shipowner? "Not one jot," argues William Kingdon Clifford, who created this thought experiment in his work, *The Ethics of Belief*. This is because "when an action is once done, it is right or wrong forever; no accidental failure of its good or evil fruits can possibly alter that. The man would not have been innocent of his selfish recklessness, he would only have been not found out. The question of right or wrong has to do with "the origin of his belief, not the matter of it; not what it was, but how he got it; not whether it turned out to be true or false, but whether he had a right to believe on such evidence as was before him" (p. 1). He extrapolates this into Clifford's famous principle, "It is wrong always, everywhere, and for anyone to believe anything on insufficient evidence," and his other principle, "It is wrong always, everywhere, and for anyone to ignore evidence that is relevant to his beliefs, or to dismiss relevant evidence in a facile way" (p. 7).

Clifford maintains that a lack of knowledge or information on a subject does not excuse one from negative effects. In fact, it is the moral responsibility for an individual to be as informed and educated as possible before one is able to make a moral assessment. In an extreme viewpoint, Clifford states that if some "purposely avoid the reading of

books and the company of men who call in question [his presuppositions] . . ., the life of that man is one long sin against mankind" (p. 7).

### An Approach to Modern Arguments

While this may seem to be an extreme view (and one that I would not fully support), the underlying principles are enlightening, particularly the binary principle. I would propose combining them into one principle, a principle that can have direct implications for modern debates and surrogate decision making. "It is always wrong to ignore evidence relevant to one's belief, or to have beliefs founded on insufficient evidence." Ignorance may be bliss, but it is not appropriate for building arguments, particularly arguments that impact the lives of others.

With this argument, it becomes the moral responsibility of individuals to educate themselves as fully as possible before they are ethically permitted to create beliefs or hold strong positions. This is an impactful stance and could greatly improve modern arguments. With our modern society tackling such strong and important issues (from health care, to race relations, to political discussions), we are finding that modern truth is increasingly subjective. One of the difficulties is the echo-chamber perspective many people hold, engaging with and reading "truth" and information only from one perspective. It would be far easier to have much more beneficial and engaging discussions and arguments if all persons upheld their responsibility to inform themselves as much as possible. Belief is a powerful thing, but with it comes additional moral responsibility.