CENTER FOR PRACTICAL BIOETHICS
GUIDANCE AT THE CROSSROADS OF DECISION

October 2022

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

- Ludwig Wittgenstein

Hot Topic: What Is Decisional Capacity? Why Does It Matter?

A recent article in Scientific American claims that some comatose patients may actually be aware of their surroundings.

Jan Claassen, Associate Professor of Neurology at Columbia University, and Brian L. Edlow, Associate Professor of Neurology at Harvard Medical School, tell the story of a 30-year-old woman named Maria Mazurkevich. Maria suffered a ruptured blood vessel in her brain on a hot summer's day in New York City. She was admitted to the ICU, where she was placed on ventilator support. Her medical team searched for signs of consciousness but found nothing. When prompted to move her limbs, there was no movement. Nor were there any visual cues during her vision test. Her brain scans, however, told a different story:

The medical team gave her an EEG—placing sensors on her head to monitor her brain's electrical activity—while they asked her to "keep opening and closing your right hand." Then they asked her to "stop opening and closing your right hand." Even though her hands themselves didn't move, her brain's activity patterns differed between the two commands. These brain reactions clearly indicated that she was aware of the requests and that those requests were different.

As time went by, Maria slowly gained bodily function. Her brain scans began to comport with her body. Within a year, she was fully recovered. The above mentioned is striking. Maria's brain activity was "disconnected" from her body. She was unable to speak, communicate, or move her body, but the EEG identified active electrical impulses in her brain.

According to the article, Maria was aware, but are we licensed to make this assumption? If there is no movement in the body, and it appears the brain is responsive to prompts and commands, does this alone constitute awareness? And what about consciousness? This may be even harder to ascertain. As many philosophers and scientists of consciousness have pointed out, conscious experience, though familiar from a subjective standpoint, may be difficult to explain from an objective, scientific standpoint.

Let's bracket the nature and extent of Maria's "awareness" or "consciousness" and instead focus on decisional capacity in the context of healthcare decision making. In Maria's case, it seemed clear that she lacked the ability to consent or decline treatment with respect to her care. In general, it is assumed that a

comatose patient inherently lacks decisional capacity. But is this necessarily true?

In short, what *is* decisional capacity, or lack thereof, and how do we know?

Bioethics in the News

- Bioethics of Gender Affirming Healthcare
- Donors can track use of their organs and stay anonymous
- Working While Sick: Doctors Working While Sick

Case Study: Whose Decision?

Jorge is a 45-year-old, male-identifying patient who was admitted into the ICU with excruciating pain in his legs.

During a cold winter's night, a neighbor found him outside reeling in pain and called 9-1-1. When EMS arrived, the EMT's identified necrotic tissue in his feet moving up into his legs, so he was immediately transported to the ICU for care.

Upon admittance, Jorge is given medication for pain. His attending physician, Dr. Gina, assures him he will be taken care of and that the medical team will do everything in their power to figure out what's going on with his feet. Jorge tells Gina he's been without a home most of his life. He says he's "managed just fine," or mostly so, and tries his best to avoid doctors due to money issues. "I don't know what's happening, but my legs and feet hurt really bad. I just want the pain to go away," Jorge says.

Dr. Gina confirms that the necrosis in both limbs is caused by frostbite and untreated Diabetes 2. Tissue damage is so severe, both legs must be amputated below the knees so as to avoid further complications.

The medical team is saddened by the diagnosis. They understand the need for amputation, but they also understand the effects that amputation will have on Jorge's quality of life. "Who will care for him?" asks one nurse. "Who will get his meds? Who will take him to doctor visits? How can we be sure his wounds will be cared for properly after he's discharged? This is tragic."

Dr. Gina walks into Jorge's room to explain the situation. She tells him, "Jorge, there is extensive tissue damage below your knees. You also have some infection down there. If we don't treat them immediately, your feet and legs will likely get infected even more. You could die and we do not want that to happen to you."

Mortified by this information, Jorge exclaims, "I don't want to die!"

The physician assures Jorge that things will be okay. "In order to avoid this, Jorge, we have to amputate both legs below the knee. I know this may seem extreme, but it's the only sure way to avoid infection. I'm so sorry."

Jorge exclaims "Please don't take away my legs!"

Again, Dr. Gina explains that the amputation is necessary to avoid a fatal infection. And again Jorge replies, "I don't want to die! But please, please, don't cut off my legs! Please, Doctor! No one will take my legs! I can't live without legs!"

Initially, the physician is unsurprised by Jorge's response. Of course, he doesn't want to die. And of course, he also does not want to lose his legs.

Who does? He can't have it both ways, but most patients come around to understanding and acceptance after getting past the shock of being told that they'll need to lose a limb. Or two.

Hoping, expecting, that Jorge too will come around, Dr. Gina decides to give her patient some time to process everything. "He's in shock," she tells colleagues. "Let's revisit this later today after he's had time to think about it and process the emotions. Poor guy!"

"Later" rolls around. No luck. Even several days later, Jorge still appears to be giving conflicting information. When told about the potentially fatal side-effects of necrosis and infection in his lower limbs, he continues to say, "I don't want to die!" When told about amputation as a treatment option for avoiding death, he shouts, "No! Don't take away my legs!"

Perplexed, Dr. Gina wonders: "Does Jorge understand what is happening? Does he comprehend his situation well enough to make an informed decision about his care? Does this patient have or lack decisional capacity for a decision about life-saving below-the-knee amputation?

And what should be done? The physician wants to honor her patient's preferences, to respect his autonomy. She also wants to do the medically right thing for him, to be beneficent and avoid harms that can be prevented. To save his life.

Dr. Gina calls for an ethics consult.

Ethical Musings: Decisional Capacity - A Matter of Degree

Why should hospital ethics committees care about a patient's ability to understand, communicate and deliberate about their care? In other words, why should they *care* about decisional capacity?

(Before answering this question, note that decisional capacity differs from legal competency in significant ways. For more on this distinction, click here.)

One answer is that determining capacity can help promote and respect patient autonomy. Patients, after all, are human beings and human beings have personal autonomy. Though there are many philosophical accounts of autonomy, they all agree that the concept involves self-governance: Persons who are adults and without a court-appointed guardian have the moral and legal authority to make decisions that govern their lives. If persons are coerced or forced into making a decision, this constitutes an impediment to or infringement upon their personal autonomy. Given this, determining decisional capacity matters because it matters whether patients have personal autonomy with respect to their care. That is, it matters whether patients are in a position to govern themselves.

What, then, is required for decisional capacity? Al Jonsen et. al (2015) offer the following characterization:

In a medical setting, a patient's capacity to consent to or refuse care requires at least an ability to understand relevant information, to appreciate one's medical situation and its possible consequences, to communicate a choice, and to engage in rational deliberation about one's own values in relation to the physician's recommendations about treatment options.

The minimal requirement above already helps illuminate Maria's and Jorge's cases. In that of Maria, the comatose patient from New York, it turns out that she may have had some awareness of her surroundings, but probably not with sufficient comprehension to make complex healthcare decisions for herself.

Even if communication were made possible by sophisticated technologies that currently exist for "locked-in" patients, it is unclear as to where Maria would land on the spectrum of decisional capacity. Given the description from one article cited, she lacked decisional capacity. There was activity in her brain scan, to be sure, but this is a far cry from rational deliberation and communication about one's goals of care.

What about Jorge's case? Does Jorge lack decisional capacity? If so, why? After all, he seems to appreciate his own medical situation and its possible consequences. He apparently understands his limbs have necrotic tissue and infection, which, if left attached to the rest of his body may lead to death. He also seems to be communicating a choice, albeit with contradictions. He does not want to die from a gangrenous infection. He values his own life. It could be argued, though, that he cannot deliberate rationally about his values with respect to his care. This is because—despite the medical team's many attempts to communicate his diagnosis, prognosis, and treatment options—Jorge seems to want two things that are at odds with each other: avoiding the amputation of his legs and avoiding a fatal infection. "Don't take away my legs!" Jorge says in response to amputation as a treatment option. He also exclaims, "I don't want to die!" when informed about a possible fatal infection.

The cases above demonstrate that decisional capacity comes in degrees. It is indeed on a spectrum. On one end, you have Maria, who is in a comatose state, perhaps locked-in, but still seems to lack decisional capacity. And then there are cases that aren't so clear, like that of Jorge. There are many patients who may have some abilities requisite for healthcare decisional capacity like the appreciation of one's medical circumstances; yet they lack other requisite abilities like that for rational deliberation. We know also that decisional capacity often ebbs and flows within a single patient, as in patients with dementia who exhibit Sundowners Syndrome. Their anxiety and confusion in the evening significantly impacts decisional capacity that may be more intact during other times of day.

As it is ethically obligatory to respect persons' autonomy, it is necessary then also routinely to assess and reassess the decisional capacity of patients for whom capacity may be in question or transitory. Our patients are cared for with the understanding that their decisional capacity comes in degrees and is ethically significant.

Polo Camacho, Ph.D.
Tarris Rosell, Ph.D., D.Min.

Did You Miss the Last Two Medical Ethics Immersion Workshops? No problem.

Director of Membership and Clinical Ethicist Ryan Pferdehirt lectured on the practice of medical ethics and challenging patient situations. Watch the first workshop here and the second workshop here! Feel free to disseminate internally.

1111 Main Street, Suite 500
Kansas City, MO, 64105
816-221-1100

See what's happening on our social media