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Commentary

Additional Ethical, Legal, and Social Considerations for Clinicians Navigating a Difficult Relationship with a Patient's Surrogate Decision-Maker

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Abstract

This commentary highlights additional considerations for clinicians encountering substitute decision-makers who want to make different decisions than the healthcare or ethics team thinks an incapacitated patient would have made. This commentary first focuses on how evolving understandings of decision-making capacity and the increased availability of formal supported decision-making matter for cases like Mr. Andrews. This commentary then discusses relational autonomy in end-of-life decision-making and how patients may prioritize their family's needs over their own medical preferences. This commentary then concludes by discussing other legal implications, namely the potential abuse of legal processes that facilitate decision-making on behalf of unrepresented patients and corresponding concern that physician paternalism is being masked as consideration for patient autonomy.

Keywords: capacity; autonomy; medical decision-making; paternalism; surrogate decision-making; supported decision-making

Meyer and colleagues provide a case study to illuminate the ethical and legal complexities that arise when surrogate or substitute decision-makers (referred to by the authors as "alternates") decide differently than an incapacitated patient expressed to their health care providers when the patient had capacity.[1] In analyzing the case study, the authors are concerned not only with ensuring patient precedent autonomy is respected but also with how clinicians should navigate conflict with substitute decision-makers and manage their resulting moral distress, particularly when clinicians are asked to provide futile medical interventions to the incapacitated patient.[2]

In this commentary, I highlight additional considerations for clinicians encountering substitute decision-makers who want to make different decisions than the health care or ethics team thinks the patient would have made. I draw extensively on my previous scholarship on end-of-life and serious medical decision-making, especially for patients with impaired decision-making. This commentary first focuses on how evolving understandings of decision-making capacity, and the increased availability of formal supported decision-making, matter for cases like that presented in Meyer et al.'s article. This commentary then discusses relational autonomy in end-of-life decision-making and how patients may prioritize their family's needs over their own medical preferences. This commentary concludes by discussing other legal implications, namely the potential abuse of legal processes that facilitate decision-making on behalf of unrepresented patients and corresponding concern that physician paternalism is being masked as consideration for patient autonomy.

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Decision-Making Capacity, Legal Capacity, and Supported Medical Decision-Making: The Possibility of Patients with Cognitive Impairments Making Contemporaneous Medical Decisions

The case of Mr. Andrews, an incapacitated patient, and his son who is also his substitute decision-maker, presented by Meyer et al. focuses on how to ensure advance care planning and shared decision-making are honored after a patient loses capacity and others are asked to decide on behalf of the patient. But unmentioned in this case study is that there recently have been evolving understandings of decisional capacity and legal capacity. This section will highlight unanswered questions arising from this and similar cases given different understandings of capacity.

First, there is a significant body of scholarship developing on how the "four abilities" criteria (i.e., the abilities to communicate, understand, appreciate, and reason)[3] for assessing and demonstrating decision-making capacity should be understood differently.[4] In addition to recent critiques about capacity *assessments*,[5] some scholars have critiqued the dominant *conceptualization* of capacity and have argued for adding criteria (e.g., assessing patient affect),[6] reducing criteria (e.g., only assessing a patient's ability to communicate),[7] maintaining the existing criteria but reconceptualizing them in different contexts (e.g., treatment refusals),[8] or understanding capacity relationally.[9]

If these different understandings of decisional capacity were applied to the case presented by Meyer et al., it may be that despite

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Mr. Andrews's cognitive impairments, he did not actually require a surrogate decision-maker. The authors refer to Mr. Andrews as "confused,"[10] but if he was conscious and able to communicate at the time the decision to enroll in hospice needed to be made, then maybe with a different understanding of capacity, and in particular the more relaxed capacity standards advocated by some scholars in the context of treatment refusals,[11] Mr. Andrews would be deemed capable of making contemporaneous decisions — in this case the decision to decline further medical intervention and enter hospice. And then Mr. Andrews's precedent and contemporaneous autonomy would be respected, his son would not have been asked to decide on his behalf, and surrogate-clinician conflict could have been avoided.

Second, and more importantly, there have been evolving understandings of legal capacity, that is, "the right 'to make decisions and have those decisions respected.'"[12] Indeed, many (although not all) states have recently adopted laws to facilitate formal supported decision-making so that individuals who have impaired cognition can exercise legal capacity despite decisional impairments.[13] With supported decision-making, individuals select others they trust to help them make decisions. These "supporters" can assist with a variety of tasks such as gathering information relevant to a decision, deliberating about the decision, or communicating the decision to others.[14] A patient's supporter does not have to be a surrogate decision-maker listed in a state's health care decision-making law although supporters will often be family members.

With support, a patient with cognitive impairments may be able to evidence decision-making capacity under the traditional "four abilities" models, and even if the patient cannot evidence decision-making capacity, the patient may under state law be deemed to have legal capacity.[15] In the case of Mr. Andrews, it is possible he could have exercised contemporaneous legal capacity with assistance from a supporter other than his son if he had known about supported decision-making and had entered into a formal agreement with a supporter.

Regardless of whether supported decision-making was possible for Mr. Andrews, in similar cases, clinicians need to know what supported decision-making is, whether it is a legal option in their state, and whether their patient has supporters. Clinicians and ethicists will also need to think about how the involvement of supporters matters for a patient's decision-making capacity, potential conflict between supporters and health care providers, potential conflict between supporters and patients' next of kin (if different individuals), and how supporters matter for advance care planning conversations and legal documents.[16]

Respect for Relational Autonomy in End-of-Life Decision-Making

The authors focus on decision-making in hospitals where a medical logic prevails and where physicians have status, power, and authority.[17] But what about the world and relationships outside the hospital? What about different, nonmedical values and logics?

There is a large body of social scientific literature that reveals that when patients make serious medical or end-of-life decisions, patients often incorporate the preferences of their loved ones or make decisions based on nonmedical factors (e.g., spiritual, economic, etc.).[18] Indeed, research shows that many patients decide based in part on their loved ones' preferences even if those do not necessarily match the patient's own, which is an exercise of relational autonomy.[19]

In the case of Mr. Andrews, the patient may express different medical and end-of-life wishes if he was asked to consider his treatment options in light of his family relationships (even if he was not close with his family members) rather than just considering his options in the context of his medical diagnosis, prognosis, and risks and benefits of various treatment options. That is, it may be the case that if Mr. Andrews's physician had asked him whether he would like to decline treatment if his children wanted him to receive treatment, he would have made a different choice and decided to pursue treatment rather than hospice.

To fully respect relational autonomy at the end of a patient's life, clinicians should consider prompting their patients to reflect on their medical options in the context of their significant interpersonal relationships. Subsequent documentation of this robust discussion would then provide compelling evidence should disputes with substitute decision-makers about an incapacitated patient's wishes arise later.

Paternalism Disguised as Concern for Patient Autonomy and Well-Being? Potential Abuse of Legal Process for Deciding on Behalf of Unrepresented Patients

The conclusion of the case of Mr. Andrews — that the conflict between his son and the clinical team led to the son disengaging with the decision-making process and the patient no longer having a surrogate decision-maker — is deeply troubling for several reasons.

First, although negative descriptors are used for Mr. Andrews's substitute decision-maker (e.g., the authors refer to his son as "belligerent"),[20] the clinicians bear some responsibility for their negative interactions with the patient's alternate and the ultimate unrepresented status of Mr. Andrews. Indeed, the loss of an eligible and involved substitute decision-maker due to conflict with the patient's health care providers is an iatrogenic dignitary harm and a profound failure of the clinical team.

Second, this case study could be read as a roadmap for how to ensure that medical teams are the ultimate decision-makers for patients who lack capacity. As Meyer et al. note, state law governs substitute decision-maker eligibility, and in this case, state law directs that the patient's son is the appropriate alternate.[21] And yet the patient ended up "unrepresented" due to surrogate-clinician conflict and was thus eligible for doctors to step in and decide on the patient's behalf and to decide differently than Mr. Andrews's son wanted to.

Perhaps this outcome is not ethically problematic in this specific instance, as the authors assert that the decision made by the two doctors and ethicist was respectful of Mr. Andrews's autonomy (i.e., consistent with his known wishes, although perhaps the clinical team did not have complete knowledge of his wishes, as I discussed in the previous section). But one could imagine abuse of this legal and policy process, which exists to ensure that incapacitated patients without surrogates can still receive appropriate medical care but is not meant to ensure that doctors decide for their patients who have surrogate decision makers.

Abuse of this process is possible because the clinical team can choose not to work with surrogates perceived as making inappropriate medical decisions (defined by the authors as decisions that are not consistent with the patient's prior wishes or decisions that are medically futile). Clinicians could choose not to mitigate conflict with surrogates and then if surrogates disengaged, the patient

would become unrepresented, and the team could make medical decisions on behalf of the patient. The authors acknowledge that the process could be abused but seem to think safeguards will prevent abuse.[22] However, given abuse of other legal processes by health care providers to ensure that patients and their surrogates are only permitted to make decisions that physicians think is appropriate, I am less optimistic.[23]

Abuse of this legal process not only ensures that medical paternalism prevails, but it is inconsistent with respect for the rule of law.[24] Further, although this process may have worked in this state and this specific health care system to facilitate end-of-life decision-making for Mr. Andrews, other states or hospitals may not allow life-ending decisions to be made for unrepresented patients,[25] which is a different harm that should be prevented by not alienating patients' surrogate decision-makers.

In brief, to prevent paternalism, to respect the rule of law by not abusing legal processes, and to ensure that a range of medical options are available for incapacitated patients, it would behoove health care providers not to alienate a patient's substitute decision-makers.

Conclusion

Meyer et al. offer an interesting case study of the ethical and legal considerations for health care providers and clinical ethicists who encounter surrogate decision-makers who want to override an incapacitated patient's prior wishes (as understood by the medical team). This commentary offers additional considerations, focusing on new understandings of decisional capacity, expanded legal capacity for patients with cognitive impairments that comes from the increasingly available option of supported decision-making, relational autonomy in end-of-life decision-making, and the possible abuse of legal process that ensures physician paternalism at the cost of family relationships, surrogate well-being, and possibly patient autonomy. It is my hope that these additional considerations are useful to the authors and other clinicians when they encounter future cases like the one presented in this article.

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Megan S. Wright, JD, PhD, is the Florida Bar Health Law Professor at Florida State University College of Law. She recently was a guest editor for *The Journal of Law, Medicine & Ethics* special issue "Supported Decision-Making and Clinical Research," which stemmed from an NIH workshop on the topic.

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19. Wright, "End of Life and Autonomy"; Wright, "Dementia, Healthcare Decision Making, and Disability Law." Supported decision-making is also consistent with relational autonomy.
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22. Meyer et al., "Difficulties in Honoring Patient Requests," at 346.
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