

CASE STUDY

To have done everything

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Abstract

When a patient loses decisional capacity, the responsibility to make treatment decisions often falls on a family member who becomes the surrogate decision-maker. This case study provides an example of a situation where the medical team and the surrogate decision-maker initially disagreed on the best course of action for the patient. The ethicist was called in to lead a guided conversation to help the team and the surrogate decision-maker reach a consensus. This case illustrates the importance of allowing the surrogate decision-maker to ask clarifying questions and process their emotions before making a decision.

Keywords: clinical ethics, inappropriate treatment, intensive care unit, surrogate decision-making, guided conversation

When a patient is no longer able to make their own decisions, a family member becomes the surrogate decision maker. It is up to them to interpret and represent the values of their loved one [1]. This case focuses on the tension between different stakeholders (families and care providers) when there are divergent goals and expectations pertaining to the medical treatment. Some literature [2] focuses on how moral distress can lead to difficult decision-making amongst families and care providers, whereas this case study focuses on the value of allowing the family time to internalise what is going on, to make sense of the issues at hand. In most hospitals across the globe, the Palliative Care team facilitates end-of-life and goals-of-care conversations to support the decision-maker. However, the Palliative Care team is sometimes met with distrust from the family. In this particular case at a Texas hospital, there was pushback from the family and the ICU team called for the hospital's clinical ethicist to be part of the conversation. As an independent consultant to the medical

team and families, the ethicist plays a crucial role in guiding this conversation, by focusing the conversation on value statements and weighing risks and benefits.

The patient's condition and living will

The patient, who will be referred to as "Bob" for anonymity's sake, was a father and ex-husband in his eighties. For the past four years, he had been living with his son, "Sam". Bob had always been a strong-willed and logical man, but was now afflicted with Alzheimer's dementia, severely impacting his ability to make his own decisions regarding his medical treatment. He had been in the Intensive Care Unit (ICU) for about three weeks, and his mental state had deteriorated significantly since his admission. Bob had a long medical history, but was currently admitted for an inability to sleep or eat, failure to thrive, severe deconditioning, dyspnea (trouble breathing,) oedema (a buildup of fluids in the body), and multiple myeloma. According to the American Cancer Society [3], multiple myeloma is a cancer of plasma cells that can cause low blood counts and damage to the bones and kidneys. In an otherwise healthy individual, Bob's breathing issues and fluid buildup could be treated with ease. However, as a result of his multiple myeloma, his blood was unusually thin. Any procedure, such as draining his excess fluids (paracentesis), had a high risk of causing excessive and potentially lethal blood loss. The most pronounced risks of performing a paracentesis for this patient (due to his haematological counts) were severe risk of bleeding (coagulation issues), infection, and damage to abdominal structures.

With this in mind, Bob's physician deemed any such procedure to be medically inappropriate. According to Kon et al [4], interventions can be considered inappropriate when there is no reasonable expectation that either the patient will improve sufficiently to survive outside of the ICU, or that the patient's cognitive functions will improve sufficiently for them to perceive the benefits of the treatment. Patients and surrogates often disagree with the physician's judgement and might pursue inappropriate treatment against the physician's recommendation [5]. When this happens, the American Thoracic Society recommends a seven-step dispute resolution process [6]. The subsequent conversation with Sam aligned with this process. The ethicist facilitated an elucidating dialogue between the medical team and the surrogate to advocate for an appropriate treatment plan that would align with Bob's wishes.

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When Bob still had decisional capacity, he completed a living will which described his wishes regarding future treatment should he lose decisional capacity. In both his living will and in prior conversations with physicians and loved ones, Bob had requested that life-sustaining treatment be used to keep him alive in a terminal condition. The care team had now arrived at a point where honouring these wishes could lead to potential harm. The care team thus turned to Sam. Bob had provided Sam his medical power of attorney and had placed no restrictions on his decision-making authority. When previously discussing treatment options with Sam, he was allegedly adamant that everything be done for his father. He stressed that he “would rather see him bleed out on the operating table, than give up on him.” Sam was a young father of two who had already lost his sister to cancer three years prior to this. He knew, from seeing his sister’s trajectory of intractable pain and poor quality of life that having his father’s fluids drained would at least enhance his comfort. What he did not appreciate was that this otherwise routine procedure could prove lethal for his father.

The dilemma

The fact that Bob was dying was clear; the ethical dilemma revolved around how he should die in a way that aligned with his wishes. There were three options that could be pursued. Firstly, if the procedure to drain his fluids was done, the risk of death or other complications was unjustifiably high. The physicians had ruled out this option, but Sam, determined to fight for his father’s comfort at all costs, still sought to pursue it. The first objective of the conversation was thus to illustrate the non-beneficial and inappropriate nature of this procedure to Sam. Secondly, if Sam agreed that the procedure should not be done, there was still a chance that he would opt to keep his father on life-sustaining treatment. In these conditions, Bob would continue to suffer due to the painful nature of his oedema and other comorbidities. Thirdly, if the procedure were not done, and life-sustaining treatment were ended, it would lead to his death and end his suffering.

Before meeting with Sam, the care team discussed the dilemma and tried to reach consensus in their recommendations to Sam. Many members of the care team expressed concern that if it were up to Sam, his father’s treatment would soon begin to cause suffering. This made the team uneasy. What would they do if Sam continued fighting for inappropriate treatment? Strategies were discussed on how to approach Sam, and it was established that the first goal would be to define what it truly means to do “everything”. Does everything include inappropriate treatment that causes the patient to suffer? For the team, “everything” had to be measured against what was medically and ethically acceptable. Would Sam understand this? Another question that the care team raised was: Are the physicians obligated by law and institutional policy to attempt resuscitation or do they have agency to withhold life-sustaining treatment?

The clinical ethicist’s strategies: a guided conversation

Bob’s lack of decisional capacity was reaffirmed by the physician, and Sam was invited to enter the room as his surrogate decision-maker. Sam was grateful to be involved, but was clearly experiencing emotional stress that would need to be addressed. The ethicist thanked Sam for coming, and took the lead in facilitating a guided conversation. According to Bruce et al [7], an ethicist can take on several roles during a meeting, ranging from that of a leader to an observer. One possible role entails facilitating a meeting without dominating the discussion. In this way, the ethicist allows room for the care team and the family to engage in a discussion, while guiding the conversation towards a productive outcome. In this particular case, the ethicist first steered the conversation to acknowledging Bob’s condition — that he was gravely ill and would in all likelihood pass away soon. The focus of the conversation would revolve around how he should die in a way that was in line with his expressed wishes. The ethicist asked Sam to describe his opinion of his father’s physical and mental status. By letting Sam give his impression, the care team could respond by clarifying Bob’s condition. This ensures he has all the knowledge necessary to make an informed decision. This is what Bruce et al [7] call the elucidation strategy, where the ethicist asks the physicians to clarify the prognosis and its implications to the family. With the prognosis clarified, the family will be less likely to make judgements based on misunderstandings throughout the guided conversation.

At the start of the meeting, it quickly became clear that the elucidation strategy was vital to Sam’s understanding of his father’s prognosis. Sam seemed to be in denial of his father’s physical and mental condition. “He spoke to me very clearly last night. He was making the same jokes he always makes,” Sam stated, as the care team explained that Bob had dementia and could no longer make his own decisions. He showed clear concern for his father’s wellbeing, but was misguided as to what would alleviate his suffering. “Why can’t you drain his fluids? He’s in so much pain,” he continued to ask. Taylor and Lightbody [8] identify several reasons why doctors provide inappropriate treatment at the end of life. One of these reasons can be the family or the patient’s insistence on doing “everything possible”. In this case, Sam and Bob had both been very adamant about doing everything possible, causing this ethical dilemma. In response to such situations, Taylor and Lightbody suggest having prognostic conversations where the prognosis of the patient is honestly and clearly discussed [8]. The ethicist asked the physician and oncologist to explain Bob’s condition and prognosis in clear but detailed terms. The intention was to clarify why the treatment Sam requested could very quickly become harmful.

The validation strategy: empowering the surrogate decision-maker

Sam asked what other options were available to make his father more comfortable. "I want to make sure everything has been done," he made clear. The physicians elaborated on Bob's prognosis, and after some deliberation Sam said he understood that his father could not have his fluids drained. This eliminated one of the options, the most inappropriate one, but it still left Sam and the team with a dilemma. Should Bob continue to receive life sustaining treatment in the intensive care unit? If he did, he would continue to suffer from his ailments, his mental state would further deteriorate; to the point where he might not even understand why he is intubated and suffering. However, his previous wishes would be honoured, and Sam could postpone the bereavement process. If he did not, Sam could be overcome with guilt at making a decision that indirectly leads to his father's death. Sam would suffer emotionally, but Bob's suffering would come to an end.

It is important to note that by ending life-sustaining treatment, the physicians did not intend to simply let Bob die in agony. This was explained to Sam. He would be moved to the palliative care unit, where the focus would be on quality of life and comfort. He would no longer receive curative treatment but would continue to receive treatments that would alleviate his pain and keep him comfortable. However, a natural death would be allowed to occur. Philpot suggests that when engaging in end-of-life conversations, the focus should be on what will be done, instead of what will not be done anymore [9]. The palliative care nurse employed this tactic as she explained the goals of her unit and the care that Bob would receive there. In doing so, she used "other-suffering emotions" [10]. Haidt identifies four categories of moral emotions: other-condemning, self-conscience, other-suffering, and other-praising. Other-suffering emotions include sympathy, empathy, and compassion [10]. Emotions such as compassion can help the care team understand and approach the patient's family. In doing so, the family's suffering is acknowledged and validated. This is crucial in helping the substitute decision-maker reach a careful decision whilst respecting and validating their emotional state.

The validation strategy ensures that the family feels heard and understood — it acknowledges them as important participants in the guided conversation who may be in the midst of their own bereavement process as the patient's condition deteriorates [7]. Internally, Sam was struggling with emotions of self-conscience such as guilt. He did not want to make a decision that would lead to his father's death. So, before he could decide, his feelings of guilt had to be addressed. In guiding the conversation, the ethicist allotted room for this and employed the validation strategy as an expression of empathy to further ensure that Sam felt that his opinions and anxiety were heard by the team [7]. This helps the

surrogate decision-maker work through their emotions of self-conscience so that they can make a decision they feel at peace with. The palliative care nurse employed a similar strategy by asking Sam about his religious beliefs to help him make a value-informed decision.

Making the decision

Taking the time to work through his emotions helped Sam ask the right questions and voice his wishes for his father's future. Sam asked if he could at least bring his father home soon, but he was met with a disappointingly realistic answer; "We do not know, the chances are slim." The care team affirmed that his desire have his father cared for at home was valid, and that the palliative care unit could be a potential step towards that goal. Noticing that the validation strategy had been effective, the ethicist moved the conversation to decision making, by employing the elucidation strategy to shed light on what Bob would have wanted, and asking Sam questions about his values [7]. What would Bob consider a good quality of life? What did Bob value in life? These evaluative questions helped Sam determine what would be in the best interests of his father. "He would want me to do the logical thing," he exclaimed, and the care team affirmed this. The ethicist asked if Sam agreed that it would be better if his father, in his frail condition, did not receive chest compressions or tubes down his throat. This was the ethicist's way of asking if Bob could be transferred from full code (everything should be done) to DNR status (do not resuscitate in the event of cardiac arrest). In using clear and concise language instead of medical jargon, the ethicist was able to broach the subject without confusing or alarming Sam. As a result, Sam was able to clearly interpret his father's wishes, and agreed that chest compressions and intubation would only harm his father. This illustrates how part of the ethicist's job is to make the conversation accessible to the family members; they need to be able to understand the implications of what is being said in order to make an informed decision.

With a decision reached, Bob was transferred to the palliative care unit the next morning. In this unit, he received comfort, care, and peace. He passed away that same evening, with Sam and the rest of his family at his bedside. While Sam would have to take time to grieve and heal, he knew that everything had been done to ensure his father had a painless and peaceful death.

Inappropriate care and physician discretion

This case study highlights the dissonance physicians often experience when they feel obligated by law to continue with inappropriate care as required by State Bill 11 of Texas [11]. This bill indicates that a physician can be held criminally liable if they unilaterally withhold care, even in cases of inappropriate care. For this reason, if a patient's living will or

advance directive indicates that they request “everything” possible be done, a physician cannot use their own discretion to withhold inappropriate care. In other regions of the world, physicians often have more agency to decide that further care will be inappropriate. In Texas, the patient’s advance directive can only be countermanded by the substitute decision-maker. However, this gives rise to another question. Does a physician have an obligation to minimise unnecessary suffering that may be caused by inappropriate care? To answer this, we look to the distinction between inappropriate care and palliative care. Kon et al [4] recommend that the ICU has two appropriate goals: to provide treatment that gives the patient a reasonable expectation for survival outside of the ICU with sufficient cognitive ability to see the benefits of the treatment, and to provide palliative care to comfort patients through the dying process. The case of Bob shows that unnecessary suffering can thus be minimised without resorting to inappropriate care, but certain criteria need to be met and a careful shared decision-making process must be employed.

In Bob’s case, his cancer and deteriorating condition meant that there were no reasonable expectations of his survival outside of the ICU. So, life-prolonging treatment was considered inappropriate. In fact, the form of treatment Sam initially requested had the risk of increasing Bob’s suffering. However, in such cases, physicians still have an ethical obligation to provide palliative care to minimise unnecessary suffering. In fact, making the surrogate aware that the patient’s suffering will be minimised through palliative care can help them accept that the previously requested form of treatment is inappropriate. This is exactly what was done in this case — upon understanding his father’s condition and the available options, Sam agreed to have Bob transferred to the palliative care unit where he received comfort through the dying process.

This case study thus provides us with a necessary reminder of the benefits to all parties of the shared decision-making process as guided by an ethicist. When there is a disagreement, escalation of conflict between the surrogate and the care team can be avoided through this process. The ethicist can ensure that misunderstandings between the care

team and the surrogate are clarified, and that the surrogate understands why inappropriate treatment is not being given. Palliative care can then take the place of what would otherwise have been inappropriate treatment.

While this case occurred in Texas and was constrained by local laws concerning physician discretion, shared decision-making takes place in a variety of settings. Even when laws and regulations differ, the principles employed throughout this case remain applicable.

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