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“Please Keep Mom Alive One More Day” - Clashing Directives of a Dying Patient and Her Surrogate

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Abstract

All medical care providers are legally and ethically bound to respect their patients wishes. However, as patients lose decision-making capacity and approach end of life, their families or surrogates, who are confronted with grief, fear, self-doubt, and/or uncertainty, may ask physicians to provide treatment which contradicts the patients' previously-stated wishes. Our work discusses the legal and ethical issues surrounding such requests, and provides guidance for clinicians to

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Disclosures:

The manuscript discusses a unique composite case created from the Memorial Sloan Kettering Cancer Center (MSK) Ethics Consultation database. The case was used for teaching and discussion purposes at the MSK Open Ethics Forum on August 7, 2018. The incident described bears no resemblance to one single patient or case, and as such, we did not seek consent from any patients or surrogates, nor the approval of the Institutional Review Board.

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ethically and compassionately respond - without compromising their professional and moral obligations to their patients.

Introduction

As patients lose decision-making capacity and approach end of life, their physicians, nurses, and other healthcare professionals must ensure that their care, comfort, and previously-stated wishes are fulfilled, while at the same time remain responsive to, and respectful of, the family's grief. Healthcare providers are generally able to honor these commitments with relative harmony. However, there are times when they encounter moral and ethical dilemmas as they attempt to balance these responsibilities with conflicting medical directives. The following case illustrates such a situation, in which a surrogate decision-maker asks a physician to administer hemodialysis to his dying mother against her previously-stated wishes, in the hope that it would prolong her life and allow them to see each other before she dies.

Misconceptions about the potential benefits and inherent risks of dialysis at the end of life are not uncommon among patients, surrogates, and non-nephrologist healthcare professionals. This case explores the unique considerations presented by renal failure at the end of life and provides practical guidance for avoiding potential clinical and ethical pitfalls. This scenario was created from a series of similar cases from our institution's large Ethics Database and the attributes of patients, surrogates, and staff have been removed in accordance with the Healthcare Insurance Portability and Accountability Act and to safeguard the privacy of all concerned.

Case Description

JB is a 56-year-old widow with an 8-year history of multiple myeloma and associated chronic kidney disease whose cancer has progressed despite multiple regimens of chemotherapy. Her oncologist has periodically discussed the probability that she would eventually need hemodialysis, which she has routinely declined. Her health care agent is her only son, a 22-year-old senior at an out-of-state college. JB has told the medical team that she is worried he would drop out of college to care for her if he knew the extent of her illness, and therefore she only wants him involved in her care if she loses decision-making capacity.

JB was admitted to the hospital with sepsis and a brief episode of altered mental status, both of which quickly improved after a course of antibiotics. However, her renal function deteriorated. She was again offered dialysis, which she declined, expressing a clear understanding of the risks and complications of her refusal, including death. The medical team deemed her to have capacity to make this decision. JB further instructed the medical team not to update her son about her condition, not wanting to distract him during his final exams. Shortly thereafter, her renal function precipitously worsened, and she developed lethargy, confusion, and additional life-threatening complications of renal failure.

Due to JB's incapacitation and imminent death, her son was contacted, and he begged the medical team to perform one session of hemodialysis to sustain her life while he travelled to the hospital. The medical team, while empathizing with the son's wish for a final visit with his mother, felt morally obligated to honor the patient's wishes, and requested an ethics consultation to help address this conflict.

Multiple Myeloma: The Oncologists Perspectives

The patient, JB, suffered for many years from Multiple Myeloma (MM), the second most common hematologic malignancy affecting plasma cells (1). Although effective drug treatments have resulted in improved survival rates (2), MM remains largely incurable, with only 50.7% of patients surviving to 5 years (3). Many initial treatment regimens have a nearly 100% response rate, but despite these advances which have provided opportunities for longer remissions (4), virtually all patients unfortunately relapse. As MM progresses, it leads to end organ damage, such as lytic bone lesions, anemia, hypercalcemia, or in this case, renal failure. The quality and duration of response to subsequent treatment regimens tend to worsen, and ultimately, most patients develop refractory myeloma and die (5).

Many factors affect prognosis in MM patients, including, as in JB's case, the presence at diagnosis and persistence of renal insufficiency, which is a poor prognostic indicator (6). Despite progressive renal dysfunction, she fared significantly better than one may have predicted, surviving 8 years post-diagnosis. In the last year of her life, JB was hospitalized three times with infections and worsening renal failure with a progressive decline in her quality of life.

Nephrologists perspectives

JB's medical condition is not unique. Many patients face co-existence of cancer with chronic kidney disease and end stage renal disease (ESRD), either because of direct toxicity of the cancer to their kidneys, or nephrotoxicity from the therapies which are used to treat the malignancy (7). While patients with certain types of cancer may be surviving longer (8), the adjusted mortality among ESRD patients with cancer has not appreciably improved over the past decade (9), even with the use of dialysis (10).

The patient was hospitalized with refractory MM and sepsis. Given the clinical presentation, she was expected to die on this admission. Dialysis would not have altered her eventual clinical outcome, nor would one session have "kept her alive" as her son requested. JB's encephalopathy was multifactorial; even though dialysis may have cleared some uremic toxins, it was unlikely to reanimate her to the point where she could have a meaningful conversation with her son. Moreover, patients with uremic encephalopathy are unaware of pain (11), and the removal of some uremic toxins by dialysis may result in the patient's feeling pain and discomfort. Dialysis is an invasive extracorporeal therapy, with several attendant risks including pain, bleeding, and infection upon insertion of the large-bore central dialysis catheter, and fluid and osmotic shifts during treatment that can cause brain edema, headaches, muscle cramping, hypotension, and hypothermia (12).

Nephrologists, as with all other healthcare providers, are obligated to abide by the principles of doing no harm (non-maleficence) and to relieve suffering when possible. The 2006

consensus statement by the Renal Physicians Association and the American Society of Nephrology acknowledges that there is *no* technical imperative to extend life without exception, and that it is appropriate to *not* initiate dialysis when a fully-informed patient with decision-making capacity voluntarily refuses it. Furthermore, it affirms that it is appropriate to *not* initiate dialysis in an incapacitated patient who had previously indicated refusal of dialysis (13), as was the case with this patient. The 2010 updated consensus guidelines emphasize shared decision making between patients, their families and healthcare teams (14).

To achieve this goal, early renal consultations for Chronic Kidney Disease (CKD) patients are highly recommended, preferably far in advance of their potential need for dialysis. Nephrologists can provide anticipatory guidance to patients, families and other healthcare providers (including oncologists) on the utility and implications of dialysis (15). Early discussion with nephrologists affords patients (and their families) an opportunity to ask questions and reflect on the physical and emotional implications - including benefits, side-effects, and logistical requirements - of this time-consuming and life-altering procedure (16).

Ideally, a trusting patient-physician relationship can empower patients to make informed decisions, and to share their wishes with their surrogates and/or family members long in advance of any acute illness or hospitalization. In this case, such forward planning may have helped the patient's son to better understand and accept the severity of his mother's illness and the futility of dialysis.

Nursing perspectives

Patients often turn to nurses for support and guidance during difficult medical circumstances, and they trust them to advocate on their behalf. At her last hospital admission, JB continued to decline dialysis and she demonstrated clear understanding of the risks and complications of treatment refusal. Often after her team finished rounding on her, she would say to her nurse *"I don't want dialysis. Why do they keep asking? I know what the risks are, and I don't want it. Can you help make them understand?"*

The nurse who had taken care of JB throughout her multiple admissions had grown very close to both her and her son. She well-understood JB's wishes to both refuse dialysis and protect her son, but also empathized with her son's wish to see his mother one last time. This case exemplifies the internal conflicts which nurses (and other healthcare professionals) often face: they must adhere to established ethical standards, such as honoring an autonomous patient's stated wishes, while at the same time respond humanely to grieving families.

Fortunately, the nursing team had recognized the importance of documenting in the medical records every instance that JB had refused dialysis, often including verbatim quotes. These were pivotal in helping her son ultimately understand his mother's motivations: *"He [my son] has finals coming up...I don't want to burden him, I want him to do well."* These quotes allowed the son to "hear" his mother, recognize her essence, and conclude, *"That's my mom. That's my mom. These really are her wishes."*

Ethical Considerations

This case was a challenging, although not uncommon situation for an acute care inpatient hospital. It involved aspects of the ethical principles of patient autonomy (including self-determination and informed refusal), beneficence, and non-maleficence, as well as the ethical complexities surrounding the responsibilities and limitations of surrogate decision-makers. The principle of autonomy imposes a series of obligations on physicians and other healthcare professionals to provide patients with clear and meaningful information about their conditions and to recommend pertinent diagnostic and therapeutic options.

Additionally, physicians must appraise the ability of autonomous patients to a) manipulate the information they receive, b) discriminate between the recommended treatment options, and c) act intentionally, free from the controlling influence of others and in accordance with their beliefs and values (17, 18).

In the context of bioethics, “respect for autonomy” implies a recognition and an acceptance by the medical team of a patient’s rights to receive healthcare information, to consent to or decline treatment, to make advance directives, and to appoint surrogate decision makers. When an autonomous patient becomes incapacitated, as in JB’s case, his/her autonomous rights to bodily self-determination are ethically and legally protected (19). Physicians routinely subscribe to these rights when they abide by their patients’ oral or written advance directives. While possessing a full understanding of the potential benefits and risks of dialysis, and demonstrating evidence for decisional capacity, JB consistently exercised her autonomous right to refuse dialysis at many junctures during the 8 years of her chronic illness. Her choice happened to align with the medical opinion that dialysis is not universally appropriate for patients with ESRD (20, 21), and that the decision to dialyze must be individualized.

Members of the clinical team may have been compelled to adhere to multiple ethical and humanistic tenets in their care of JB: they felt it was vital to a) acknowledge her intense preoccupation with her son’s emotional well-being and academic success (taking into account the anguish she may have experienced at her son leaving school to be at her bedside), b) support her unquenching needs to care for her son, and c) shield her from the potential harm, pain and suffering that often derive from dialysis. Sometimes healthcare professionals interpret beneficence as a need to act or to introduce additional therapies for a patient. In reality, the withholding or withdrawing of invasive interventions with little to no therapeutic benefit - e.g. dialysis - can be an expression of beneficence.

Conversely, a few nurses and physicians believed that honoring the request made by JB’s son for dialysis would be consistent with the patient’s known values, and that offering JB dialysis would be an alternate manifestation of beneficence. They were uncertain about the patient’s full appreciation of the - however limited - benefits of dialysis, particularly in terms of how such a therapy may have enabled her to care for her son. They opined that had JB been aware of how desperate her son was to see her before she died, she may have agreed to one dialysis treatment in order to mitigate his grief and spare him the suffering of not being able to say goodbye.

One may consider that healthcare professionals have a responsibility to extend the principle and practice of beneficence towards patients' families and friends. In this case, JB's son was on the cusp of significant emotional trauma, and some members of the clinical team felt that it was their professional and humanistic duties to care for him as well. However, acting beneficently does not require clinicians to honor family members' clinical requests. In this case, JB's nurse exhibited exemplary beneficence toward the son by showing him his mother's direct quotes in the medical record. These records gave voice to her intense love for her son, desire to see him succeed and rationale for eschewing dialysis, which allowed him to fully appreciate his mother's wishes.

Acting beneficently towards patients' loved ones also entails providing them with comprehensive and ongoing supportive services both during the patients' illnesses and after their death. Ethically responsible end-of-life care acknowledges not only patients, but families as well. "Who survives and how well?" becomes an important ethical concern in comprehensive supportive care (22). At various medical institutions social workers, psychologists, chaplaincy, support groups, etc. are available to help families navigate the stresses of caregiving and address grief after the loved ones' death.

Both patient and surrogate may have been ultimately motivated by mutual affection and profound altruism. Therefore, the request by JB's son for a singular session of dialysis merits careful consideration on a humane level and should not be summarily dismissed on the basis of an ethical analysis that is too clinical or even indifferent. After all, physicians and nurses cannot always dilute their human inclination to empathize with patients' surrogates in the service of abstracted ethical principles. The clash between their feelings and their duties exposes them to moral injury or - worse - to indifference (23).

Roles, responsibilities, and limitations of surrogate decision-makers

Surrogate decision-making has elevated the core bioethics principle of autonomy in the decades since the passage of the 1991 Patient Self Determination Act (19). A surrogate decision maker is responsible for supporting and, at times, augmenting an incapacitated patient's right to self-determination by advocating on the patient's behalf (24) and making the medical decisions that the patient, if competent, would have made - not those that the surrogate might make for himself or herself (25). The standards for surrogate decision-making are in order of preeminence:

1. Known wishes - Surrogates must follow the patient's expressed (written or oral) wishes, such as advanced directives, living will, or, other documented instructions.
2. Substituted judgment - When there is no evidence of a patient's expressed wishes, a surrogate must infer the patient's preferences based on prior statements, conduct, and/or evidence of religious, spiritual, personal, philosophical, or moral beliefs and ethics.
3. Best interest - If there is no reliable evidence of the patient's wishes, values, or preferences, the focus must shift from patient's autonomy to patient's welfare,

and the surrogate must base healthcare decisions upon clinical assessments of what would best promote the patient's well-being (25).

While these standards present a 'roadmap' for surrogate decision making, they also can present challenges for clinicians and surrogates (especially as patients approach end of life), since they are not always available or clear, nor do they reflect clinical realities or the interests of patients and families (26). Advance directives are often considered ideal standards, but they are generally static, and unable to convey the complicated, and possibly vacillating nuances of a patient's values and choices. Most patients cannot anticipate all possible future circumstances, and their preferences may change with an acute illness (26). Surrogate decision making is very complex, dynamic and nuanced, and should incorporate a wide range of patients' concerns and interests that may not align with the traditional ethical standards. Many patients grant latitude to their surrogates in deciding about treatment options. Clinicians are encouraged to account for surrogates' perspectives in the decision-making process to mitigate the negative emotional burdens that frequently arise when patients' wishes and preferences are ambiguous or diluted by the uncertainty of the clinical scenario (27, 28). In our case, for example, had JB been presented with the option of undergoing short-term dialysis in order to allow her son to see her, she may have altered her directive. Employing substituted judgment may be similarly difficult: even if a surrogate is keenly aware of the patient's values and beliefs, there may be unforeseen circumstances which make it difficult to infer what the patient might have wanted (26).

Furthermore, surrogates may be uncertain as to patients' preferences, be unduly influenced by others, or make requests or choices that elevate their own interests over those of the patients. JB's son request for dialysis may have been to further his own interests, albeit without fully understanding or appreciating his mother's wishes. Alternatively, his request may have been animated by his altruistic concerns of his mother's dying alone, surrounded by strangers and without the comforting company of her son.

To improve surrogate decision-making practices (and mitigate uncertainties or potential conflicts), healthcare providers should encourage both advanced planning and open communication between patients and their surrogates. Had the healthcare team been able to motivate JB to discuss her health status and preferences with her son, he may not have attempted to override her advanced directive.

Conclusion

The healthcare team had clear and comprehensive notes in the medical records regarding JB's treatment preferences, which were ultimately pivotal in helping her son respect her wishes and rescind his request to initiate dialysis. Healthcare providers should urge patients to articulate their wishes for end-of-life care and they should help patients communicate their health status, prognoses, and treatment preferences to their agents and surrogates. JB wanted above all to protect her son from distress. Open communication may have better-achieved this goal, by allowing JB's son to better prepare - logistically and emotionally - for his mother's death, thereby averting his desperate 11th-hour plea.

Misconceptions about the indications, benefits, and risks/complications of dialysis are prevalent among healthcare professionals. Early involvement of nephrologist helps calibrate patients' expectations about the values and limitations of dialysis in the context of ESRD and refractory MM. Please see Table 1 - *Avoiding Clinical and Ethical Pitfalls as Renal Failure Occurs*. Finally, the bioethical concept of fidelity compels clinicians to remain faithful to the promise they make to patients to follow and implement their medical directives (29, 30). Healthcare providers have an ultimate responsibility to place the interests of their patients above their own and those of the family or surrogates. They are ethically obligated to honor their patients' wishes, even if they believe them to be intentionally or unintentionally insensitive or inhumane (17). Emotional ambivalence among healthcare providers is not uncommon. However, there should be no equivocation over this case's ethical foundation, which is rigorous, neutral and objective: this patient's stated wishes were inviolable.

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Table 1:

Avoiding Clinical and Ethical Pitfalls as Renal Failure Occurs

Healthcare Teams Should:
Upon diagnosis, cultivate an interdisciplinary relationship which is maintained throughout the illness trajectory
Initiate renal consultations far in advance of potential need for dialysis to provide anticipatory guidance to patients, surrogate, family, and other healthcare providers
With patient's consent, include surrogates, agents, family members, or close confidants in renal consultations and discussions of goals of care and end-of-life care
Encourage patients to inform surrogate decision maker or family members about care preferences
Consistently document the patient's expressed wishes, including the reasons for his/her choices. Direct quotes are helpful
Appreciate that their first ethical obligation is to respect patient autonomy and to honor the patient's wishes

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