Substitute decision making and code status at end of life

Patient's loss of capacity highlights complexity

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This case involves an 80-year-old male patient, Mr B., who was admitted to hospital with delirium in the context of metastatic prostate cancer. Mr B.'s prior wishes were for a comfort approach to care involving a do-not-resuscitate (DNR) and do-not-intubate (DNI) code status and end of life in a palliative care unit (PCU). When the patient lost his capacity to make complex treatment decisions, his substitute decision maker (SDM) reversed his code status and advocated for full investigation and treatment of his underlying illnesses. These decisions led to a prolonged hospital stay for the patient, with admission to an intensive care unit (ICU), artificial hydration and nutrition, and eventual death after a cardiopulmonary resuscitation (CPR) attempt that was considered futile by the medicine team, which caused moral distress for all involved.

Mr B.'s case highlights complexities that arise when an SDM makes decisions that are not in keeping with an incapable patient's prior expressed wishes. We discuss approaches to discussions around resuscitation when these types of interventions are considered futile by the treating team, as well as ways to support the providers involved. These approaches include not proposing resuscitation as a treatment option if it is considered futile and involving ICU consultation teams early to help guide care and discussions. With more complex and chronic disease in the population, we can expect increasing complexity in medical decision making, especially when caring for patients at the end of life,[1] making these topics especially important for family physicians.

Case

Mr B. was an 80-year-old man with prostate cancer that had metastasized to the liver and bones. He had been living at home alone before presenting to hospital with delirium. He was followed at home by a palliative care team.

Mr B.'s home palliative care physician had previously discussed his goals of care in detail in several well-documented encounters. Mr B. had expressed a desire for a DNR-DNI code status. Interestingly, at the time of the discussions, he noted that his only involved family member, a nephew, would very much disagree with this decision. Mr B. expressed hesitation at discussing his wishes with his nephew, despite the fact that his nephew would be his SDM by hierarchy. He did not indicate the nature of his nephew's potential objections or indicate a preferred SDM.

Mr B. eventually developed pain and functional decline at home and an application to the PCU was launched. Before he was able to transfer to the PCU, he became acutely delirious and agitated and was urgently transferred to hospital, as he could not safely remain at home alone to wait for transfer to the PCU.

In hospital, he was delirious in the context of hypercalcemia and was admitted to the medicine floor with consultant palliative care involvement. Paramedics had brought his community DNR form with him. The admitting team verified his code status as DNR-DNI.

Mr B. was treated multiple times for hypercalcemia to try to clear his delirium. Each time, his calcium levels would correct and then slowly

Editor's key points

- As chronic disease and multimorbidity become more prevalent, treatment decisions will become more complex, especially when caring for patients at the end of life.
- Early involvement of intensive care unit access teams for patients whose health is at high risk of deterioration can help inform complex discussions around code status.
- Substitute decision makers who do not act in accordance with patients' prior expressed wishes can be challenged using consent and capacity boards.
- Resuscitation is an intervention that is not indicated for all patients and does not need to be offered universally as a treatment option.

Points de repère du rédacteur

- À mesure qu'augmente la prévalence des maladies chroniques et de la multimorbidité, les décisions thérapeutiques se compliqueront encore davantage, surtout dans les soins aux patients en fin de vie.
- L'implication précoce des équipes d'accès à l'unité des soins intensifs pour les patients dont l'état de santé est à risque élevé de détérioration peut aider à éclairer les discussions épineuses entourant le code à suivre pour la réanimation.
- Si les mandataires spéciaux n'agissent pas conformément aux souhaits exprimés antérieurement par le patient, leurs actes peuvent être remis en question par l'intermédiaire de comités sur le consentement et la capacité.
- La réanimation est une intervention qui n'est pas indiquée pour tous les patients et il n'est pas nécessaire de l'offrir universellement comme option thérapeutique.

increase again. However, even with corrected calcium, his cognition never improved between episodes. He was found to have profound, refractory delirium with no reversible cause. He was found to be incapable to make decisions on proposed treatments and planning throughout his entire stay.

When the care team made initial contact with his nephew, the nephew refused to be involved in care decisions. Given that the SDM had refused to engage and that there were no other SDMs by hierarchy, the Office of the Public Guardian and Trustee (PGT) in Toronto, Ont, was contacted, and, given the patient's prior expressed wishes, the care team proposed a plan outlining a comfort-based approach to care in line with what could be offered in the PCU. However, in reviewing the case, the representative from the PGT called the nephew again, and this time he changed his position and agreed to become involved in decisions rather than defer to the PGT.

The SDM began to advocate for aggressive interventions and investigation despite a knowledge of his uncle's end-stage and incurable illness, as well as of his prior expressed wishes. The SDM felt that his uncle had been pressured into his prior expressed wishes and code status. The SDM also indicated that his own strongly held religious beliefs were guiding his decisions, although his uncle did not share these beliefs. The hospital's spiritual care service liaised with the nephew's spiritual leader to facilitate visits and support.

During this time the patient's code status was reversed to full code by the medicine team, and he was restarted on enzalutamide. The care team was becoming more and more uncomfortable with the decisions being made by his SDM; accordingly, a bioethics consult was launched and the hospital's legal risk team was involved. The legal risk and bioethics teams reviewed the case in preparation for potential legal issues or consent and capacity board involvement, but did not recommend any changes to the team's approach. The team empathized with the SDM regarding the perceived difficulty of this decision making and attempted to reframe the decisions not as matters of life and death but more as preferences about end-of-life care. These and other communication strategies over many hours of meetings did not improve the situation.

Discussions with the SDM were ongoing while the patient continued to deteriorate clinically. Mr B. was admitted to the ICU and required ventilation and nasogastric tube feeding following a suspected aspiration event. While Mr B. was in the ICU, the new care team involved did not continue to challenge the decisions of the SDM, so the consent and capacity board never became involved. Mr B. had a prolonged stay in the ICU but was successfully extubated and sent back to a medicine floor, where he remained on artificial nutrition.

Mr B. had ongoing issues with delirium and agitation and on several occasions pulled out his tube. He continued to deteriorate clinically and eventually went into cardiac arrest. Given his code status, he was resuscitated through 30 minutes of pulseless electrical activity, eventually leading to a pronounced death. Notably, the team in charge of the resuscitation tried to call his SDM in the periarrest period to readdress code status and resuscitation efforts but could not reach him.

Discussion

This case is an important reminder of the difficulties that can arise when an SDM begins to make decisions that are not in keeping with an incapable patient's prior expressed wishes. While our case occurred in Ontario and there is variation in policies and laws among provinces and territories, general lessons can be gleaned from this case.

The medicolegal landscape surrounding code status discussions in advanced illness is changing. In August 2019, in a landmark legal decision (*Wawrzyniak v Livingstone*),[2] Ontario Superior Court Justice Peter J. Cavanagh ruled in favour of 2 physicians who wrote a DNR order in a patient's chart and refused to start CPR for a patient despite the patient's SDM requesting it.[3] The ruling explained that in Ontario, an SDM makes decisions only on proposed treatments, and that CPR and intubation do not always need to be proposed as treatments if they are felt to not be medically indicated, such as in the context of imminent end of life or medical futility.

While this new legal precedent opens the door to allowing physicians to withhold treatments that they feel will be futile and injurious, it does not provide clinically relevant guidance on how treating teams should approach conflicts with SDMs, as in Mr B.'s case. Even if resuscitation had not been offered, there would still have been conflict with the SDM. As physicians we strive to treat patients and family members compassionately, and this conflict does not sit well with us.

Open, clear, and compassionate communication with patients and families should always be a priority in these situations. We recommend using interdisciplinary meetings with patients and their SDMs as venues to discuss treatment plans. When communication breaks down or an impasse is perceived, involving bioethics and legal risk teams is important. If the team feels that an SDM is not acting in accordance with a patient's prior expressed wishes, the SDM's ability to make a specific treatment decision (for instance, around resuscitation) can be contested using the consent and capacity board. If the board intervenes, however, the SDM remains the SDM for other decisions; the consent and capacity board would rule only on the specific contested decision.

Our group has begun to involve our ICU access team for patients who are deteriorating on general medical floors and who are felt to be poor candidates for aggressive resuscitation despite a full code status. Involving

the ICU access team allows for an expert assessment of whether CPR and intubation would be futile and can inform difficult conversations with patients and families. Our clinical team, sometimes in conjunction with our bioethics and psychiatry colleagues, will host group debriefs for the providers involved in challenging end-of-life cases, such as this one, as venues in which to discuss moral and emotional distress.

Conclusion

We hope that this case causes clinicians to pause and reconsider how they approach goals-of-care conversations about resuscitation at the end of life. Just as chemotherapy is not indicated for all patients with cancer, resuscitation is sometimes not indicated and should not be made universally available as a treatment option to be decided on by a patient or SDM. This stance might actually relieve patients and SDMs of the burden of making what they perceive to be life-and-death decisions and allow them to refocus their attention at the end of life.

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Competing interests
None declared

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