

Medical Decision Making for Patients Without Surrogates

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Patients who lose decision-making capacity and lack advance directives and next of kin present a quandary for physicians. Current mechanisms for making treatment decisions for these patients rely on decision makers, such as courts, public guardians, committees, and physicians, who typically do not have sufficient knowledge to predict the patients' preferences. Thus, these mechanisms likely yield decisions that are inconsistent with patients' treatment preferences in many cases. A population-based treatment indicator is a computer-based tool that predicts which treatment a given patient would prefer based on the treatment preferences of similar patients in similar situations. A recent analysis suggests that a population-based treatment indicator could predict patient preferences as accurately as patient-appointed surrogates and next of kin. This analysis suggests that a population-based treatment indicator may provide a mechanism to respect the treatment preferences of patients without surrogates and ensure that their treatment preferences are respected as much as the preferences of patients who have surrogates. Collection of data on patients' treatment preferences, especially those without surrogates, incorporation of these data into a treatment indicator, and exploration of ways to implement this approach for patients without surrogates are called for.

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A primary goal in making treatment decisions is to respect patient preferences. Physicians consult capacitated patients to determine their preferences and consult the advance directives, next of kin, and loved ones of patients who lose decision-making capacity. Similarly, when surrogates make decisions for incapacitated patients they are directed to exercise "substituted judgment," choosing the treatments they believe the patient would prefer.¹ Unfortunately, many individuals do not complete advance directives or designate surrogates.²⁻⁵ When these individuals also do not have any available next of kin, physicians find themselves in a quandary.

Particular concern has been raised about the absence of surrogates for individuals

with dementia,⁶ nursing home residents,⁷ and mentally ill individuals.⁵ During a 3-month study, no surrogate or next of kin could be identified for 3% of nursing home residents, and 45% of patients' designated surrogates could not be reached.⁸ A study of 1 urban hospital's intensive care unit found that 24% of patients lacked decision-making capacity and surrogates for part or all of their intensive care unit stays.⁹ Another study found that 5.5% of deaths in intensive care units occur in incapacitated patients who lack a surrogate decision maker and an advance directive.¹⁰ These data suggest that the problem of incapacitated patients lacking surrogates is relatively widespread. To ensure these patients receive the same level of respect afforded those with surrogates, it is important to identify ways to help physicians make treatment decisions that are consistent with these patients' preferences to the greatest extent possible.

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MAKING DECISIONS FOR PATIENTS WITHOUT SURROGATES

Encouraging individuals without available family members to complete advance directives would likely decrease the number of incapacitated patients who lack surrogates or documented treatment preferences. However, some individuals will not complete an advance directive even with encouragement and support. Others lose their family members or surrogates after they themselves lose capacity. Finally, designated surrogates often are unavailable when treatment decisions must be made.

The mandated processes for making medical decisions for incapacitated patients without advance directives or surrogates vary by state.^{5,11-13} Some states require approval of major treatment decisions by a court or a court-appointed public guardian. Others give decision-making authority to community- or health care facility-based committees, whereas others leave treatment decisions to treating physicians.

In general, when decisions are made for incapacitated patients, the ethically preferable standard for decision making is substituted judgment, that is, making the decision the surrogate believes the patient would make if able to decide. When there is insufficient evidence to make a substituted judgment, the focus shifts to attempting to determine what is in the patient's best interest. Some treatment decisions are relatively easy for physicians, courts, public guardians, and committees. However, in challenging clinical situations in which reasonable persons have different treatment preferences, these decision makers typically do not have sufficient knowledge of individual patients to predict their preferences.

Current approaches have pragmatic drawbacks also. Reliance on courts is costly, time-consuming, and inconvenient, and may be impractical when decisions must be made fairly quickly. Although community-based and facility-based committees have been instituted in some places to address these drawbacks, these committees need to be

convened and thoroughly informed about what are likely complex cases, also creating delays in decision making.

Some jurisdictions give physicians the authority to make treatment decisions for incapacitated patients without surrogates or advance directives.⁵ To avoid the burdens of court or committee proceedings, physicians in other states may decide to make these decisions themselves.^{10,14,15} However, research shows that physicians often do not accurately predict their patients' treatment preferences¹⁶⁻¹⁸ and are consistently less accurate than patient-appointed and next-of-kin surrogates.^{18,19}

Taken together, these considerations suggest current methods often fail to respect the treatment preferences of patients without surrogates to the same extent as the preferences of those with surrogates. Therefore, it is important to seek new methods of decision making for incapacitated patients without surrogates. Such a method should predict patients' treatment preferences at least as well as surrogates. Ideally, this method also would be relatively easy to implement and could be carried out by physicians already familiar with the patient.

AN ALTERNATIVE APPROACH TO PREDICTING PATIENTS' PREFERENCES

A population-based treatment indicator is a computer-based tool that predicts a patient's treatment preferences based on the treatment preferences of individuals similar to the patient. Analysis reveals that it is possible to produce a population-based treatment indicator that is at least as accurate as patient-appointed and next-of-kin surrogates.²⁰ In light of this analysis, a population-based treatment indicator may offer a viable method for making treatment decisions for incapacitated patients without surrogates.

A population-based treatment indicator takes as input patient characteristics, such as age and sex, and features of the patient's clinical situation, such as diagnosis. The treatment indicator then uses data on the preferences of individuals who share the patient's characteristics to predict whether the patient would prefer to

have or forgo a medically indicated treatment in that situation. For example, a physician faced with the choice of whether to intubate an 80-year-old man with dementia who develops respiratory failure, and lacking evidence of his preferences, would enter variables that may include the patient's age, sex, and diagnoses and the proposed intervention. The treatment indicator would estimate the likelihood that this patient would want the intervention based on analysis of a database of treatment preferences of individuals who share his characteristics. If this analysis indicated that most individuals with the patient's characteristics would prefer to be intubated, intubation would be performed; if it indicated that most would forgo intubation, it would be withheld.

A recent analysis²⁰ considered the idea of population-based treatment indicators and whether they may be worth pursuing for patients in general. This analysis found that existing data on the public's treatment preferences are sparse, but a preliminary population-based treatment indicator could be built with existing data. The treatment decisions suggested by this preliminary treatment indicator were compared with existing data on the accuracy of surrogates. In this comparison, the population-based treatment indicator predicted patient preferences just as accurately as patient-appointed and next-of-kin surrogates, correctly predicting patients' preferences approximately 78% of the time.²⁰ Because of the paucity of data on individuals' treatment preferences that can be incorporated into the treatment indicator, the analysis ended by calling for more data on individuals' treatment preferences.

These findings suggest that a population-based treatment indicator specifically for incapacitated patients without surrogates may provide a mechanism for respecting their treatment preferences as much as the preferences of patients with surrogates. Given that surrogates predict patients' preferences more accurately than physicians,^{18,19} it follows that a population-based treatment indicator would be more accurate than physicians and other

decision makers for incapacitated patients without surrogates. Further development of a population-based treatment indicator for this purpose, including further data collection, validation, and assessment of implementation methods, should be pursued (**Figure**).

FURTHER DEVELOPMENT OF A POPULATION-BASED TREATMENT INDICATOR

To develop a population-based treatment indicator for incapacitated patients without surrogates, it will be necessary to gather more data on the treatment preferences of a wide range of patients under varying medical circumstances, with special attention to patients who lack surrogates. Data collection should focus on treatment decisions for which physicians typically explicitly consult the surrogates of incapacitated patients, including decisions about mechanical ventilation, cardiopulmonary resuscitation, and artificial nutrition and hydration, among others. These data could be built into the treatment indicator, along with the currently sparse data on the public's treatment preferences.

It would be useful to know the extent to which patients' treatment preferences vary based on patient characteristics, such as age, sex, religion, and current health, and clinical variables, such as the intervention's invasiveness and likelihood of success. Any variables shown to predict patients' preferences should be incorporated into a population-based treatment indicator. To develop a treatment indicator for use with patients without surrogates, it will be particularly important to investigate the predictive power of characteristics that are more common in this population, such as homelessness or advanced age. Some evidence suggests that homeless individuals may want more aggressive treatments than other groups.²¹ It is also possible that being without family or other close relationships influences individuals' treatment preferences. Further research is needed to determine to what extent these factors predict patient preferences and, if they do, to incorporate these sources of variation into a treatment indicator.

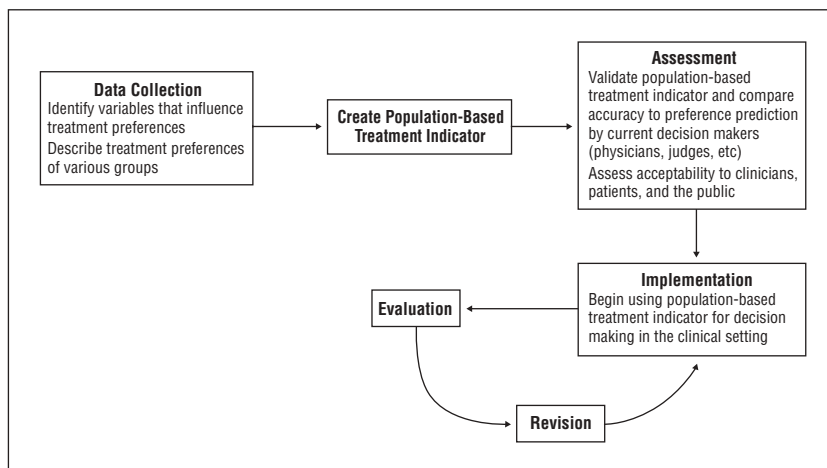


Figure. Process of development and implementation of a population-based treatment indicator.

Patients who share characteristics such as age and sex do not always have identical treatment preferences. As a result, even a treatment indicator that incorporates variations in treatment preferences by many variables will not predict individuals' preferences perfectly. For this reason, patients should always be encouraged to document their treatment preferences. However, when patients fail to do so, the data suggest that a population-based treatment indicator could predict their preferences at least as accurately as surrogates. Once a more refined treatment indicator is developed, it ought to be validated in a cohort of patients who lack potential surrogates and its accuracy compared with that of current decision makers for patients without surrogates. Although even a refined population-based treatment indicator will not be 100% accurate, if it proves more accurate than those who currently make decisions for incapacitated patients without surrogates, this tool could improve decision making for this population.

IMPLEMENTATION

Physicians might use a population-based treatment indicator to improve decision making for patients without surrogates in several ways. One possibility is to present the treatment indicator as an option in advance care planning. In addition to the options of recording treatment preferences and appointing surrogates, patients could be given the option of directing physicians to use a

population-based treatment indicator to make decisions on their behalf if they become incapacitated. This approach would allow patients to decide on an individual basis whether they consider a population-based treatment indicator an acceptable tool to make decisions on their behalf, and if not, to make other arrangements such as documenting specific treatment preferences.

The major drawback of this approach is that some patients will never indicate how decisions should be made for them if they become incapacitated, raising the need for a default approach. Decision making for patients without next of kin who still choose not to do advance care planning would likely still fall to physicians, courts, and committees. However, presenting an additional option might make advance care planning more attractive to individuals without surrogates.

Another possibility is to implement facility- or community-level policies of routinely using a population-based treatment indicator when medical decisions are made for incapacitated patients without surrogates or known treatment preferences. This approach could allow treatment decisions to be made based on evidence of patients' wishes at least as reliable as the decisions of surrogates, which is the currently preferred approach, even when surrogates are not available. Physicians may have information about a patient's treatment preference from other sources, such as the patient's friends or their own prior relationship with the patient. In some cases,

these sources may raise doubts about the accuracy of a specific prediction by a population-based treatment indicator, particularly if the majority predicted to have a certain preference is not overwhelming. In general, there should be a presumption in favor of following the treatment indicator, if on average it is demonstrated to be more accurate than physicians' predictions of patient preference and avoids problems of physician overconfidence,¹⁸ projection of their own preferences,²² and possible bias.²³ Still, difficult cases will arise. In these cases, objecting physicians or acquaintances should be asked about their confidence in their prediction compared with the treatment indicator. If the treatment indicator estimates a 60% likelihood that the patient would prefer the treatment, are others more confident than that that the patient would prefer to forgo it? If the treatment indicator's prediction is still disputed for that particular patient, oversight bodies such as ethics committees should join the decision making to ensure thorough weighing of all the evidence concerning the patient's preference.

Because this approach would not rely on individual patients explicitly stating that the treatment indicator is an acceptable tool to use on their behalf, it would be important to assess the acceptability of the population-based treatment indicator to the public, patient groups likely to be affected, and physicians.

ETHICAL CONSIDERATIONS

The possibility that a population-based treatment indicator may predict patients' treatment preferences as accurately as surrogates raises the question of what values other than accuracy are important in making decisions for incapacitated patients. One consideration is that patients may have preferences not only about treatments but also about the process of making treatment decisions. For example, homeless individuals without families might prefer that physicians decide for them rather than court-appointed guardians.²¹ It is unknown whether, if a population-based treatment indicator with the same or better accu-

racy as surrogates were available, patients without surrogates would prefer it over other decision-making methods. When individuals' process preferences are known, they should be respected. It may also be useful to conduct research on a sample of patients without surrogates to learn how they prioritize the accuracy of decisions made on their behalf vs their preferences for certain decision makers.

Accountability and transparency are particularly important in decision making for patients without surrogates. When a patient-appointed or next-of-kin surrogate makes decisions for an incapacitated patient, we generally assume the surrogate takes a strong interest in the patient and will uphold the patient's rights and interests. In contrast, when decisions are made by individuals without a close relationship to the patient, there is greater concern that the patient's rights and interests will be ignored, particularly if the mechanism for decision making is a seemingly inscrutable computer program. It is important to have mechanisms to ensure that individuals without family or close friends are not mistreated or their rights infringed when they lose decision-making capacity.

This concern supports the need for transparency of the data and analysis underlying the treatment indicator to the public and oversight of cases in which a population-based treatment indicator is used to make decisions for incapacitated patients without surrogates. Whether a population-based treatment indicator was used, including the variables used to predict the patient's preference and the result shown by the treatment indicator, should be documented. A body such as an ethics committee or patient advocate should routinely review uses of the treatment indicator prospectively to verify that the patient is incapacitated and has no available surrogate or retrospectively by reviewing documentation of how the treatment indicator was used.

The factors other than patient preferences that may be relevant to all medical decisions, such as physicians' professional judgment and allocation of health care resources, are

equally relevant to decisions for incapacitated patients without surrogates.^{24,25} Just as a patient, surrogate, or advance directive might identify a treatment preference that the treating physician believes is medically inappropriate, so might a population-based treatment indicator. However, if the treatment indicator is a comparable predictor of patient preferences to other available methods, such as patient-appointed and next-of-kin surrogates, then the preferences it indicates should be taken just as seriously. Integrating physicians' professional judgment and resource allocation concerns with patient preferences in medical decisions is complex, but this does not diminish the need to improve prediction of the preferences of incapacitated patients without surrogates.

LEGAL CONSIDERATIONS

The legal status of a policy to use a population-based treatment indicator for incapacitated patients without surrogates depends on current laws about decision making for these patients in different jurisdictions. Existing laws generally use 1 of 3 approaches.⁵ The first approach is to require judicial proceedings to either appoint a guardian or authorize specific treatment decisions. The second approach is to empower committees of health care professionals, community members, and others to authorize treatment decisions, taking into account physician recommendations. The third approach is to authorize physicians to make treatment decisions on behalf of their incapacitated patients who lack surrogates.

In states where physicians have the legal authority to make treatment decisions for incapacitated patients without surrogates, physicians should be able to simply incorporate a population-based treatment indicator in making these decisions. In other jurisdictions, it may not be possible to implement a population-based treatment indicator without legal or regulatory changes. In cases in which decision making for incapacitated patients without surrogates currently requires judicial proceedings, delegating this authority to physicians using a population-based treatment indicator may require updat-

ing laws and regulations. Altering the role of existing community- or facility-based committees to oversee use of a population-based treatment indicator by physicians, rather than make decisions independently, may similarly require altering laws that established these committees. Until relevant laws are changed, courts, court-appointed guardians, and committees might consider appealing to a population-based treatment indicator in making their decisions, if data suggest a treatment indicator predicts patient preferences more accurately than physicians.

Although implementing a population-based treatment indicator to make decisions for incapacitated patients without surrogates may require altering laws and regulations, there are good reasons to pursue such changes. An approach that predicts patients' treatment preferences more accurately than current methods would be more respectful of individuals' preferences, which is an objective in medical decision making that has been difficult to achieve for patients without surrogates. In addition, using a population-based treatment indicator may enable decisions to be made in a less costly and timelier manner, further improving the care of patients without surrogates.

CONCLUSIONS

The recent description of a population-based treatment indicator that predicts patient preferences as accurately as surrogates suggests a possible avenue to improve medical decision making for patients without surrogates, when their individual wishes are unknown. Further research into the potential use of this tool in this population is necessary. More data on the treatment preferences of patients with various characteristics should be collected and incorporated into a treatment indicator and the treatment indicator tested against the accuracy of those who currently make decisions for incapacitated patients without surrogates. In addition, methods of implementing a population-based treatment indicator for patients without surrogates should be explored, along with their

acceptability to patients, the public, and physicians. This approach may be a promising way to help physicians make decisions consistent with the preferences of incapacitated patients without surrogates.

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