

No Patient Is an Island: Accounting for the Importance of Relationships in Medical Decision Making

KELSEY GIPE, PH.D.

While the pandemic has forced many into social isolation, it's important to remember that patients often rely on trusted people in their social circles and family for input and assistance with difficult medical decisions.

Imagine an 80-year-old man, Frank. Although Frank has some mobility challenges, he's able to live independently at home with the help of a wheelchair and a caregiver who visits a couple of times a week to tidy up and deliver groceries. Frank also maintains an active social life, particularly in his church, and enjoys spending time with friends in his neighborhood.

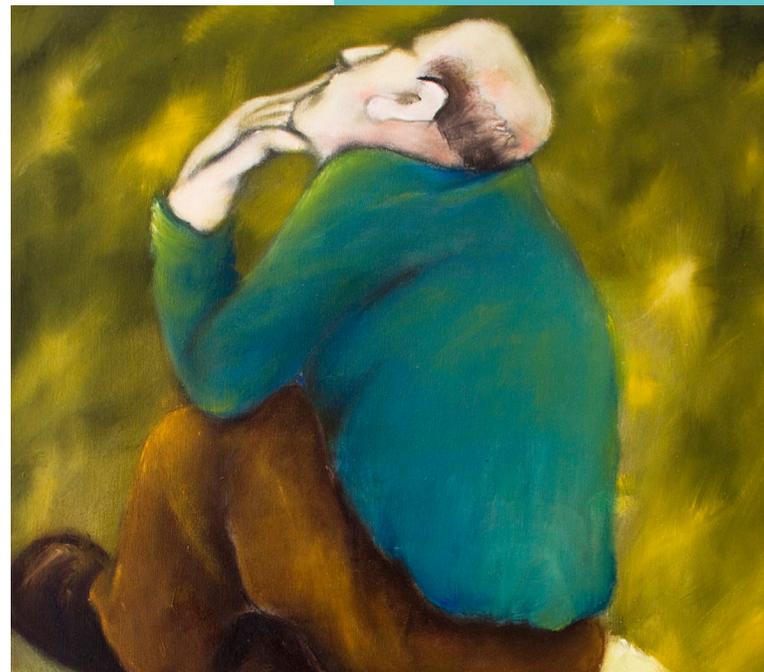
Frank's kidney function has been compromised for some time, but it only recently progressed to the point where the subject of dialysis became more urgent. A few years ago, when his kidney function began to worsen, Frank's nephrologist raised the possibility of dialysis. Frank explained that going to appointments multiple times a week would be too burdensome. He also shared that he had seen one of his closest friends "waste away" after beginning dialysis and didn't want to end up in such a state.

Over the following years, Frank consistently maintained his wish not to initiate dialysis and stated that when it's time for "the Lord to take him," he'll be ready to go to heaven. There's no doubt among his doctors that Frank possesses sufficient ability to make his own decisions regarding medical treatment.

Keep in mind the possibility that if Frank became sick enough to be hospitalized, he could be at imminent risk for a cardiopulmonary arrest unless dialysis were started as quickly as possible. As it happened, Frank's condition did deteriorate. At the beginning of his hospitalization about a week ago, Frank once again clearly stated that he did not wish to initiate dialysis. However, after speaking with his son, Frank is now begrudgingly saying that he's ready to give dialysis a try.

Throughout the hospitalization, Frank's son has been in frequent communication with the medical team, and his manner of interaction has been perceived as "pushy," "domineering," and "dismissive." There is concern that Frank's son may be coercing his father, through guilt or sheer force of personality, to undertake dialysis against Frank's own wishes and considered preferences.

What ought to be done in such a situation? What ethical considerations should healthcare providers take into account in trying to determine whether Frank's ability to exercise his autonomy and freely choose whether or not to begin dialysis has been compromised by undue pressure or coercion from his son?



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The Ethicist Is In

ROBERT FULBRIGHT, J.D., M.A.

The Case:

A request for a consult came into the Ethics Hotline regarding Mr. Kolff, a 72-year-old man in the hospital with

early-stage dementia and worsening kidney function. Per the attending physician, the patient arrived at the hospital after a mechanical fall at home, and shortly after admission required inpatient dialysis due to urine retention.

The physician and nephrologist were concerned that establishing outpatient dialysis may not be in the patient's best interests given his declining cognitive function. During his hospital stay, Mr. Kolff's thought process improved and he was able to communicate with the healthcare team. However, the attending physician determined the patient did not have decision-making capacity with respect to complex medical decisions, such as dialysis. How should decisions regarding dialysis be made in this situation?

The Ethicist:

Mr. Kolff's daughter, Joann, was acting as her father's appointed surrogate, participating in shared decision making with the medical team. The ethicist recommended a family meeting to learn more about Mr. Kolff's values and preferences, and to determine if ongoing dialysis would meet the patient's goals of care.

The patient was able to receive dialysis as an emergency procedure and this helped him participate in some discussions regarding his care. He was able to provide a reasonable amount of information about his medical history and the support he receives from his daughter. He also recalled the names of both the attending physician and the nephrologist. Mr. Kolff said he gets confused on occasion, though he is "straightened out" by his daughter. He struggled to explain his medical conditions and the benefits and risks of dialysis. He did recall receiving dialysis the day of the meeting and "a couple times before." Mr. Kolff acknowledged that his daughter's support was the main reason he feels he's still healthy. The ethicist asked what brings him joy and what his goals are moving forward. Mr. Kolff shared how he enjoys time spent with his daughter, loves to eat, and has a good relationship with his neighbor; they have been fans of the Warriors and Giants for years, so they always have something to talk about.

The attending physician and nephrologist discussed Mr. Kolff's medical condition and likelihood that he would require additional support at home and dialysis three times per week. Joann was agreeable to having additional support at home. The remaining question was whether or not Mr. Kolff was agreeable to having dialysis performed three days a week. His answer was, "It won't be so bad. If I can still be at home

The ethicist asked what brings him joy and what his goals are moving forward.

most of the time, I'll try it." The medical team was realistic in emphasizing that there would likely be a time when dialysis would become too great a burden, especially if Mr. Kolff was no longer able to enjoy the parts of life he values, and said "we would recommend considering hospice once that time comes." Mr. Kolff and Joann were informed about hospice and both expressed that they understood. Mr. Kolff was discharged home with his daughter after establishing outpatient dialysis and follow-up care with a primary care provider.

Mr. Kolff returned to the hospital about 11 months later, coming from a skilled nursing facility (SNF). The same day he was admitted, he became somnolent after dialysis. It turned out that staying at home had become more challenging and Joann had requested placement at a SNF because she no longer felt able to care for him at home, even with home health support. She said that her father had experienced a noticeable decline in mobility, increased confusion, and limited ability to eat and drink on his own. The attending physician noted that Mr. Kolff had continued to receive outpatient dialysis while at the SNF; however, the patient's declining cognitive function had led to requests to stop dialysis and attempts to get out of his chair. He also had intermittent episodes of attempting to remove the surgically placed arteriovenous (AV) fistula while receiving dialysis. Encouragement from dialysis facility staff prevented any injury or harm.

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It's important to bear in mind that patients don't make decisions within a vacuum; they are socially situated individuals embedded in a network of relationships, any of which may influence their decisions. But influence in itself does not entail coercion. And the preferences, wishes, and fears of the people patients care about may be valid considerations (among many) that patients rightfully consider when making decisions.

In addition to other-directed considerations in medical decision making, it's important to take seriously the complex role of social relations in patient deliberation. In some cases, the assistance of those close to them may have the power to supplement and enhance a patient's capacity for autonomous decision making. The sort of serious illness that necessitates acute hospitalization can detrimentally affect, both physically and psychologically, a patient's ability to make rational decisions. The experience of illness can be exhausting and overwhelming. Even patients with full decision-making capacity may benefit from the support of others when facing the challenging decisions that often accompany health crises.

There are also ways in which patients with limited capacity may benefit from the support of others in decision making. Take, for example, patients in the early stages of dementia. They may be forgetful and easily confused. However, appropriate family support may strengthen their capacity for autonomous decision making. Family involvement can both expand the options available to patients and supplement their ability to engage in deliberation and decision making.

Of course, not all relationships are healthy. Not all individuals involved in a patient's life will be good, rational actors who increase a patient's ability to make autonomous decisions. Coercion, exploitation, abuse, and neglect are all very real and should be addressed when present. A medical provider may be better able to draw a distinction between influence and coercion by knowing their patient as a person and developing a professional relationship grounded in trust and honesty.

Returning to Frank and his decisions regarding end-stage kidney disease, a sudden and radical shift to start dialysis after years of refusal does warrant a closer look to rule out undue influence by his son. Some important questions to consider include whether Frank consistently endorses this recent choice, even when his son is not present. Also, is Frank's new position consistent with his expressed values and preferences? If Frank is explicit in his wish to continue living, and understands dialysis to be an essential prerequisite



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for continued life, then his decision to initiate dialysis would be rational and consistent with this clearly held preference, despite his ambivalence toward the dialysis process itself.

Here, it's important to look carefully at the patient's familial relationships. The fact that Frank's son has an adversarial communication style may be an important contextual feature, but it should be considered that perhaps the son's mode of communication may be different within his own family circle. His aggressive and unhelpful interactions with providers may be prompted by his desire to protect his father. Frank's love for his son may be motivating him to give considerable weight to his son's strongly held views regarding treatment decisions. Awareness of the harmful effect that foregoing dialysis would have on his son may be a substantial consideration in Frank's change of mind.

Under such conditions, the decision to initiate dialysis now, even after years of refusal, could perhaps be re-evaluated from a different perspective: one motivated by relational factors but no less autonomous, and perhaps even a more genuine expression of the patient's autonomy, than a decision made in isolation.

The poet John Donne correctly reminded us that "no man is an island." People depend on a community—perhaps even more so when they are patients.

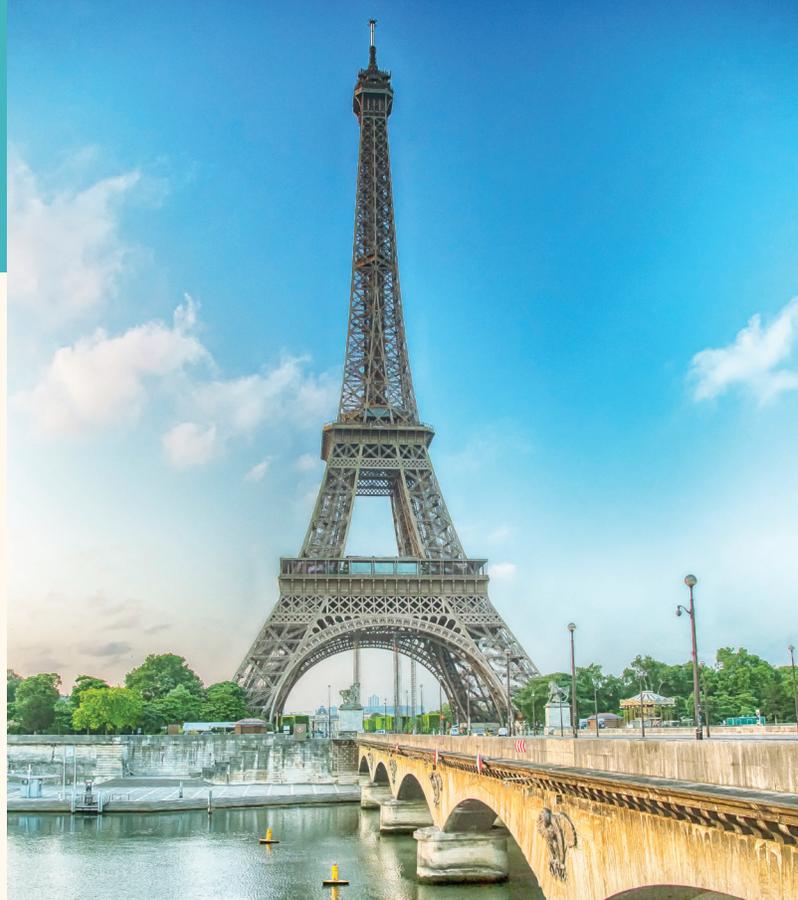
Dispatches From Paris

Ernest Hemingway was right: Paris is a moveable feast. When COVID-19 made international travel to France impossible, we took up the challenge and, for three weeks in February, turned our traditional **Neuroethics Network**, **International Bioethics Retreat**, and **Cambridge Consortium for Bioethics Education** meetings into virtual events.

A central feature of our new format was lively debates among noted experts on such controversial topics as:

- “Does a Mind Need a Body?”
- “Should Cerebral Organoids Be Used for Research if They Have the Capacity for Consciousness?”
- “Has the Time Come to Eliminate Controls That Involve Burr Holes in Neurosurgical Sham Research?”
- “Should We Use Technology to Merge Minds?”
- “Should Whole-Genome Sequencing Be Heavily Subsidized by the Government?”
- “Should There Be Compensation for Organ Donation?”
- “Are Some Lives ‘More Equal than Others’ in Allocating Coronavirus Vaccine?”
- “Should Euthanasia Be Expanded to Include Children?”

These debates will be transcribed and will appear in upcoming issues of the *Cambridge Quarterly of Healthcare Ethics*, published by Cambridge University Press.



An integral part of the program involved prerecorded presentations, available for viewing throughout the meetings and for 30 days after they ended. The new format proved so successful that it will be incorporated into future onsite meetings.

True to our goal of developing an international community of bioethicists, the following countries were represented in the meetings: Australia, China, Colombia, Croatia, Denmark, England, France, Germany, Ireland, Italy, Malaysia, Norway, Russia, Saudi Arabia, Spain, Switzerland, Turkey, and the USA.

Welcome and Introduction: John W. Frye III, Ph.D.



Dr. Frye joined PMHV after completing a clinical ethics fellowship at UCLA Medical Center. He received his Ph.D. in bioethics from Case Western Reserve University and master’s degrees in both bioethics and theological studies from Loyola Marymount University. In the past, he has taught classes at Loyola Marymount, University of Akron, and Case Western Reserve. Before starting at PMHV, Dr. Frye served as an ethics consultant at University Hospitals in Cleveland and performed independent ethics assessments for hospitals in California. His professional interests are clinical ethics professionalism, ethics informatics, artificial intelligence ethics, and assisted dying.

The Ethicist Is In

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Joann shared her concern that stopping dialysis would mean “giving up on him.”

Though the patient’s daughter requested that dialysis continue during the current hospitalization, the medical team was concerned dialysis was now causing greater harm than benefit; and, according to Mr. Kolff’s stated goals 11 months ago, he was no longer experiencing what appeared to be an appropriate quality of life. A follow-up meeting was held with the medical team and Joann. Mr. Kolff could no longer participate and was unable to engage in conversation with the medical team during this hospitalization.

Joann shared her concern that stopping dialysis would mean “giving up on him.” The medical team discussed how Mr. Kolff was at risk of injury if he became confused and attempted to remove the fistula or get up from the chair during dialysis. The team and the ethicist also discussed the limits on restraint use during dialysis. A patient cannot be restrained during dialysis and staff must consider whether dialysis is appropriate if any form of restraint is necessary to prevent harm.

While expressing understanding of Joann’s concerns, the ethicist transitioned the conversation toward her father’s previously stated goals. The team shared the concern that dialysis would not reverse his cognitive decline. The team also discussed that her father had stated his willingness to try dialysis if he would still be able to enjoy certain aspects of his life. Joann was reminded of the patient’s prior statements and encouraged to consider what her father would likely say about continuing dialysis if he could not enjoy the aspects of life that he described as having been so important to him.

The medical team discussed the possibility of returning Mr. Kolff to his home on hospice so that he could be at home with his daughter, one of the previously stated goals that could still be achieved. The ethicist discussed how treatments like dialysis are appropriate when a patient is still able to enjoy a quality of life they find to be acceptable, but not to simply prolong a life that no longer promotes a patient’s values and known preferences.



Joann expressed how difficult it was to accept that her father’s remaining time was limited. She agreed to him returning home to spend the rest of his days in peace, saying, “It is probably best for him.” She added, “At least I can make sure he is at home with me while he listens to a Giants game in the background.” She had set new goals of care for her father and was committed to help him realize them.



Publication Spotlight:

Kelsey Gipe, Ph.D.

“Heartbeats, Burdens, and Biofixtures”

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BIOETHICS WEBINAR

Words Matter: How To Communicate Effectively During Complex Patient Situations



As a part of our ongoing bioethics webinar series, PMHV hosted a live training class on March 17 titled “How To Communicate Effectively During Complex Patient Situations.” Our guest speaker was Ramy Y. Salah, M.D., medical director of palliative care and ethics committee chair at Mills-Peninsula Medical Center. Nearly 100 people from multiple health systems across California and other states viewed the webinar, which provided communication strategies and skills that clinical staff can use

during difficult conversations with patients and families. Dr. Salah noted specific terms and phrases to use or avoid while highlighting how to better communicate a poor prognosis. When utilized, these strategies will allow for a better alignment of medical treatments with patient goals, thereby reducing conflicts between healthcare providers and patients.