Canadian Journal of Bioethics
Revue canadienne de bioéthique

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Revue Canadienne de Bioéthique

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Volume 7, Number 2-3, 2024

Numéro hors-thème & Ateliers de la SCB
Open Issue & CBS Workshops

URI: https://id.erudit.org/iderudit/1112295ar
DOI: https://doi.org/10.7202/1112295ar

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Publisher(s)

Programmes de bioéthique, École de santé publique de l'Université de Montréal

ISSN

2561-4665 (digital)

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Cite this document

Dezort, S., Palmer, A. & Nortjé, N. (2024). "We Don't Want to Talk About It": Building Trust for Difficult Decisions. *Canadian Journal of Bioethics / Revue canadienne de bioéthique*, *7*(2-3), 192–194. https://doi.org/10.7202/1112295ar

Article abstract

Clinical ethicists must be attuned to nonverbal cues and the deeper issues they raise and, if needed, be willing and agile to change course from discussing goals of care to establishing trust. We present a case study where a family and care team disagree about whether a lack of a do-not-resuscitate and do-not-intubate (DNR/DNI) order for a patient with a terminal prognosis is leading to medically justifiable and ethically defensible decisions. An ethicist called a family meeting to discuss the order but determined, after reading the family's nonverbal cures, that establishing trust was first needed in order to have that discussion, and that such trust could be built by not discussing the order.

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ÉTUDE DE CAS / CASE STUDY

"We Don't Want to Talk About It": Building Trust for Difficult Decisions

Steven Dezort[a], Amitabha Palmer[b], Nico Nortjé[b]

Résumé
Les éthiciens cliniques doivent être à l'écoute des signaux non verbaux et des questions plus profondes qu'ils soulèvent, et être prêts et agiles pour changer de cap si nécessaire, de la discussion des objectifs de soins à l'établissement de la confiance. Nous présentons une étude de cas où une famille et une équipe de soins sont en désaccord sur la question de savoir si l'absence d'ordonnance de non-réanimation et de non-intubation (ONR/ONI) pour un patient dont le pronostic est en phase terminale conduit à des décisions médicalement justifiables et éthiquement défendables. Un éthicien a convoqué une réunion de famille pour discuter de l'ordonnance, mais a déterminé, après avoir lu les remèdes non verbaux de la famille, qu'il fallait d'abord établir la confiance pour avoir cette discussion, et que cette confiance pouvait être établie en ne discutant pas de l'ordonnance.

Mots-clés
fin de vie, confiance, communication non verbale, intubation, principe de tort

Abstract
Clinical ethicists must be attuned to nonverbal cues and the deeper issues they raise and, if needed, be willing and agile to change course from discussing goals of care to establishing trust. We present a case study where a family and care team disagree about whether a lack of a do-not-resuscitate and do-not-intubate (DNR/DNI) order for a patient with a terminal prognosis is leading to medically justifiable and ethically defensible decisions. An ethicist called a family meeting to discuss the order but determined, after reading the family's nonverbal cures, that establishing trust was first needed in order to have that discussion, and that such trust could be built by not discussing the order.

Keywords
end-of-life, trust, nonverbal communication, intubation, harm principle

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CASE STUDY: INTUBATION AT THE END-OF-LIFE

"Don't let me suffocate" Mr. D repeated to hospital staff about his terminal prognosis. Mr. D was a 63-year-old male who had been diagnosed with high-grade leiomyosarcoma with metastatic disease to the lung. With his blood chemistry indicating lung infection and low oxygen exchange, he expressed concern about difficulty breathing and discomfort as the disease continued to spread. Sadly, Mr. D had no more cancer-directed therapies available, and the team expressed that the goals of care ought to be reoriented from aggressive interventions towards end-of-life and symptom-controlled methods. Deeply spiritual, Mr. D and his family were hoping for a miracle.

Over the course of the next few days, Mr. D's condition worsened, and the non-invasive respiratory treatment became steadily less effective. The care team knew that, in the absence of a code change, they would have to intubate Mr. D. Given the fact that Mr. D showed laboured breathing, which was due to the lung metastasis, his attending physician spoke with Mr. D's wife and other family members about his prognosis and the lack of benefit offered by continued aggressive treatment and intubation. The medical staff recommended the family consider a do-not-resuscitate and do-not-intubate (DNR/DNI) order and converting to palliative care. Although his family, including his wife, who was his official medical power of attorney, expressed that they did not want him to suffer at the end-of-life, they resisted these recommendations and instead requested that Mr. D be intubated in the event that he should go into respiratory distress.

This created moral distress amongst all team members, as it was evident to them that intubation would not be a bridge therapy leading to a net medical benefit. As a bridge procedure that anticipates a return to baseline, intubation presumes eventual extubation. While Mr. D expressed his preference to live, his prognosis was terminal: no return to baseline and no eventual extubation were prognosticated. Intubating Mr. D would only reinforce his family's belief that his condition could be improved through continued treatment, while such improvement was not medically indicated. Intubation, therefore, was neither medically indicated, nor ethically defensible according to the harm principle (1). Understanding the ethical dilemma, the team reached out to the clinical ethicist on call.

Since the patient became altered due to his respiratory status, the ethicist arranged a family meeting to discuss goals of care (GOC) and code status. However, as soon as the meeting began, the family strongly verbalized their unwillingness to discuss DNR/DNI, and they showed nonverbal cues such as clasped hands on the conference room table that suggested suspicion and hostility towards medical staff. Furthermore, some of the family members had kept their handbags on their laps, often a

ISSN 2561-4665

sign of wanting to be ready to leave. While listening to the family and reading these nonverbal cues, it became clear to the ethicist that the family was not ready to have these conversations, which raised an additional ethical issue about how to prepare the family for the decisions they would inevitably have to make.

An ethicist, like all medical staff, would do well to read body language in addition to listening (3). Being aware of the surroundings and the non-verbal messages families send are important skills for the ethicist to use in family consultations, and in this case, they influenced how the ethicist chose to proceed.

ETHICAL GUIDANCE AND TRUST

At the meeting, Mr. D's family appeared suspicious of the judgements of medical staff and made it clear that they did not want to discuss code status. As the meeting facilitator, the ethicist realized that it would be counter-productive to attempt to have a conversation about code status when the family clearly did not trust the team. Therefore, the ethicist decided not to pursue discussions about code status at that time and instead focused on building trust with the family to support them in the eventual difficult decisions they would have to make.

The family did not trust the team, in part, because they felt that the team did not understand their enduring hope for a miracle and believed that medical decisions were based on financial ability to pay. They also felt the team was starving their loved one, as he was not being provided solid food due to his inability to digest it. Before the meeting, the invisibility of these concerns impeded effective communication with medical staff and prevented the family from accepting a DNR/DNI for Mr. D (2).

To respond to the family's concerns, the ethicist invited various members of the care team to address them fully, agreeing with the family that all were hoping for the same miracle but stating that God also works through the physician. Making sure the care team did not use jargon, the ethicist created an environment of understanding by asking the care team clarifying questions if there seemed to be any confusion amongst the family members. The care team assured the family that Mr. D alone was central to any decisions made about his care, not finances, reiterating that they were providing Mr. D with the best possible clinical care. Restating that the values of patients and their families are always integrated into care planning, the care team also explained how supportive care could make Mr. D comfortable enough to consume solid food.

By listening to the family's concerns and inviting the appropriate multi-disciplinary team members to address them thoroughly, the ethicist facilitated the family's understanding and acceptance of Mr. D's prognosis. Although neither intubation nor DNR were discussed at the meeting, the ethicist aided medical staff in fostering a relationship of trust for when decisions concerning those issues would have to be made. Ultimately, the family that had arrived at the meeting understandably suspicious and hostile left the meeting less suspicious and more trusting.

READING NONVERBAL CUES TO CHANGE COURSE

The initial ethical issue of whether medical staff should intubate was found to be linked to a deeper ethical concern about distrust of the medical staff. In order to circumvent a deeper level of suspicion, the ethicist had to "read the room" and be agile in changing the course of the meeting upon sensing tension, and to honour the family's wish not to discuss DNR/DNI at that time. Once trust in the care team and their recommendations was reestablished, Mr. D's family ultimately decided to accept DNR/DNI so as not to prolong his suffering. Mr. D passed away peacefully with his family at his side.

DISCUSSION QUESTIONS:

1. What approaches might an ethicist take if the family had continued to insist on not discussing DNR/DNI?
2. How could an ethicist and medical staff support a surrogate who accepted DNR/DNI but then hesitated in their decision and expressed a desire to reverse the order?
3. If several more meetings are required to build trust with the family before they are able to make their decisions, how might that trust be built incrementally?

Reçu/Received: 17/11/2023
Publié/Published: 21/06/2024

Conflits d'intérêts
Nico Nortjé est éditeur de RCB.

Conflicts of Interest
Nico Nortjé is a section editor of the CJB.

Édition/Editors: Patrick Gogognon, Marie-Alexandra Gagné & Julien Brisson
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