CLINICAL PRACTICE

*Exercises in Clinical Reasoning***The Unbefriended Patient: An Exercise in Ethical Clinical Reasoning**

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In this series, a clinician extemporaneously discusses the diagnostic approach (regular text) to sequentially presented clinical information (**bold**). Additional commentary on the diagnostic reasoning process (*italics*) is integrated throughout the discussion.

A 57-year-old man with chronic kidney disease, hearing impairment, limited literacy, paranoid personality disorder, alcohol use disorder, and venous thromboembolism was admitted for declining kidney function.

The patient had a history of violent behavior, and although now physically debilitated, he continued to be verbally abusive. He frequently refused blood draws and medications. The medical team attempted to persuade him to accept treatment, but with intermittent success. He refused to discuss his worsening kidney disease, and it was challenging to determine whether he had decision-making capacity. He had no known family or other surrogate decision-makers. Because of his behavior, he was viewed as a ‘difficult patient.’^{1,2}

We should remain skeptical of the label "paranoid personality disorder." Personality disorders are chronic traits persisting throughout adulthood. Without adequate history and collateral information, it is unclear whether this patient's paranoia is a long-standing pattern or a recent development requiring further evaluation. With sensory impairments and stressors such as homelessness, paranoia can actually be an appropriate response, providing a protective advantage. Hospitalization, with its many intrusions, from phlebotomy to exams, can escalate baseline paranoia. Furthermore, for those who cope with stress through substance abuse, the inability to use street drugs to lessen anxiety while hospitalized can lead to behavior that is maladaptive

and mistrustful. A history of substance abuse frequently goes hand in hand with a history of difficult encounters with the medical system, resulting in mistrust of providers by patients and, similarly, mistrust of patients by providers.

While we cannot control the behavior of hostile patients, we can control how we approach our relationships with them. Avoiding traditional medical interviewing in favor of patient-centered questions, and eliciting a patient's life story can foster rapport. Questions such as "How can I help you?," "Tell me what your goals are for this hospitalization," and "What do you see as barriers to reaching your goals?" demonstrate to a mistrustful patient that we are on his side, by changing the conversation from one on our terms, anchored in the medical model, to one focused on his goals. Directly addressing a patient's mistrust of the medical system can also be useful. Simply acknowledging that he may feel that he has received substandard care in the past due to bias against patients with addiction can build trust. When we fail to stay patient-centered, and instead are preoccupied with medical details, patients may resist efforts at relationship-building, leaving us in the dark about their healthcare objectives.

Incorporating a distrusting patient's ally into goals of care discussions can be helpful. Nurses, dieticians, physical therapists, and social workers who have developed alliances with the patient, and acquaintances outside the healthcare system, can be invaluable in facilitating communication. Palliative care providers, with their expertise in sensitive communication, can also be outstanding resources.

Once labels are applied to patients in the chart, providers may accept them without fully investigating. By questioning the label "paranoid personality disorder," the clinician avoids the cognitive trap of diagnostic momentum, and is able to think more broadly about what this patient's mistrust might signify. With this in mind, the clinician focuses first on rapport building rather than on medical details, a more constructive approach to engaging this patient.

Previous neuropsychology testing in this patient had documented cognitive impairment exacerbated by sensory impairments and paranoia. His acute-on-chronic kidney injury did not respond to fluids; urine sediment was bland and renal ultrasound unrevealing. His creatinine increased from 3.0 mg/dl before admission, to 4.5 mg/dl on

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admission, to 5.7 mg/dl 1 month into his hospitalization. His worsening renal failure and nephrotic-range proteinuria were thought to be secondary to myeloma kidney versus primary light-chain amyloidosis. Bone marrow biopsy revealed <10 % plasma cells; PET/CT showed no suspicious lesions. The appearance of his kidneys on ultrasound was consistent with advanced disease, so a renal biopsy was not pursued, as it was felt to be unlikely to yield a diagnosis. Despite multiple attempts to explain the need for dialysis, the patient repeatedly disengaged, saying only that he did not want dialysis. He was unwilling or unable to discuss his reasoning, alternatives, or consequences of his refusal.

To demonstrate capacity to make medical decisions, individuals must have a factual understanding of their illness, be able to rationally weigh treatment options and consequences, and communicate clear and consistent choices.³ Providers must also keep in mind that medical decision-making capacity is decision-specific, requiring separate assessment for each major decision.

Determining decision-making capacity is challenging in this patient with cognitive, sensory, and psychiatric limitations. Explaining the problem in simple terms, minimizing sensory impairments (e.g. with hearing aids), and engaging in repeated discussions are critical steps. Despite these efforts, patients may remain unable or unwilling to engage in discussions about their decisions. In these cases, decision-making capacity cannot be adequately assessed, and we find ourselves facing *the enigmatic refusal*.^{4,5}

In some cases of enigmatic refusal, patients do have decision-making capacity but will not engage in discussion to allow providers to confirm that capacity. It is important to assess the doctor–patient relationship. If the relationship lacks trust, we should offer patients the opportunity to discuss the decision with an alternate provider.⁴ Explaining that our attempt to assess capacity stems from our desire to protect patients who lack capacity may promote dialogue.⁴ Finally, it is essential to inform patients that silence could result in their wishes being overridden—this explanation may motivate engagement.⁴

When all efforts to engage a patient fail, providers must assume that the patient lacks the capacity to make the decision at hand. This assumption is based on our duty to protect patients who cannot protect themselves. Inferring a lack of capacity in cases of enigmatic refusal comes at the cost of sacrificing the autonomy of patients who do, in fact, have capacity, but simply refuse to engage in discussion. Therefore, it is only when decisions involve life- or limb-saving treatments whose benefits far outweigh the potential harms that we are on strong ethical footing to disregard a patient's refusal. Enigmatic refusal moves decision-making power from the patient to a surrogate decision-maker who must weigh the risks and benefits of the intervention while considering the negative consequences of treatment against a patient's will.

To guide decision-making, those who assume surrogacy must still try to discern the patient's preferences. Lacking concrete information, we may cautiously take cues from behavior. Refusal to discuss his disease or comply with treatment

could be the patient's behavioral expressions of his wishes to avoid intervention. While we should not rush to this conclusion given the many other potential reasons for such behavior, when we are faced with limited insight into a patient's wishes, patterns of behavior can serve as a rough guide. Based on his actions, it would be reasonable to consider that dialysis might represent a major burden for this patient, and that the negative consequences of forcing him to accept treatment against his will may outweigh the benefit.

As his renal disease progressed, the patient became increasingly cooperative. It was unclear whether this change was due to debilitation and uremia or to improved rapport with staff. However, he continued to oppose placement of a hemodialysis catheter, without offering a reason. Eventually, he developed severe hyperkalemia and was transferred to the ICU. He again emphatically declined a hemodialysis catheter. The ICU team felt he lacked the capacity to make this decision, but were able to temporize his hyperkalemia medically. Despite an extensive search, no one who could serve as a surrogate decision-maker was identified. A conservatorship application was submitted to the public guardian's office, but was denied without explanation.

As mentioned above, capacity is a medical determination linked to a specific situation. Individuals might have the capacity to refuse medications but not to accept or refuse dialysis—as the decision becomes more complex, our standards for capacity become more stringent. When they were confronted with a patient lacking the capacity to make key decisions, the team searched for a surrogate decision-maker, but, finding none, sought conservatorship. Table 1 outlines the prioritized order of surrogate decision-makers that healthcare teams must consult.

Patients who lack medical decision-making capacity and have no surrogates are known as “unbefriended” or “unrepresented.”⁶ In many states, these vulnerable patients are referred for public guardianship. Unfortunately, with the growing number of referrals, the demand far exceeds the resources of county agencies. Declining to consider cases in which the medical team has deemed a patient to lack capacity is a symptom of this over-taxed system. With no public guardian, but with agreement that a patient lacks capacity, the institution caring for the unbefriended patient must determine how to honor the patient's wishes while also considering the best-interest standard, “a legal standard of caregiving for incompetent patients, defined by the courts in terms of what a ‘reasonable person’ would decide in the same situation...[it]

Table 1 Flow of Decision-Making for Patients Lacking Capacity for a Given Medical Decision⁶

Decision-Making Type	Decision-Maker
Directed	Patient outlines wishes in advance (living will)
Delegated	Surrogate decision-maker designated by patient
Devolved	Default surrogate (family or friends) as defined by law, varies by state
Displaced	Judicial intervention (guardianship)

attempts to weigh the burdens and benefits of treatment to the patient...when no clear preferences...can be determined."⁷

In this challenging situation, the clinician focuses on the question of the patient's capacity to make a specific medical decision. In practice, physicians are often confused by the difference between capacity and competency. It is important to remember that competency is a legal determination, not a medical one. While it is also specific to certain kinds of decisions (i.e. competency to handle one's finances), competency generally has more far-reaching, global implications than the more narrowly defined question of decisional capacity. When urgent medical questions need to be answered, the expert clinician focuses on decisional capacity, and defers the broader and more time-consuming question of competency to the courts.

Despite the patient's refusal of dialysis, he remained future-oriented, expressing interest in physical therapy and discharge to a rehabilitation facility. He never endorsed depression, or expressed any indication that he did not want to continue living. However, because he refused a catheter, and much of the treatment offered as well, it was considered unlikely that he would cooperate with dialysis. Review of outpatient notes demonstrated a pattern of disengagement with medical care and refusal of medical interventions. It was unclear to what extent this pattern related to personal preferences versus long-standing psychiatric illness.

Given his history of violence and unpredictability, there was concern that he could represent a risk to himself or others at dialysis. Specifically, concerns were raised about the practical realities of attempting to force a patient to undergo dialysis, including the risk that he would pull out his catheter, resulting in large-volume blood loss, the subsequent need for chemical or physical restraints during dialysis, and the negative psychological impact that repeatedly forcing this invasive procedure would have, not only on this patient, but also on other patients witnessing this intervention in the dialysis center.

The institution's ethics committee was consulted. After much debate, the primary team was advised that it would be reasonable not to dialyze the patient and to change his code status to do-not-resuscitate/do-not-intubate (DNR/DNI) based on safety concerns, and on the fact that the patient's behavior, refusals, and history were important clues to his lifelong desire for non-intervention.

When patients have no advocates to oppose our recommendations, special scrutiny is needed. Difficult cases engender strong feelings in providers that can adversely influence decision-making. In these cases, multidisciplinary ethics committees can serve as a safeguard to prevent bias, ensuring that decisions are well vetted. By including diverse viewpoints of individuals not directly involved in patient care, we reduce the risk of allowing emotion to dictate care.

Unlike loved ones, who through their intimate knowledge of an incapacitated patient can use substituted judgment when making decisions, when a patient's prior wishes are unknown, ethics committees are limited to using the best-interest

standard. Providers live within the culture of medicine, a culture distinct from that of many patients. Studies comparing physician preferences, particularly around end-of-life issues, with those of the public demonstrate that doctors' values frequently differ from those of their patients.⁸ In particular, we tend to value intervention and biological factors at the expense of psychosocial and spiritual concerns. The inclusion of community members who may share the patient's background, values, culture, or religious beliefs helps ethics committees more thoughtfully apply the best-interest standard.

The skilled clinician is able to recognize his or her own biases and how they may impact decision-making, and gathers a multidisciplinary team who can more fully represent the patient. When ethics committees are consulted, the classic principle-based method of ethical analysis in which one considers the four canons of autonomy, beneficence, non-maleficence ("first, do no harm"), and justice is often used. Alternatively, Jonsen's four-box method can be helpful in framing difficult decisions.⁹ With this method, four factors are considered: the medical indications for the intervention (often the easiest to determine), the patient's quality of life with and without the intervention, the patient's preferences, and the case's contextual features. Biases of surrogate decision-makers are major factors considered within contextual features. For example, in this case, if the patient's record of violence triggers negative feelings toward him by the provider, that bias is acknowledged and, through its acknowledgement, hopefully discarded as a factor influencing clinical decisions.

Contextual factors can be thought of as a source of potential attribution error, a common cognitive trap in clinical decision-making. Attribution error occurs when positive or negative feelings about a patient unduly influence clinical decision-making. For example, such bias can lead a provider to assume a patient with a history of substance abuse has "cocaine chest pain" when, in fact, there is plaque rupture. Negative feelings about patients can lead providers to overlook historical clues suggesting plaque rupture, resulting in an inappropriate decision—i.e. to defer cardiac catheterization. When life-and-death decisions are involved, guarding against the influence of bias and attribution error is crucial. In this case, the team aims to do this by employing the diverse viewpoints of an ethics committee.

The patient's renal disease progressed. He was transitioned to hospice care and died 1 month later due to complications of his renal disease.

DISCUSSION

In this case, two questions needed to be answered: who was this patient, and what did he want. The answers required the medical team to listen to preferences very different from its

own. In situations like this, providers face stark contradictions between patient-centered care and quality care as defined by medical standards. The team's decision not to dialyze this patient hastened his death, but also honored his apparent desire for non-intervention. When patients lack decision-making capacity and have no surrogates, we must try to make decisions based on their values, not ours, with an eye toward weighing the burdens and benefits for the patient. To guard against biased decision-making, engagement of multidisciplinary ethics committees can be helpful.

This case touches on the practical and ethical issues surrounding a growing epidemic in the U.S.: the unbefriended patient. Many such patients are elderly, with comorbidities that compromise capacity. The aging of our population will exponentially increase the number of unbefriended patients. Furthermore, the U.S. Census Bureau projects that the proportion of those considered the "oldest old," over age 85, will more than triple by 2060, from 5.9 to 18.2 million.¹⁰ Many of the "oldest old" had surrogates earlier in their lives, but as they reach the extremes of age, those surrogates may be unavailable to act as decision-makers.

Information about the number of unbefriended in the U.S. is limited, with estimates that range from 5–10 % of ICU deaths¹¹ to 3–4 % of long-term care residents.¹² In one study, three-quarters of physicians reported having made a medical decision within the past month for a patient who lacked that capacity.¹¹ In another, one-third of ICU doctors reported making decisions for patients related to withdrawal or withholding of life-sustaining treatments.^{13,14}

Patients who retain the capacity to make medical decisions but lack healthcare directives or surrogate decision-makers are called adult orphans. These individuals present a critical window of opportunity—by helping them document their healthcare wishes, it is possible to protect their future autonomy before they become

unbefriended patients. However, providing anticipatory guidance can be difficult. Many adult orphans have a history of psychiatric disease, substance abuse, trauma, or homelessness. These issues create barriers and mistrust between adult orphans and the healthcare system, making it challenging to encourage documentation of healthcare wishes. Commitment to patient-centered and coordinated models of care, including case managers, social workers, and primary care providers, is needed in order to forge alliances with these patients well before they lose capacity.

There is no uniformity across the U.S. in how surrogacy is addressed for unbefriended patients. Laws vary by state, and even by county. An overview of approaches currently in use is provided in Table 2, which clearly shows that these models have significant limitations. The last model listed, which is based in the non-profit sector, is the most promising. By offering anticipatory guidance to adult orphans, encouraging them to document healthcare wishes, and then acting as private conservators when clients lose capacity, these organizations bypass the lengthy public conservatorship route. This paradigm identifies patients before they become unbefriended, forges relationships with them, and provides a roadmap of their healthcare wishes to eventual conservators. Few organizations have the capacity, however, to take on this task. Expansion of this community-based model through federal support is a worthy avenue of exploration.

Providers should engage policymakers and advocate for a just and efficient model for surrogate decision-making. As summarized by the American Bar Association's Commission on Law and Aging, "we owe these patients the highest level of ethical and medical scrutiny...to protect them from over-treatment and from under-treatment...to help them live better or to die in comfort and not alone."¹²

Table 2 Overview of Current Approaches to Surrogate Decision-Making for Unbefriended Patients

Strategies currently in use in the U.S.	Limitations
Public guardianship	<ul style="list-style-type: none"> • Not equipped to handle growing number of unbefriended • Quality, sophistication, and involvement of public guardians vary
Physicians as surrogates without the need for judicial intervention (often with ethics committee involvement)	<ul style="list-style-type: none"> • Potential for bias and conflicts of interest when only members of a particular institution make decisions for their patients
Trained volunteers used as surrogates for unbefriended individuals ¹²	<ul style="list-style-type: none"> • Typically focused on those with developmental disabilities and psychiatric disease rather than on the elderly • Requires resources for training
Detailed institutional decisional pathway, e.g. Department of Veterans Affairs: degree of review increases as risk and invasiveness of the proposed treatment increases ¹⁵	<ul style="list-style-type: none"> • Potential for bias and conflict of interest since decisions are made internally (somewhat mitigated by multiple levels of review) • Only suitable for internal medical decisions (i.e. cannot be used to allow long-term placement in a community facility)
Non-profit organization proactively seeks out adult orphans and encourages documentation of healthcare wishes, and then acts as private conservator when/if clients lose capacity	<ul style="list-style-type: none"> • Requires resources and investment for use on a large scale

Clinical Teaching Points

- When caring for patients with values different from our own, we should re-calibrate our approach and be willing to diverge from the medical model
- Capacity is a medical determination linked to a specific situation
- Enigmatic refusal creates an ethical dilemma; we must assume lack of capacity when dialogue fails
- Unbefriended patients are a growing segment of the population, and a multidisciplinary approach to surrogate decision-making is crucial
- Early identification of adult orphans is of key importance in addressing goals of care before loss of capacity occurs

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