

## Respecting Cultural Differences in Goals of Care Conversations

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### Article abstract

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## ÉTUDE DE CAS / CASE STUDY

# Respecting Cultural Differences in Goals of Care Conversations

Divya Choudhury<sup>1</sup>, Nico Nortjé<sup>2</sup>

### Résumé

Les conversations sur les objectifs des soins sont souvent difficiles lorsque les patients font face à un mauvais pronostic, mais lorsque les patients proviennent d'une autre culture, cela peut être encore plus difficile. Cependant, le fait de considérer les valeurs culturelles comme complémentaires plutôt qu'opposées pourrait être bénéfique pour les soins du patient.

### Mots-clés

objectifs des soins, conversations, patients, culture, valeurs

### Abstract

Goals of care conversations are often tough when patients face a poor prognosis, yet when patients are from a different culture it may be even more difficult. However, seeing cultural values as complementing rather than opposing could be beneficial to the care of the patient.

### Keywords

goals of care, conversations, patients, culture, values

## Case Study

Mr X. was a sixty-something year old male with high-risk myelodysplastic syndrome (MDS) and a history of colon cancer and diabetes mellitus. The patient and his family were from the Middle East, where he was initially diagnosed, but came to the USA for further and more aggressive treatment.

MDS constitutes a group of bone marrow failure syndrome associated with leukemia [1]. In patients with MDS, cause of death is often bone marrow failure, although MDS can also be a precursor to acute myeloid leukemia (AML) [2]. The treatment course for MDS depends on the health status of the patient and their goals of care. One option which is often presented is stem cell transplant, which can lead to long-term disease-free survival, but it can also result in life-threatening complications [3]. In this situation, Mr. X and his family decided to pursue intensive treatment, and he received an allogeneic stem cell transplant 301 days prior. The transplant was successful and put Mr. X in remission, but he developed significant complications, including steroid-resistant Graft-versus-Host-Disease (which is common following non-autologous stem cell transplants), disseminated viral infections (adenovirus and cytomegalovirus), renal failure, and persistent gastrointestinal (GI) bleeding. Furthermore, Mr. X was intubated for airway protection.

## Goals of Care Conversation

As the days turned into weeks, the medical team wanted to speak with him regarding his goals of care, given that he developed new lung infiltrates, progressive pneumonia, pneumothorax and anasarca with renal failure that would require the patient to be on dialysis. These goals of care included palliative treatment, code status changes, and even transitioning Mr. X back to the United Arab Emirates, as he was developing other issues and his GI bleed was a major concern and not responding to any treatments. But when attempting to have a conversation with the patient, his family constantly blocked any attempt. Their reasoning was that they felt it would be unfair to tell the patient about his dire medical situation. The family repeatedly insisted that no "negative news" or questions regarding choices should be given to the patient.

The patient was deconditioned, on total parenteral nutrition (TPN), anemic and thrombocytopenic, but was alert and oriented with appropriate mood and affect. He was able to communicate via a white board on which he could write in Arabic. Essentially, the patient had decision-making capacity, and considering his critical, terminal condition, the team felt he should be involved in a conversation about his goals of care and code status.

## Cultural Values

The primary ethical issue of this case was a disagreement between the medical team and the family regarding what should be disclosed to the patient regarding his medical condition. This disagreement is likely the result of cultural differences. In the USA, it is standard practice to inform the patient of his or her medical condition, and to be honest about prognosis, whereas in many other cultural contexts it is common to withhold information from a patient and let the family make medical decisions on the patient's behalf [4]. It is also common within the Islamic tradition for families to continue care to the greatest possible extent because of their belief that the patient's life is in God's hands [5]. The central ethical issue involves a conflict between upholding the values of patient autonomy and nonmaleficence and respecting the cultural views that inform the wishes of the family. Because the family was preventing the medical team from speaking with the patient directly, his preferences and goals of care could not be known. Since in this case there were no further treatment options to consider, the contentious aspect of the situation is the question of what should be disclosed to Mr. X regarding his medical condition. Open and honest communication with the patient is especially important because of the lack of knowledge about the patient's preferences and goals of care.

To navigate this stressful situation, a family meeting without the patient was held with the assistance of an interpreter. The medical team explained to the family why they believed it was important for the patient to be informed about his condition, and that since the patient was alert and aware, he retained decision-making capacity and had a right to exercise his autonomy,

within the US context. With the help of the ethicist a dialogue was had with the family to understand their reasoning behind not wanting the patient to know the truth about his situation. After a long, but respectful conversation, it was agreed that the team would engage with the patient about his goals of care.

The medical team entered the room with the patient's family present and in a culturally sensitive manner, respecting their values, first asked the patient what he knew about his present situation and how much information he wanted. It turned out that Mr. X was well informed and wanted to know his full clinical prognosis. The team updated him in an honest, yet respectful manner by not mentioning the word "death" or any other negative aspects of his situation, as requested by the family. Mr. X understood that his condition was dire and his wish was to transition back to his home country. Furthermore, he also changed his code status to do not resuscitate (DNR), indicating that if Allah was ready to take him he would not stand in the way. The case management team worked with the medical team and organized Mr. X's transition back to the Middle East.

The take-away from this case study is that cultural values may come into conflict with the value systems of healthcare systems. Navigating this conflict in a culturally sensitive manner, i.e., by creating a platform for the family to explain why they have specific opinions/ways of doing things, can be hugely beneficial to the care of the patient and also to the respect afforded to the family. In the case of Mr. X, it was important to the family not to crush the spirit of Mr. X by being negative, although as it turned out he already knew his medical situation. Cultural values should not necessarily stand in opposition to other value systems. In entering into a non-threatening dialogue, it is possible to respect patient autonomy as well as other value systems.

## Questions to Consider

1. What resources exist at your institution to conduct a family and goals of care conversation with patients who do not necessarily speak English?
2. What is the role of the ethicist to assist in facilitating goals of care conversations with patients from different cultural backgrounds?

### Conflicts d'intérêts

Nortjé est éditeur à la *Revue Canadienne de Bioéthique*.

### Conflicts of Interest

Nortjé is an editor at the *Canadian Journal of Bioethics*.

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