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

Ludwig Wittgenstein

# **Hot Topic**

# Autonomy and Decisional Capacity

A fundamental aspect of principalism in medical ethics is that the value of a principle is to never eliminate. Individuals (specifically patients) never lose their rights to the principles of respect for autonomy, beneficence, nonmaleficence and justice. It is only due to complications and circumstances that particular principles become more applicable or overriding than others. An important way to think about this is how the principle of respect for autonomy is impacted when a patient is determined to lack decisional capacity.

Just because a patient lacks the ability to understand and express his or her own autonomous medical decisions does not imply that the principle of respect for autonomy is void. It only implies that traditional methods for accessing and understanding that information are not effective and other methods need to be utilized.

This is where the value of precedent autonomy is established. By documenting one's medical preferences beforehand, one is able express in a form one's medical preferences. An establishing premise of all of this is the determination that the patient lacks decision-making capacity, i.e., the patient is not able to understand and make an informed decision. Only when a patient is determined to not have capacity does it become appropriate to utilize the patient's precedent autonomy (e.g., advance directive, advance care plan).

## **Controlling Constraints**

So, what is decision-making capacity, and how does one determine whether a patient has it?

Written as a positive obligation, the principle of respect for autonomy obligates professionals in health care and research involving human subjects to disclose information, to probe for and ensure understanding and voluntariness, and to foster adequate decision making. It is even more easily understood as a negative obligation; patient's actions should not be subjected to controlling constraints by others (Beauchamp & Childress, 107).

This can then be extrapolated and expanded to consider what are "controlling constraints"? For a patient to be able to properly express their autonomous decision, they must be truly free to be able to. This requires, as stated above, that the patient not be controlled by being coerced by authorities, family, medical professional, or even their medical condition. Obviously, this is a high standard to meet and many patients are impacted by these factors, including additional ones such as stress, fear and literary comprehension. But there is a difference between being influenced by and being coerced. It would be atypical (potentially an understatement but one should never talk in absolutes) to have a patient who is not influenced in some degree by outside factors. Still, while the decisions of most patients are influenced, they are not determined by. It is one thing to imagine a patient who consults the opinion of their spouse or family when making a medical decision; it is another for that spouse to be making decisions for the patient and overruling decisions that patient personally made.

Moreover, not only outside factors can have a coercive effect on a patient. Internal factors such as stress and medical condition can impact the ability of a patient to understand, process and properly express their autonomous decisions. This is one reason why it is important to ensure that patients have decision-making capacity and are not being negatively influenced by internal and external factors.

#### **Determining Capacity**

The potential involvement of coercive factors begs the question: What is decision-making capacity and how does one determine whether a patient has it?

Strictly speaking, all patients are considered to be competent unless a court has declared them as lacking in decision-making capacity, deeming them *incompetent*. This means that all patients should initially be understood to have capacity unless/until they are determined to lack that decision-making capacity. This is typically done by a physician or other medical professional, prioritizing particular aspects of understanding.

The clinical standards for decision-making capacity looks for patients to be able to:

- Make and communicate a choice
- Understand and appreciate the relevance for the medical situation and prognosis, nature of the recommended care, alternative courses of care, and risks, benefits and consequences of each alternative
- Make decisions that are consistent with the patient's values and goals
- Make decisions that do not result from delusions
- Use reasoning to make a choice

(Lo, 77)

Unfortunately, determination of decision-making capacity is not always straight forward and can exist in the gray margins. Take for example patients with a dementia diagnosis. Many have argued that just because a patient has a diagnosis of dementia does not immediately determine that the patient lacks capacity. More so, patients should continue to be assessed while their mental abilities potentially decline (Pennington et al.) (Trachsel et al.)

An additional potential problem that perfectly exemplifies the difficulty in determining capacity is cognitive fluctuations in patients diagnosed with dementia and the impact of their dementia on decision-making capacity (DMC). This is outlined in a study from 2014 in which the authors state, "that cognitive fluctuations are associated with fluctuations in DMC. However, this association has never been empirically tested. Decision-making capacity not only changes during different situations and tasks (decisional relativity), additionally and because of cognitive fluctuations, it may also change over time. It follows that the assessment of DMC must be case specific, task specific, and time specific." (Trachsel et al., p. 361). They further state how this can be a particular change for clinicians as they assessed patients because, "on the one hand, the case, task, and time specificity must be taken seriously, which means that DMC can change from one moment to another in the worst case. On the other hand, the law demands that DMC or incapacity is clearly ascribed to persons for important decisions such as medical treatment choices." (p. 361).

# Meaningful Advance Care Planning

The subtlety, difficulty and changing nature of capacity introduces additional ethical challenges. One in particular is the fact that capacity is typically not questioned when the patient agrees with the recommendations of the medical providers. Conversely, it highly likely to be questioned if the patient disagrees with established standards of care and recommendations. This can create situations and relationships between patient and physician that exacerbate a power divide between the two.

The right to autonomy is fundamental to ethical patient care, but the ability to access and communicate that right can be a challenge. The ideal scenario to access patient preferences is through communication with a patient who has capacity. In the absence of this, the right to autonomy remains, with that right best assured by valuing the individual person, creating opening and respectful communications, sharing decisions, and having meaningful advance care planning conversations.

#### Bioethics in the News

- KC-based Center for Practical Bioethics helps guide families, doctors during pandemic
- Are we heading towards 'bioethics nationalism'?
- Bioethics in a Pandemic: The Basics
- The ethics of infecting healthy people
- MPs and medical experts urge Ottawa to green-light vaccine trials that would deliberately infect healthy volunteers with COVID-19
- Med Students 'Feel Very Behind' Because Of COVID-Induced Training Disruptions

# Case Study

The patient is an 88-year-old female, admitted due to shortness of breath and complications due to severe dementia. Pt is known the hospital, having been following her for several years including the death of her husband, original dementia diagnosis, and monitoring of her progression. Upon original diagnosis, pt completed an advance care planning session and documentation, strongly stating that the pt would not want aggressive measures. Pt signed a DNAR. At the time of completion of the advance care plan, pt was still mourning the death of her husband and is suspected to have been suffering from depression. Pt said during the ACP conversation statements like, "No one cares about me anyway" and "What good is going on anyway".

As the pt's dementia progressed, her family moved her to assisted living. While there, she progressed to a point where she could no longer give informed consent and was determined to lack decision making capacity and competency. Socially though, while at the living facility, she met and became very friendly with another resident. The staff describe them as very much in love. Now, when asked about her long-term goals of care, the pt says she is very much happy and would like to continue living. This seems to be in direct conflict with the ACP documentation completed at original diagnosis over twelve years ago.

The attending physician has requested an ethics consult regarding determination of code status and goals of care for this admission.

# **Ethical Musings**

# Protecting Your Future Self: Another Way to Think about Advance Care Planning

Imagine the scenario that human teleportation is possible. Famed scientist Dr. Q says that he has successfully built a machine (similar to and inspired by the transporter from Star Trek) that can teleport him. He then says he has another machine on Mars and will be able to teleport people to Mars at the speed of light. Dr. Q demonstrates the functioning teleportation machine by teleporting himself to Mars, picking a Martian rock, and teleporting back with the rock as proof. He says the teleporter works by mapping your genetics, breaking you down into individual atoms, and relaying that information to another station across the planet, where then the machine on Mars will reconstruct you atom by atom on the surface of Mars, while the atoms on Earth are deconstructed. This process is repeated for the return journey.

The question then becomes, say you used the transporter, does the same person come out on the other side of the transporter? The person that transports would look exactly like you, talk like you, think like you, and even think that they were you. But are they really you? Imagine something goes wrong with the transporter and the self on Earth is not deconstructed, but instead that self survives and there is another self now on Mars. Who is the real self? How many selves are there? Are there two, one or zero? All could be easily thought to be the right answer.

#### The Nature of Personhood

This is a thought experiment done by Derek Parfit in a paper titled, <u>Divided Minds and the Nature of Persons</u>. Parfit was an Oxford ethicist who was very interested in the ideas of identity and personhood, and he developed this thought experiment to demonstrate our limited understanding of what personhood really is. Parfit (and me personally) believes that the new person that is created on Mars is not the same person that was on Earth. Instead, it is a completely new person who only believes themself to be the same self because of memories.

This is what Parfit calls "Relation R", meaning that the only reason a new person believes themself to be the same person as a past person is because of a cognitive connection between the two. This means that because both persons seemingly share memories and personality, they both believe themselves to be the same person. But just because two separate persons believe themselves to be the same person, at different times, does not mean they are the same person. Only that they believe themselves to be.

## A Moral Obligation

Parfit further extended this argument into the realm of ethics, arguing that because there are two different persons, a present self and a future self, the present self actually holds a moral obligation towards the future self. They should be seen as two separate persons, and within society we establish moral obligations of one person towards another, such as murder and crimes. In the same argument that a person should not be ethically permitted to commit murder towards another person, a person should not be ethically permitted to commit crimes against their own future self, since the self is a different/new person who is vulnerable to the actions of the previous self.

This can be exemplified by refraining from tobacco and cigarette use. Because your future self is a different person, you hold a moral obligation to protect that person from potentially preventable cancer, the same obligation you have towards others currently in the present time. Think of it as avoiding secondhand smoking towards your future self.

Furthering this idea, your future self has rights, such as the right to respect for autonomy. This is where the value of advance care planning is seen. Under a Parfit argument, it could be argued that you have a moral obligation to complete advance care planning so as to protect the autonomy of your future self. While some may disagree with the philosophical arguments regarding self and personhood, the benefits of advance care planning are well documented. Whether you are a different person or the same person, there should be a sense of obligation for ensuring that medical preferences are known and documented.