

## Helping Surrogate Decision-Makers Through Difficult Conversations

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[See table of contents](#)

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### Article abstract

Difficult conversations in the ICU are often seen as ones of getting a surrogate decision-maker to make an end-of-life decision. However, allowing the surrogate decision-maker to become a narrator can alleviate the daunting task lying ahead.

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## ÉTUDE DE CAS / CASE STUDY

# Helping Surrogate Decision-Makers Through Difficult Conversations

Nico Nortjé<sup>1</sup>**Résumé**

Les discussions complexes dans les services de soins intensifs sont souvent perçues comme un processus permettant d'amener un mandataire à prendre une décision de fin de vie. Toutefois, le fait de permettre au mandataire de devenir narrateur peut atténuer la tâche ardue qui l'attend.

**Mots clés**

mandataire, service de soins intensifs, décisions de fin de vie, narrateur

**Abstract**

Difficult conversations in the ICU are often seen as ones of getting a surrogate decision-maker to make an end-of-life decision. However, allowing the surrogate decision-maker to become a narrator can alleviate the daunting task lying ahead.

**Keywords**

surrogate decision-maker, ICU, end-of-life decisions, narrator

## Introduction

It is estimated [1] that less than 20% of adults who are admitted to the intensive care unit (ICU) have discussed their wishes about end-of-life treatment with their loved ones. This often leads to surrogate decision makers having to make high-stakes decisions about life-sustaining critical care, under conditions of heightened psychological stress and uncertainty [1]. This uncertainty is often tied with the fact that the surrogates themselves are unprepared for the role abruptly bestowed upon them. Making sense of the circumstances, prognosis and values of the individual for whom they need to make decisions of great importance as this will alleviate depression, anxiety and maladaptive reasoning [2,3].

The following case will illustrate the turmoil that surrogate decision makers often face when they are left to make decisions without prior knowledge of the patient's choices.

## Case study

John was in his early 20s when he was diagnosed with cancer to the bone, which quickly spread to the lungs. Unfortunately, John kept his diagnosis to himself and for the next few months he did not keep to his appointments and the result was that he was rushed to the Emergency Room with impending respiratory failure. Unfortunately, John's cancer, together with all the metastases, progressed so much that he was not a candidate for any kind of treatment. As time lapsed, John became progressively unresponsive and eventually lost capacity to make decisions. His mother, as his appointed medical power of attorney, stepped in to make decisions on his behalf. Mrs. B was very distraught, as can be expected, and she kept focussing on the fact that she did not know about his prognosis, that he was so young, and how he still wanted to do so many things in his life. Mrs. B was by no means ready to change the code status of her son and transition him to comfort care. She wanted to keep on fighting and pursue treatment.

## Framing Effect

The aforementioned case is not uncommon in many ICU's; often the surrogate decision maker is caught off guard and forced to make tough decisions for which they themselves feel ill-prepared, given the circumstances. This stress, as well as the onset of the grief process, often result in surrogate decision makers wanting heroic treatment, even if it is against medical advice. Given the fact that the practice of medicine has developed to encapsulate patient autonomy and rights, healthcare teams are often left despondent when they know what the prognosis is, but also need to follow the instructions of the patient or as in this case, the surrogate decision maker. It is in cases like these that healthcare teams often reach out to an ethicist to be a bridge between the patient (and family) and the health care team.

Consequently, the ethicist was consulted and after reviewing the medical records of the patient, and the notes from the different team members, a family meeting was organized to discuss goals of care with the surrogate decision maker. In this case the ethicist drew on the seminal work of Tversky and Kahneman [4] which focus on the psychology of choices and how the framing of decisions can be greatly beneficial to use. The authors argue that choices that individuals make are framed by the formulation of the problem. In ICUs, the problem is often framed as one of end-of-life decisions that need to be made. Patients (and or families) will use this framework in a context where the consequence of not trying (death) outweighs the gains (prolongation of life, regardless of quality), and so it would be beneficial to keep on trying. Tversky and Kahneman [4] argue that it is best to use alternative frames for a decision problem. These different frames do not necessarily mean that one does not pay attention to the end-of-life issue at hand (because that would be ignoring the elephant in the room), but rather change the focus of the conversation from doing everything to keeping the patient alive to having a VALUE conversation (explained below) as proposed by Curtis and White [5]. The ethicist in this case found that if the focus of the conversation could be shifted away from making a life altering decision, to instead focussing on the surrogate decision maker's position to tell a story as a narrator, an alternative frame could be provided and hence given rise to the usefulness of the framing effect.

## VALUE conversation

Unfortunately, the first goals of care conversation were unsuccessful in this case as the surrogate decision maker was insistent on pursuing medically inappropriate care. The ethicist met with the surrogate decision maker the following day and focussed on having a VALUE conversation. The contraction VALUE stands for 1) **V**alue the surrogate's statements; 2) **A**cknowledge his/her emotions; 3) **L**isten to him/her without interruptions; 4) try and **U**nderstand the patient as a person. What did he/she do; what gave him/her pleasure in life; what were the highlights in his/her life?; 5) **E**licit any questions from the surrogate and get accurate feedback for him/her.

In this case as in others, as the ethicist engaged with the team and the surrogate in situations like these to help ascertain the best way forward and to respect the patient's values, the VALUE conversations do not happen in one day but over the course of a few days. Once the ethicist gained the surrogate's confidence the next phase of the conversation was to focus on what the surrogate wished for the patient. Most surrogates, approximately 87% [6], wish for their loved ones not to die in pain and to be comfortable.

When Mrs. B was given the opportunity to be the narrator and tell her story about her son and the person he was, and not necessarily the cancer patient, she was able to come to a resolution. Mrs. B changed her son's code status and transitioned him to comfort care. The patient passed away two days later with his whole family at his bedside.

When narrators tell a story, they give 'narrative form' to experience. This narrative form often gives insight to the personal experiences of the surrogate decision maker. They position characters in space and time and, in a very broad sense, give order to and make sense of what has happened. Often a cancer diagnosis, and especially end-of-life decisions, are unexpected and the person who hears it/needs to make a decision has not had time to internalise the facts and the reality. Thus, it can be argued that narratives provide a way to explain or normalize what has occurred; they lay out why things are the way they are or have become the way they are. Narrators then have the freedom to finish the chapter of the story.

## Questions to consider

1. What resources exist or does your institution have available to assist surrogate decision makers in this time when they need to make end-of-life decisions?
2. What is the role of the ethicist to assist in normalizing end-of-life conversations?

### Conflit d'intérêts

L'auteur est éditeur de la *Revue canadienne de bioéthique*.

### Conflicts of Interest

The author is an editor at the *Canadian Journal of Bioethics*.

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