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Article abstract

This case study explores the ethical complexities surrounding the treatment of Mrs. H, an elderly woman with multiple myeloma. Divergent goals between her family, rooted in cultural and religious values, and the medical team prompted ethical deliberation. The divergent goals centered around the family's desire for aggressive cancer treatment, driven by their Ubuntu and Christian beliefs in the sanctity of life and hope for divine intervention, contrasted with the medical team's focus on palliative care, prioritizing comfort over aggressive medical interventions with unlikely benefits. Faced with this tension, the care team, guided by principles of solidarity and cultural humility, engaged in meaningful dialogue facilitated by an experienced ethicist. The resolution respects the family's cultural and religious beliefs while adhering to medical ethics. This case highlights the importance of understanding and integrating cultural values in healthcare decision-making, ultimately achieving a patient-centered approach that respects the diversity of perspectives.

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ÉTUDE DE CAS / CASE STUDY

Culturally Informed Care: Solidarity, Cultural Humility, and Medical Ethics

Hailey G. Hawkins[a], Nico Nortjé[b], Amitabha Palmer[b]

Résumé

Cette étude de cas explore les complexités éthiques entourant le traitement de Mme H, une femme âgée atteinte d'un myélome multiple. Des objectifs divergents entre sa famille, ancrée dans des valeurs culturelles et religieuses, et l'équipe médicale ont suscité des délibérations éthiques. Les objectifs divergents étaient centrés sur le désir de la famille d'un traitement agressif du cancer, motivé par leurs croyances Ubuntu et chrétiennes dans le caractère sacré de la vie et l'espoir d'une intervention divine, contrastant avec l'accent mis par l'équipe médicale sur les soins palliatifs, donnant la priorité au confort plutôt qu'à des interventions médicales agressives dont les bénéfices sont peu probables. Face à cette tension, l'équipe soignante, guidée par les principes de solidarité et d'humilité culturelle, s'est engagée dans un dialogue constructif facilité par un éthicien expérimenté. La résolution respecte les croyances culturelles et religieuses de la famille tout en adhérant à l'éthique médicale. Ce cas souligne l'importance de comprendre et d'intégrer les valeurs culturelles dans la prise de décision en matière de soins de santé, afin de parvenir à une approche centrée sur le patient qui respecte la diversité des points de vue.

Mots-clés

Ubuntu, solidarité, humilité culturelle, soins de fin de vie, bioéthique mondiale

Abstract

This case study explores the ethical complexities surrounding the treatment of Mrs. H, an elderly woman with multiple myeloma. Divergent goals between her family, rooted in cultural and religious values, and the medical team prompted ethical deliberation. The divergent goals centered around the family's desire for aggressive cancer treatment, driven by their Ubuntu and Christian beliefs in the sanctity of life and hope for divine intervention, contrasted with the medical team's focus on palliative care, prioritizing comfort over aggressive medical interventions with unlikely benefits. Faced with this tension, the care team, guided by principles of solidarity and cultural humility, engaged in meaningful dialogue facilitated by an experienced ethicist. The resolution respects the family's cultural and religious beliefs while adhering to medical ethics. This case highlights the importance of understanding and integrating cultural values in healthcare decision-making, ultimately achieving a patient-centered approach that respects the diversity of perspectives.

Keywords

Ubuntu, solidarity, cultural humility, end-of-life care, global bioethics

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CASE

Mrs. H, an elderly lady who immigrated from the Southern region of Africa to the United States, was diagnosed with multiple myeloma. She was admitted to our tertiary cancer center, with a large family at bedside, for cancer-related fatigue, dysphagia (difficulty swallowing), and toxic encephalopathy (brain damage from exposure to harmful substances or chemicals). She was nonresponsive and had several other medical issues, including acute hypoxic respiratory failure, malignant pleural effusion (a buildup of cancer cells and fluid between the chest wall and lungs), acute renal failure, heart failure, high blood pressure, a brain bleed, and severe protein-calorie malnutrition. Given her complex medical situation, it was deemed best to transfer Mrs. H to the Intensive Care Unit (ICU).

Much to the surprise of her family, the care team deemed respiratory failure, altered mental status, and hypernatremia to be her most critical medical issues and not her cancer. This approach left the family uncomfortable, and they did not want to consent to any invasive treatments that did not also address their loved one's cancer. Due to this discrepancy in goals between the family and the care team, an ethicist was consulted. At the time, Mrs. H was intubated and sedated on a ventilator, and a meeting was held with the family. As is customary at our institution, the ethicist asked the family for their understanding of Mrs. H's clinical situation. The family representative acknowledged that things were not looking great, but they were primarily concerned with the lack of aggressive cancer treatment. The care team explained that due to Mrs. H's progressive organ failure, she was not a candidate for any systemic cancer-directed therapies. The team mentioned that they had an ethical obligation not to do any harm to the patient. However, this was countered by the family who offered to sign any legal documentation to take full responsibility if only the care team would "fight the cancer." This clearly made the care team uncomfortable, and the family changed their goal to receiving a promise that as soon as Mrs. H's health improved, the team would start her on aggressive cancer therapies. Again, the team reiterated that this was highly unlikely and that the best thing to do for their loved one was to change the focus away from aggressive treatments to prioritizing the patient's comfort.

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For the first time during the encounter, the patient's husband, Mr. H, spoke up and said that pure comfort care would not be acceptable. He professed strong faith in God and Jesus Christ and his belief that God would heal Mrs. H. This led the medical team to defer raising the issue of hospice care despite believing that hospice was the most appropriate plan. It soon became clear that the ethical question was: How should the medical team balance what they believed was medically appropriate with the family's faith-based values?

UBUNTU

Ubuntu, a prevalent worldview in the Southern region of Africa, differs from the dominant individualistic worldview prevalent in North America (3). Ubuntu focuses on collectivism and emphasizes social interdependence, so much so that an individual's sense of self is shaped by their relationships with others and their societies/communities (1). It is thus essential to make unified decisions in the name of togetherness. Many individuals who practice Ubuntu mix it with Christianity, which they interpret as maintaining that life is the greatest gift from God and should therefore be preserved by all means, even in seemingly hopeless cases (1). Adherents are thus unlikely to accept the removal of life-sustaining treatment once it has started (1). It is common for these families to "leave fate" to God and look forward to living eternally in Heaven (2). This value for preserving life is deeply connected to their sense of community and shared responsibility for one another.

ETHICS APPROACH

Navigating this culturally rich case involved turning to global bioethics principles of solidarity and cultural humility. The principle of solidarity requires that the medical team weigh their concerns against the autonomy interests of their patients, while cultural humility holds that, as professionals, they must consider and address their own personal biases (4,5). Understanding an individual's culture and religion is valuable for gaining insight into their perspectives. However, it is important to avoid making assumptions based on these aspects alone. People are unique and may interpret their cultural and religious backgrounds in diverse ways. We encourage maintaining cultural competence by recognizing and respecting individual differences.

In the case of Mrs. H, her family's concerns about her multiple myeloma and their request to continue life-sustaining treatment align with the Ubuntu belief in preserving life, even in seemingly hopeless situations. In their view, leaving the cancer unaddressed failed to acknowledge the possibility of Mrs. H overcoming her immediate medical needs. From the Ubuntu-Christian perspective, Mrs. H's multiple myeloma is perceived as the *bonki*, or root of the evil, and addressing it is considered crucial; failure to do so may hinder the resolution of her other confounding medical issues (6). Concerning code status, the injunction to "do everything to protect life" led the family to reject a DNR order. In their view, refusing CPR is rejecting a chance to restore life.

Families act as surrogate decision-makers, helping the care team understand what is important to the patient and their worldview. Of all the events in one's life, few if any are as important as one's death. Since dying is not a singular physical occurrence but is shaped by contextual, familial, religious, cultural, and geographical forces, it is critical that patients and their families be able to experience death in accordance with their deeply held values. Respecting the family where they are, within their own worldview and experience, is one of the kindest acts any care team can perform.

Although, at first, it may appear that the family's values are at odds with the medical team's position, the values of each were not mutually exclusive. Given the family's expressed wish not to harm the patient or shorten her life, the ethicist was able to reconcile the family's goals with those of the care team to withhold more cancer-directed therapies. The medical team sought to avoid harming the patient, which justified withholding cancer-directed treatment. However, although performing CPR on a nonresponsive patient may not benefit the patient, the medical team was confident it would not harm the patient since she was not capable of experiencing it. As a general rule, medical interventions that do not provide any reasonably foreseeable medical benefit should not be performed; nevertheless, they are permissible (but not obligatory) when they provide a benefit that is more broadly construed. In this case, performing CPR ensured that the final moments of the patient's life conformed with her and her family's values.

One of the goals of clinical ethics is to seek common ground between parties. The family sought to prolong Mrs. H's life, while the team didn't want to shorten it. Ethical analysis revealed these to not be mutually exclusive. In the end, the family was appreciative that the care team was not only respectful but also "on their side." Medicine is a moral discipline, and it can never just be about narrowly construed harms and benefits; it must strive to incorporate a broader conception of human values.

DISCUSSION QUESTIONS

1. Suppose Mrs. H had been responsive to pain. Would it be ethically permissible to perform CPR? Why/Why not?
2. Suppose you are the clinical ethicist facilitating an end-of-life care consultation similar to this case. When you introduce the topic of code status, the spouse says, "We want you to do everything because, in our culture, we must protect life." Do you accept the issue as settled, or do you ask further questions? If you ask further questions, why do you do so, and what questions do you ask?
3. The authors claim that if an intervention will not cause harm nor provide any reasonably foreseeable benefit, it's provision is permissible but not obligatory. Do you agree? Why/Why not?

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