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Article abstract

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ÉTUDE DE CAS / CASE STUDY

Decision-making at Life's End: Sharing the Burden of Responsibility

Amanda Quinn^a, Amitabha Palmer^b, Nico Nortjé^b

Résumé

Cette étude de cas aborde les défis de la prise de décision en fin de vie dans la pratique, en se concentrant sur l'équilibre délicat entre le paternalisme médical, la prise de décision partagée et les droits des décideurs de substitution. La famille a d'abord du mal à saisir la gravité de l'état de santé de l'être cher, mais un moment charnière lors de la réunion sur les objectifs de soins apporte une clarté soudaine. Ce cas explore la pertinence et les implications de la pratique du non-dissentiment éclairé. Cette analyse suggère que cette pratique est inappropriée à moins qu'il n'y ait des preuves irréfutables de paralysie de la décision. Des stratégies pratiques sont proposées pour faciliter l'accompagnement de la mort dans la compassion, tout en tenant compte des contraintes de l'urgence clinique.

Mots-clés

prise de décision partagée, non-dissentiment éclairée, paternalisme médical, fin de vie, deuil compliqué

Abstract

This case study discusses the challenges of end-of-life decision-making in practice, focusing on the delicate balance between medical paternalism, shared decision-making, and the rights of surrogate decision makers. The family initially struggles to grasp the severity of their loved one's medical condition but a pivotal moment during the Goals of Care meeting brings sudden clarity. This case explores the appropriateness and implications of the practice of informed non-dissent; and our analysis suggests that it is inappropriate unless there is compelling evidence for decision paralysis. Practical strategies are offered that facilitate compassionate dying care within the constraints of clinical urgency.

Keywords

shared decision-making, informed non-dissent, medical paternalism, end-of-life, complicated grief

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CASE

Mr. J, a 30-year-old patient with testicular cancer – metastasized to the lungs, liver, lymph node, and bone – arrived at our tertiary cancer centre's emergency room with shortness of breath. The patient had less than 20% lung capacity at arrival and was transferred to the Intensive Care Unit (ICU), where he was intubated overnight and became non-responsive. After extensive work-up, the medical team concluded that, despite any medical interventions, Mr. J's condition was irreversible, and death imminent. Given this prognosis, the team agreed that medically appropriate treatment was restricted to palliative care and a code-status change from Full Code to Do Not Resuscitate (DNR). The family, unaware of this information, believed that aside from his underlying cancer, Mr. J suffered only from pneumonia and that through proper treatment he would make a full recovery. This asymmetry prompted apprehension among the medical team about how best to disclose the reality of Mr. J's condition to the family.

An ethics consult was held which included four family members, the attending physician, the patient's case worker, an ethicist, and a hospital chaplain. The care team met briefly prior to the family's arrival – a practice that is especially useful for difficult cases given potential risks and challenging psycho-social factors. During the pre-meeting, the medical team commented that, based on previous interactions with the family, they were in a state of denial regarding the severity of Mr. J's condition, especially given his young age and the rapid disease progression, and would likely ask for medically inappropriate treatment. For this reason, the medical team favoured taking the decision to remove life support "off the shoulders" of the family to avoid prolonging Mr. J's dying process. In the meeting with the family, the medical team described the patient's physiological state, and the family began to demonstrate understanding that Mr. J was actively dying through expressions of pre-emptive grief. As this recognition occurred, the attending physician introduced the matter of code-status, a term used only to indicate whether a patient will be resuscitated given the need (Full code), or if they abstain from resuscitation under all circumstances (DNR).

In response to this, the wife asked the medical team, "What do we do?", and the nephew asked, "How long does [Mr. J] have?". The medical team proceeded to inform the family that they should call anyone who wished to say final goodbyes and when they were ready the following day, the team would begin compassionate extubation. Appearing distressed, the wife asked the medical team, "Do I have a say in what happens?". The ethicist reassured the wife that, as the medical power of attorney (MPoA), no medical decisions would be made without her consent.

Once the meeting had ended, the attending physician approached the ethicist and shared that the weighty consequences of end-of-life medical decisions can lead to paralyzing guilt which in turn leads to poor medical decisions and outcomes. This is

especially true when families are highly distressed. And as if to remove any doubt of her distress, the wife fainted immediately upon returning to her husband’s room. The consult raised a deep ethical problem: How to support grief-stricken families who may be in decision paralysis while simultaneously avoiding the harm of prolonging a patient’s dying process?

INFORMED NON-DISSENT

The attending physician was advocating for a kind of medical paternalism, a decision-making model wherein medical professionals, based on their wider breadth of knowledge and experience, make treatment decisions without necessarily informing the patient or obtaining their consent (1). Medical paternalism can be justifiable, or even obligatory, if the decision-maker lacks the ability or capacity to make decisions according to the patient’s interests (2). In these cases, such as when a patient or their MPoA succumb to decision paralysis, medical teams may employ informed non-dissent (IND), in which providers unilaterally determine appropriate care, inform the surrogates of their course of actions, and then act unless directly overridden by the subjects of care (3). However, this practice is rare, as most patients and their families prefer to participate in a shared decision-making process.

In this particular case, IND was inappropriate because, although distressed, there was no compelling evidence to suggest that the wife was experiencing decision paralysis. Were the wife to flee when faced with this decision, or the family dissolve into intractable conflict, then the immediacy of Mr. J’s medical condition (and the subsequent harms of resuscitation, should it be required) may have justified an appeal to IND (4); however, the family displayed no dire conflict in values during the ethics consult, nor did the wife avoid her responsibility. Moreover, through asking, “Do I have a say in what happens?”, any assumption that the wife did not want to participate was undermined. Beyond this, the wife had the right to be informed of her decision-making power, a right that follows from the principle of respect for autonomy. This right is the default clinical position which should only be overridden for compelling reasons (2).

SHARED DECISION-MAKING

Beyond respect for autonomy, medical teams should also appreciate the impact that medical decision-making has on a patient’s loved ones. When a patient dies in the ICU, their loved ones are at increased risk of complicated grief, post-traumatic stress disorder, and mental health issues (5,6). The burden of individual medical decisions rests heavily on the shoulders of those left behind. Shared decision-making recognizes the burden on both the family, who must live with the decision, as well as the medical team, who must administer the care (7). Mr. J’s wife actively inquired about her husband’s treatment, signifying her desire to be involved. A paternalistic response to her attempted participation ignores this shared burden, thus eliminating the opportunity for a shared decision-making process that would simultaneously reduce the risk of poor familial outcomes and unethical medical practice.

Rather than overriding the wife’s power as the MPoA, the decision-maker should be provided with time, resources, and reassurance of the medical team’s commitment to shared decision-making. Examples of such provisions include:

Table 1. Examples of provisions

Provision	Action	Discussion Guide
Time	<ul style="list-style-type: none"> • Allow for silence • Provide a suggested timeline based on compromise • Provide time for reflection • Offer time for farewells 	<p>“Continuing intubation prolongs your loved one’s dying process. The medical team would prefer, for the patient’s sake, to take the patient off the ventilator as soon as possible. However, if you need time to process this information or gather family members to say final goodbyes, then we can ensure you have enough time for this.”</p>
Resources	<ul style="list-style-type: none"> • Consultation with chaplaincy • Hospital psychologist/counseling resources • Offer grief pamphlets/bereavement support • Provide resources on local funeral and burial procedures/costs 	<p>“During these challenging times, we often offer resources like counseling or chaplaincy, grief pamphlets, and information on bereavement options. These resources are here to assist you, so please do not hesitate to seek them out or use them.”</p>
Commitment to shared decision-making	<ul style="list-style-type: none"> • Ask emotionally reflexive questions • Practice empathetic listening • Offer assistance through the process • Address questions or concerns • Provide reassurance that care will continue 	<p>“Do you have any other questions about the patient’s condition?”</p> <p>“Is there anything we can do to assist you through the patient’s dying process?”</p> <p>“Do you have any concerns about our suggested treatment plan/ timeline?”</p>

The patient is inextricably linked to those they care about, meaning that the patient’s well-being, in part, depends on the well-being of their loved ones. By acknowledging the vulnerability of decision-makers in environments of high acuity, it would be wise for care teams to allow families and decision-makers to contemplate their fears, anxieties, grief, hopes, and thoughts and be given what time is available. Rushing loved ones to make a decision based on medical time is not beneficial to the loved

ones or the care team. It can not only lead to feelings of disrespect and overwhelm the family, but it also needlessly places the burden of decision-making solely on the care team.

While the demanding nature of the ICU often imposes constraints on the luxury of time, it is essential to hold values tight so as not to lose them in the chaos of emergency. Rushed practices and paternalism without due cause fail to acknowledge the values held dear by the patient's loved ones. Shared decision-making allows for the tightest hold, both on ethical practice and good patient outcomes. Though it is not always convenient, shared decision-making is the process by which the human element is preserved in medicine.

DISCUSSION QUESTIONS

1. How can care teams better engage families in shared decision-making, especially in cases where there is a high risk of complicated grief or deep denial?
2. As suggested in the case review, should it be the responsibility of the physician or the direct care team to inform the patient of available resources? If not, what medical professional should assume the role of bereavement-informant?
3. How can we better support physicians and care teams who work in high-stress environments when faced with moral dilemmas regarding patient care?

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Conflicts of Interest

None to declare

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