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Article abstract

A surrogate or substitute decision-maker is tasked with making medical choices that the patient would make for themselves. However, most of the time the surrogate decision-maker is also emotionally involved with the patient, which makes the execution of these choices very difficult. This case study looks at a wife's struggle to honour her husband's wishes, because she did not want to lose him.

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ÉTUDE DE CAS / CASE STUDY

When a Surrogate Knows What to Do, but Can't Do It

Victor Esteban Grado[a], Maureen Pontarelli[a], Ian Doherty[a], Nico Nortjé[a]

Résumé
Un mandataire ou un décideur de substitution a pour mission de prendre les décisions médicales que le patient prendrait lui-même. Cependant, la plupart du temps, le mandataire est également lié émotionnellement au patient, ce qui rend la mise en œuvre de ces décisions très difficile. Cette étude de cas examine les difficultés rencontrées par une épouse pour respecter les souhaits de son mari, parce qu'elle ne voulait pas le perdre.

Mots-clés
mandataire, prise de décision médicale, éthique clinique

Abstract
A surrogate or substitute decision-maker is tasked with making medical choices that the patient would make for themselves. However, most of the time the surrogate decision-maker is also emotionally involved with the patient, which makes the execution of these choices very difficult. This case study looks at a wife's struggle to honour her husband's wishes, because she did not want to lose him.

Keywords
surrogate decision-maker, medical decision-making, clinical ethics

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CASE STUDY

Mr. X, a 68-year-old man, was diagnosed with metastatic non-small cell lung cancer in 2022 at the age of 65. He received four cycles of combination chemotherapy with palliative intent, but his treatment was complicated by ICI-induced colitis, an adverse effect in which the immune system becomes overactive. Other than this complication, he also had a history of cardiac arrest and respiratory issues. Given Mr. X's complicated clinical picture, and four Intensive Care Unit admissions within 2 months, it was not a surprise that he twice had a cardiac event where his heart stopped. Both times, Return of Spontaneous Circulation (ROSC) (getting a pulse again) was achieved, however he had to be intubated given his history of respiratory issues. A week after he was intubated, he self-extubated. He was very alert and oriented and was found to have decision-making capacity. Mr. X was adamant that he did not want to be intubated again and requested a Do-Not-Resuscitate/Do-Not-Intubate (DNR/DNI) order to be placed.

Surprisingly, Mr. X started to improve, and he was moved to a non-acute care setting floor within the hospital, and discharged home. Sadly, a few days later, Mr. X was in another crisis and was admitted through the Emergency Room. Given local legislation, a previously indicated DNR/DNI is only valid for the specific admission and could not be transferred to the new admission. Mr. X was admitted as a FULL code patient (he would need to be resuscitated and intubated should he code or have respiratory distress). Given the fact that Mr. X did not have capacity, the team turned to his wife to decide on her husband's code status. Mrs. X felt hugely conflicted as she did not want to lose her husband, but likewise she also did not want him to suffer.

WHY DO SURROGATE DECISION-MAKERS HAVE DIFFICULTY IN MAKING DECISIONS AT THE END OF LIFE?

Surrogate decision-makers, occasionally referred to as substitute decision-makers, are integral to making medical decisions for patients who are incapable of consenting or refusing to consent to proposed treatments themselves. However, surrogate decision-makers can encounter numerous obstacles when trying to make decisions. Some difficulties include knowing the patient's true preferences in relation to the specific context, accurately assessing the patient's quality-of-life, and the psychological and emotional burden of making the decisions.

When surrogate decision-makers carry out the patient's wishes recorded in advance care planning documents, they operate under the substituted-judgment standard. Surrogate decision-makers using this standard are supposed to act as if they are the patient and choose what the patient would have chosen (1). These decisions can be easier when a patient's wishes are explicit or written down in a living will or other advance care documents. However, trouble arises if the wishes are not documented, or if the surrogate decision-maker needs to infer what the patient would want based on previous conversations, which can be confusing. A patient's values may be misapplied, misconstrued, or not receive proper priority. One study evaluated surrogate decision-makers and their ability to predict whether patients would forgo life support. The study showed that surrogate decision-makers decisions were no better than chance at representing patients' end-of-life wishes (2). Another hurdle surrogate decision-makers may need to overcome is accurately assessing the current quality-of-life (1). For example,

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a surrogate decision-maker may perceive living life with a tracheostomy to be challenging and burdensome for the patient. The maintenance and limitations may be seen as cumbersome and too restrictive. However, the patient may deem life with a tracheostomy to be entirely acceptable because it would enable them to still enjoy aspects of life that are essential.

Stress and other psychological factors that arise when making end-of-life decisions may over-burden the surrogate decision-maker. For instance, the surrogate decision-maker may be re-traumatized during the decision-making process. The surrogate decision-maker may have witnessed the toll that making medical decisions for someone else can have on another individual. The surrogate may worry that they will develop poor coping habits because they saw someone else in the same situation poorly cope with medical decision-making. Making end-of-life decisions for a loved-one may cause the surrogate decision-maker to have flashbacks or re-experience a previous traumatic event as if it were happening in that moment (3). Knowing how to navigate the complexities that arise in surrogate decision-making is important for clinicians and clinical ethicists alike.

HOW CAN ETHICISTS HELP SURROGATE DECISION-MAKERS?

Clinical ethicists can play a crucial role in supporting and guiding individuals tasked to make decisions on behalf of others. Most surrogate decision-makers do not have experience or expertise in making such decisions prior to being declared as the legal next of kin or appointed as a healthcare or medical power of attorney (4,5). Clinical ethicists can help these individuals by offering emotional support, using good communication skills, and maintaining focus on the patient.

It is critical for clinical ethicists to understand how the surrogate understands and processes their role as decision-maker. To some this role could feel honorary, to others it could feel daunting or emotionally burdensome (6,7). Understanding the surrogate's perception may help clarify how and where the clinical ethicist can support decision-making. For instance, in the case above, Mrs. X is conflicted because she does not want to lose her husband but also does not want her husband to suffer. It would be reasonable to assume that Mrs. X feels somewhat burdened to make this decision or that the decision is a daunting task. The clinical ethicist may be able to support Mrs. X by acknowledging her conflict and articulating that two things can be true at the same time, i.e., her not wanting to lose her husband but also not wanting him to suffer. By doing so, the clinical ethicist not only emotionally supports Mrs. X but also builds trust and rapport with through acknowledgement of difficulties.

Good communication skills, such as acknowledging difficulties in decision-making and clear rearticulation of feelings, can aid in ensuring that the surrogate decision-maker feels heard and respected. Having surrogate decision-makers answer these questions aids them in organizing their thoughts and allows them to articulate their goals and identify their fears for an individual's health and future care. This approach also helps recentre the focus of the care conversation on the patient. Clinical ethicists should ensure that the patient remains at the centre of the care conversation and should make efforts to limit feelings of guilt or overwhelming responsibility by articulating patient's previous stated wishes, when known, and by using pluralistic language.

Pluralistic language uses terms such as, 'we' or 'us' to offer a sense of solidarity and teamwork. When wishes are known, like in the case of Mr. X, the clinical ethicist should ensure that Mr. X's previous wishes are stated out loud during care conversation; this could help reduce Mrs. X guilt or burden of decision-making by acknowledging that Mr. X had made a decision in regard to this situation in the past. In addition, saying 'we' instead of 'you' can help surrogates feel supported and lessen the burden of the role of sole decision-maker. For instance, "I hear you say that you don't want Mr. X to suffer, we also don't want him to suffer. The healthcare team's fear is that doing CPR will cause unnecessary pain and would go against what Mr. X had previously wished for, which was no chest compressions or intubation." This statement uses pluralistic language, identifies areas of agreement and concern, and refocuses the care conversation on Mr. X while hopefully reducing guilt or burden felt by Mrs. X.

QUESTIONS

1. What is the role of a surrogate decision-maker?
2. How does a surrogate decision-maker assess a patient's wishes?
3. How can an ethicist help reframing conflicting values for a surrogate decision-maker?

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