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Résumé de l'article

Être un décideur de substitution est un défi pour de nombreuses personnes et devoir décider de retirer des thérapies de maintien en vie peut être extrêmement difficile. Aider les mandataires à recentrer leurs décisions sur le non-dissentiment éclairé peut considérablement réduire les souffrances inutiles pour toutes les personnes concernées. Cette étude de cas décrit comment l'atteinte à la dignité a été minimisée en utilisant le concept de non-dissentiment éclairé.

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ÉTUDE DE CAS / CASE STUDY

The Benefits of Informed Non-Dissent when Families have Difficulty Making a Decision

Mila Nortje[a], Sajid Haque[a], Nico Nortje[a,b,c]

Résumé
Être un décideur de substitution est un défi pour de nombreuses personnes et devoir décider de retirer des thérapies de maintien en vie peut être extrêmement difficile. Aider les mandataires à recentrer leurs décisions sur le non-dissentiment éclairé peut considérablement réduire les souffrances inutiles pour toutes les personnes concernées. Cette étude de cas décrit comment l'atteinte à la dignité a été minimisée en utilisant le concept de non-dissentiment éclairé.

Abstract
Being a surrogate decision-maker is challenging for many people and having to decide to withdraw life sustaining therapies can be extremely difficult. Helping surrogates to refocus their decisions on informed non-dissent can greatly minimize unnecessary suffering for all involved. This case study describes how dignitary harm was minimized by using the concept of informed non-dissent.

Mots-clés
non-dissentiment éclairée, atteinte à la dignité, désistement, famille, décideur de substitution

Keywords
informed non-dissent, dignity, harms, withdrawing, family, surrogate decision-maker

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CASE STUDY

Mr. P, an 83-year-old gentleman, was diagnosed with squamous cell carcinoma of the mouth at the age of 76. He had been receiving cancer directed treatment at a tertiary institution and was admitted via the Emergency Room (ER) with severe jaw pain and hyperglycemia, given his history of type 2 diabetes. Upon closer examination, it was also noted that Mr. P had developed renal failure, heart failure, bilateral pneumonia, hyperkalemia, hyperglycemia, and post-hemorrhagic anemia. Mr. P's son accompanied him to the ER and indicated that his father lived by himself, as he is a proud and independent man. A religious man, Mr. P had previously told his children that he was aware that every occasion celebrated could be his last, before God comes and gets him to be with their mother. Mr. P's son reported that his father became more-and-more withdrawn, had a noticeable lack of energy, did not eat as much as before, and his fluid intake had dwindled over the past two weeks. Since Mr. P had squamous cell carcinoma of the mouth, Mr. P's son initially thought that it must have been painful for his father to eat and drink much. As a result, the family prepared high energy meals for their father as they did not want to see him decline by not eating enough. Unfortunately, this may have contributed to Mr. P's elevated blood sugar (hyperglycemia).

Once Mr. P's initial work-up was completed, he was admitted to the Intensive Care Unit (ICU) as his situation was further complicated by bilateral pneumonia and general failure to thrive. Mr. P had progressive multi-organ failure, including the respiratory system, cardiovascular system, renal system, and endocrine system. Unfortunately, Mr. P's cancer had metastasized, and his oncologist, after reviewing the imaging and other clinical parameters, determined that Mr. P was not a candidate for any further cancer-directed therapies. Unfortunately, all these compounding issues led to Mr. P being unable to protect his airway and he consequently had to be intubated while unconscious.

All of this happened relatively fast, which caught the family off-guard. Their father never shared with them his views and wishes about life-sustaining therapies and aggressive measures. When the ICU care team approached the family to talk about the next step and share their recommendation of transitioning to comfort care measures only (to allow natural death in light of his irreversible condition) the family declined to make any decision – given that Mr. P was a religious man, the family insisted that it was up to God to decide when it was the right time.

ETHICAL CONSIDERATIONS

As a surrogate decision-maker one bears the responsibility to become the voice of the incapacitated patient and relay to the care team the choices the patient would have made were they able to interact. Given Mr P's irreversible clinical condition, and the family's unwillingness to decide on which action to take, this situation created an ethical dilemma: to continue with life-sustaining therapies that may cause unnecessary harm to the patient or transition to palliative care to create comfort in the process of dying. Medicine at no point should suspend people between life and death without justifiable reasons. Given that the patient was not a candidate for further systemic treatment, and was in multi-organ failure, no medical intervention could be

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a bridge therapy to recovery. Furthermore, given that Mr. P had been described as a very proud and independent person, the argument was made by the care team that they were inflicting harm on his dignity (dignitary harm) by keeping him in this suspended position between life and death.

The concept of dignitary harm can be used to argue that even when a patient is not aware, does not feel, or does not understand that any harm or pain is being inflicted on them, it is still unethical to perform interventions on the patient (1). Dignitary harm is inflicted on patients when life-sustaining therapies are performed without the intervention being a bridge to a cure, or at least to a quality of life that the patient would deem acceptable (2). This situation causes an ethical dilemma for medical providers as there is sometimes a conflict between a surrogate's decisions (or lack of) and the moral obligations of a healthcare provider. When surrogates make decisions for unresponsive, unconscious, or impaired patients, it is difficult to navigate the difference between surrogate and patient end-of-life preferences (3).

ETHICAL RESPONSE

Given the fact that the family was unable to make a decision to withdraw life-sustaining therapies, the ethicist on the unit employed the approach of informed non-dissent (4). This approach is described as a variation to informed consent with the caveat that the care team does not ask consent to do something, instead they propose an action (or inaction) and allow the participants (in this case the surrogate decision-makers) to object to or accept the proposition (4,5). In a practical sense this can be applied when the care team understands that the patient would not benefit from resuscitation and therefore would pre-emptively ask the family members whether they agree that CPR should not be done. Since the burden of decision-making is not solely on the shoulders of the surrogates, there is a psychological benefit to them to be active members in the shared decision-making process without having to feel guilty that they unilaterally made the decision to let the patient die (6). When the team met with the family and explained that they would not be offering any dialysis or resuscitation measures like CPR since it was not a bridge to a net benefit for the patient, the family did not oppose this and commented that they would respect the team's decisions. Mr. P coded the same evening, but the trauma of CPR was avoided, and he died peacefully.

The present case study helps demonstrate how informed non-dissent can be a useful approach for surrogate decision-makers when a patient is unable to make decisions for themselves.

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