Locating and Identifying Third-Party Decision-Makers

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The use of third-party decision-makers such as proxies and surrogates for incapacitated patients has become widespread in the United States. More recently, lawmakers and ethicists have grappled with the challenge of rendering decisions for unbefriended individuals without an identified third-party decision-maker. Far less attention has been paid to the question of how to determine whether a patient is, in fact, unbefriended. Jurisdictions vary regarding how much effort must be invested by clinicians in locating an appropriate decision-maker and also regarding how certain must clinicians be of the identity of apparent decision-makers before acceding to their decisions. This article collects in tabular form the relevant state statutory language on this subject. A decision-relative, context-based approach for addressing these questions as they arise in clinical practice is then proposed, with application in several composite cases.

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Third-party decision-makers, either agents authorized through an advance directive or surrogates serving in the absence of a patient-designated proxy, can play an important role in effectuating the medical wishes of incapacitated persons. Every U.S. state has now adopted legislation that allows for individuals to appoint agents (i.e., proxies) to render health care decisions if they should lose the ability to do so directly; the vast majority of U.S. jurisdictions also provide for close relatives or other interested parties (i.e., surrogates) to render such decisions for those patients lacking a designee.[1] A federal statute, the Patient Self-Determination Act of 1990,[2] even requires hospitals to inform all patients regarding state laws about the appointment of third-party agents.[3] The use of such proxies and surrogates is now widely accepted among both ethicists and clinicians, and, in the absence of extraordinary circumstances such as bad faith, their directions must be honored. Most states, with the exception of Colorado and Hawaii, impose a hierarchical order among potential surrogates.[4,5] Legislatures have established a wide range of methods for resolving disputes among would-be surrogates, including consensus, majority rule, and, in Tennessee and West Virginia, physician discretion.[6] Fewer jurisdictions and some professional organizations have also adopted guidelines for the care of so-called "unbefriended adults" who do not have relatives or close friends to serve as their decision-makers.[7,8] What remains unclear is the extent to which clinicians must strive both to locate a potential proxy or surrogate and to confirm the identity of that proxy or surrogate.

Questions regarding the availability and identity of third-party decision-makers likely occur with considerable frequency in clinical settings. Every day, physicians must grapple with how much effort is required to find surrogates for patients who appear unbefriended, especially those patients who lack the lucidity to clarify whether such surrogates even exist. Similarly, when a proxy or surrogate is identified, clinicians must be certain how much effort must be exerted in locating the proxy (e.g., several unsuccessful phone calls, a certified letter, or more effort). A related question that arises is under what circumstances a physician may skip over a designated agent or ranked surrogate for lack of availability and proceed to an alternate. The acuity of the patient's condition may play a role in such determinations. In cases

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where an apparent proxy or surrogate is identified, physicians should know how much effort must be rendered to confirm that identity. They must have a clear understanding of whether would-be agents and surrogates should be presumed to be the appropriate decision-makers until proven otherwise, as well as whether high stakes exist, such as declining intubation or withdrawing life support, in which a greater level of confidence is required. Many of these decisions are rendered on an ad hoc basis by providers in the field, sometimes with the guidance of hospital legal departments, but at other times likely with limited reflection. In part, that may be because ethics and law in this area are both unclear and unsettled.

This article strives to review existing law on this subject. Then an ethics framework for handling such situations is proposed and applied to several clinical scenarios.

Status of Current Law

The Appendix summarizes existing state statutes regarding the effort that must be rendered in identifying decision-makers and in confirming the identity of such decision-makers. A number of states follow the Uniform Health-Care Decisions Act (UHCDA),[9] a model law proposed by the National Conference of Commissioners on Uniform State Laws in 1993.[10] The uniform statute adopts a "reasonably available" standard with regard to locating a decision-maker. It offers a specific definition of reasonably available: "readily able to be contacted without undue effort and willing and able to act in a timely manner considering the urgency of the patient's health care needs" (Ref. 10, p 4). The model statute proposes a "good faith" approach regarding the confirmation of the identity of an apparent third-party decision-maker, noting that "[a]bsent bad faith or actions taken that are not in accord with generally accepted health care standards, a health care provider or institution has no duty to investigate a claim of authority or the validity of an advance health care directive" (Ref. 10, p 31). Although this approach may appear straightforward, the Appendix reveals that, while many jurisdictions adopt a reasonably available approach or use similar language, they define reasonable in rather different ways. For example, seven states (Hawaii, New Hampshire, New York, Ohio, Texas, Vermont, Wyoming) define reasonably as some variant of "diligently," while the majority of other states, following the UHCDA, use a lower standard. In fact, as New York uses a reasonableness standard without the diligence definition in many other areas of law, one can presume the legislature, in adopting its statute, intended a higher level of effort beyond ordinary reasonableness where locating decision-makers was concerned. Some states (e.g., Tennessee) use language stating that the third-party decision-maker should be contacted "if possible," with California outlining detailed criteria regarding the mechanism for doing so. Other jurisdictions (Idaho, Kansas, Oklahoma, Missouri, Rhode Island) do not appear to resolve this question at all in their statutes. In the same way, some states grant physicians immunity for following the instructions of an apparent proxy or surrogate in good faith; others allow for the physician to require a sworn statement from the purported agent (under various circumstances), whereas others do not address the question at all.

The wide variation in state laws might be interpreted to reflect a lack of ethics consensus. More likely, the variability is simply an artifact of the legislature's failure to consider this specific question with any particular reflection. Both the medical and legal literature reveal a striking absence of discussion of this distinct topic. This contrasts, for example, to disagreements between identified surrogates, a concern addressed in many state laws, or of seeking nontraditional decision-makers for unbefriended patients, a subject of considerable academic interest.[11,12] As a result, the statutory guidance that does exist is not particularly useful to practitioners in the field.

A Decision-Relative Approach

Most state statutes, with the possible exception of California's, allow for a wide range of approaches to both the location and identification challenges. This article proposes the adoption of a decision-relative and context-based approach to both of these questions. Decision-relative evaluation is most often associated with the model of competence assessment developed by Buchanan and Brock.[13] According to their model, whether a patient possesses capacity to render a particular decision will depend not only upon the state of the patient but also upon the nature of the decision, the environment in which the decision is to be made, and often the behavior of other parties.[13] Such an approach recognizes that more uncertainty is ethically tolerable in situations where the risk of severe injury or death is lower. This article adopts a similar approach to both the challenges of agent location and of agent identification. By

investigating four factors (the stakes of a decision, the timeframe in which it must be rendered, existing evidence regarding the availability or appropriateness of particular decision-makers, and the prospect of identifying and contacting the appropriate decision-maker), the model offers a method that evaluates each case in context and that can be implemented practically in the hospital setting. Whether using a possible, reasonable, or diligent standard, the physician should render a holistic, decision-relative, and context-based approach to the question of how much effort to invest in locating a decision-maker that addresses the four factors.

Potential Consequences

The nature of the medical decision or decisions required of the patient will go a long way in determining how much effort is required in finding a third-party decision-maker. In the course of routine clinical care, some consequences may prove so minimal (such as agreeing to have vital signs measured) that the assent of the patient is all that is required. With medications or physical interventions, as the risk increases, so does the need to obtain substituted judgment for the patient. In addition, whether the patient stands in agreement with medical guidance may play a role in assessing this risk. A patient amenable to having a fractured hip pinned may not raise the same level of concern as one refusing to have a fractured hip pinned. While statutes might only require reasonable or diligent attempts at location, ethics may demand even more effort in cases related to the rejection of life-saving therapies or the withdrawal of ventilator support. In these cases, the statute will serve as a floor, but a committed physician may have a duty to exceed the statutory minimum.

Time Frame

The urgency of the decision must also be factored into the amount of effort required to contact a surrogate. Sending a certified letter might prove necessary when decisions are made regarding nursing home placement but would clearly prove fruitless when rendering decisions about emergency surgery. Barring compelling evidence to the contrary, all efforts should be made to keep a patient alive until a proxy or surrogate can be contacted, if there is a prospect for doing so, and irreversible decisions should be avoided in the interim.

Evidentiary Indicators

Although some patients genuinely do not present with indicators of whether a decision-maker will prove available, many do, if providers put in the minimum effort required to examine these indicators. For instance, contacting a primary care provider may provide evidence that the patient has referenced family in the past or conversely has denied having any living family. Even photographs in a wallet or purse may influence a clinician's assessment of the likelihood that a third party is vested in the patient's health care. Physicians are not private investigators, nor should they be. Rather, they should harness the common sense they possess as human beings to determine whether further sleuthing is indicated.

Prospect of Success

One factor largely absent from discussion in the statutes or other literature is the prospect of success, yet this is a crucial factor in determining when to cease efforts. For example, in states that have an advance directive registry, contacting that registry may prove fruitful and can be expected under certain circumstances. In high stakes cases, it may be necessary to send the authorities to the residences of domiciled patients to search for address books or phone numbers of close contacts, or even (when consistent with confidentiality laws) to seek assistance from neighbors. In contrast, undomiciled patients without belongings may be harder to help in this regard. Even the relative commonality of a surname may play a role in determining whether an Internet search for relatives is likely to prove beneficial.

Adding Context to the Approach

Similarly, whether a jurisdiction allows a physician to follow the instructions of an "apparent" decision-maker or prescribes a higher standard, a decision-relative and context-based approach should be adopted that addresses the following three factors.

Consequences

In ascertaining the authenticity of an identified decision-maker, the assessment of potential consequences is somewhat different than in cases where the agent has yet to be contacted. The primary concern here is for impersonators and individuals acting in bad faith. While a good faith individual who mistakenly believes himself to be the agent is not ideal, the

damage such an agent is likely to render to the patient's interests are far lower. (One situation where this occurs with some frequency is that of couples who believe themselves to be common-law spouses in jurisdictions that do not afford formal medical decision-making abilities to these relationships.) When assessing stakes when the authority of the agent has not been confirmed, one might consider how the decision is likely to affect third parties such as the claimed agent. For instance, the identity of an apparent agent who is financially dependent upon the patient should be investigated with greater scrutiny in a case involving life support than a similar apparent agent when the question to be decided does not involve matters of life and death.

Time Frame

The amount of time available to ascertain an apparent agent's identity will play a large role in this assessment. Circumstances may arise where it is appropriate to defer to the apparent agent for the time being while simultaneously investigating the claim. One may even have an ethics duty to continue such an investigation after all medical decisions have been rendered, if there are significant concerns in the claim, so that similar uncertainty does not arise again in the future.

Evidentiary Indicators

In most cases, the identity of the apparent agent can be confirmed either directly by the patient (even one who lacks formal capacity for certain medical decisions) or the context in which the patient and apparent agent present. If the patient says, "This is my wife," it would not be necessary to ask for a marriage license. Cautions may arise, however, such as when the would-be agent does not know information about the patient that a clinician would expect the agent to know based upon the purported relationship (e.g., an alleged spouse being unaware of previous medical interventions or the patient's mention of other relatives).

Cases Applications

The following three composite cases offer some considerations in the applications of these principles.

Case #1

An elderly man presents to a major teaching hospital with moderate dementia and renal failure. According to the emergency medical services report, he lives alone in an apartment and did not provide them with an emergency contact or next of kin. The patient is placed on dialysis, but once he is stabilized, he demands that no further dialysis occur because of the side effects. On psychiatric evaluation, he is found to lack capacity to refuse. When asked if he has family or close friends, he says, "That's my business. Besides, if I did, I wouldn't want to burden them."

In this case the question is how much effort has to be rendered to ascertain whether an appropriate decision-maker does in fact exist. The potential consequences here are high; without dialysis, the patient will eventually die. The timeframe is limited, but not urgent. Most patients can survive days to weeks without dialysis, giving clinicians an opportunity to seek a decision-maker without overriding the patient's autonomy by compelling dialysis (such as through a court order). An evidentiary indicator here suggests that such a decision-maker may in fact exist. Otherwise, the patient would most likely have just stated that he has no family or close friends. While objecting to the involvement of family members because the patient doubts their ability to act in good faith or to honor his wishes may be compelling reasons for abandoning a search, it seems far less reasonable to honor a request not to find them for fear of burdening them. In theory, however, the patient should be separately evaluated for capacity to render this decision. A search of the patient's effects may help determine whether success is likely but is probably not sufficient under the circumstances. In light of the stakes and context, and consistent with confidentiality laws, efforts should be made to contact previous medical providers and possibly even the patient's landlord or neighbors to identify a third-party decision-maker.

Case #2

An elderly patient presents to a major teaching hospital with moderate dementia and osteomyelitis leading to the amputation of his foot. After he recovers from surgery, his adult son, who lives with the patient, demands to take him home immediately rather than allowing for placement in a rehabilitation facility with a likely subsequent transition to a skilled nursing facility. The medical team does not believe the patient will be well-served by this choice. When asked his own views as part of a capacity assessment at which the adult son is present, the patient responds, "Leave me alone. I don't know who any of you are!"

An apparent surrogate has been identified in this case, but questions have arisen as to the certainty of that identification. In this case, evidentiary indicators (namely that the patient denies recognizing the son) suggest further investigation. The stakes here are particularly high in that whether the patient is placed in a nursing facility or ultimately returns home might have significant financial implications for other inhabitants of the residence, and there is the remote risk that the "son" is actually a squatter who is taking advantage of the patient's debility. That the decision runs against medical recommendations raises further concerns. Finally, the matter lacks acuity. Under the circumstances, time is available for the medical provider to request appropriate documentation (possibly even something as simple as asking the son for a government-issued identification) at no significant additional risk or consequence to the patient.

Case #3

A 22-year-old patient with a diagnosis of schizophrenia is admitted to a medical service for treatment of a potentially life-threatening bacterial pneumonia after being found unconscious on the street. When the patient is given intravenous fluids and revives, he refuses all further treatment, stating that he does not trust the doctors and wishes to place his hope in prayer alone. In addition, he states that if he loses his ability to make decisions, he wishes his medical decisions to be rendered by the leader of a local religious sect, which he has recently joined, several of whose followers visit the patient daily. When consulted, the leader of the sect states that the patient had discussed his health care goals with him, and they had agreed that the patient would decline all medical care in the future. According to the patient, Western medicine is not merely inefficacious but also immoral. The patient refuses to provide information regarding any other friends or family. On psychiatric evaluation, the patient appears to be paranoid and intermittently responding to internal stimuli.

An apparent surrogate has been identified in this case, but questions may arise regarding the appropriateness of the surrogate in light of the patient's psychiatric illness. As in the preceding case, evidentiary indicators suggest further investigation is warranted. The physicians may wonder whether the patient had decisional capacity when he voiced his preferences to the sect leader, as well as whether his capacity to designate a decision-maker at present is compromised by his psychiatric symptoms. While the stakes are high, this case differs from the cases of patients with dementia in that the patient may prove restorable to capacity in a timeframe that allows for clarification of his wishes regarding a third-party decision-maker. At the same time, if the patient's preferences reflect authentic cultural or religious values, rather than psychiatric pathology, he will suffer an irreparable wrong in having his autonomy curtailed. The question of whether to render life-saving care in such a circumstance, when the clinicians remain uncertain about the authority of the purported surrogate, raises concerns that may need to be addressed through the judicial system.

Conclusion

Many clinicians in the field likely already follow the approach outlined above on an implicit basis without formally consulting hospital legal departments or ethicists. Even when physicians do seek outside assistance, formal guidance beyond broad statutory language is highly limited. By outlining states laws in the Appendix and offering a rubric for handling such cases, this article strives to establish a more structured approach both to analyzing and to grappling with an all too common challenge that unfortunately has so far evaded meaningful discussion in the medico-legal literature. Additional empirical work would also prove of value in this area to ascertain how providers address these cases in the absence of clear directives. Ideally, further academic discussion will also lead to legislative change: a consistent, national standard in this area is highly desirable. Whereas matters of genuine ethics or legal dispute may be served by individual states pursuing what Supreme Court Justice Louis Brandeis described as "novel social and economic experiments" (Ref. 14, p 51), the inconsistency here is not a product of laboratories of democracy but rather of artifact and oversight. One can meaningfully debate the ethics question of how much effort a physician must invest in locating or identifying an agent under a given set of circumstances, but there is no logical reason that the required effort should vary from state to state.

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APPENDIX

State	Effort Required to Find Decision-Maker	Effort Required to Confirm Identity and Role
Alabama[15]	"reasonable inquiry"	If more than one claimant, county circuit court will decide
Alaska[16]	"reasonably available"	"A supervising health care provider may require an individual claiming the right to act as a surrogate for a patient to provide a written declaration under penalty of perjury stating facts and circumstances reasonably sufficient to establish the claimed authority."
Arizona[17]	"reasonable effort"	Not specified by statute
Arkansas[18]	"reasonably available"	Not specified regarding proxies. Regarding surrogates: "In the event of a challenge to the designation of the surrogate or the authority of the surrogate to act, it is a rebuttable presumption that the selection of the surrogate was valid . . . . A person who challenges the selection of the surrogate has the burden of proving the invalidity of that selection by a preponderance of evidence."
California	"if possible"[19]; "reasonable efforts"[20] "Notwithstanding any other provision of law, within 24 hours of the arrival in the emergency department of a general acute care hospital of a patient who is unconscious or otherwise incapable of communication, the hospital shall make reasonable efforts to contact the patient's agent, surrogate, or a family member or other person the hospital reasonably believes has the authority to make health care decisions on behalf of the patient. A hospital shall be deemed to have made reasonable efforts, and to have discharged its duty under this section, if it does all of the following: (1) Examines the personal effects, if any, accompanying the patient and any medical records regarding the patient in its possession, and reviews any verbal or written report made by emergency medical technicians or the police, to identify the name of any agent, surrogate, or a family member or other person the hospital reasonably believes has the authority to make health care decisions on behalf of the patient. (2) Contacts or attempts to contact any agent, surrogate, or a family member or other person the hospital reasonably believes has the authority to make health care decisions on behalf of the patient . . . . (3) Contacts the Secretary of State directly or indirectly, including by voice mail or facsimile, to inquire whether the patient has registered an advance health care directive with the Advance Health Care Directive Registry, if the hospital finds evidence of the patient's Advance Health Care Directive Registry identification card either from the patient or from the patient's family or authorized agent . . . . (b) The hospital shall document in the patient's medical record all efforts made to contact any agent, surrogate, or a family member or other person the hospital reasonably believes has the authority to make health care decisions on behalf of the patient. (c) Application of this section shall be suspended during any period in which the hospital implements its disaster and mass casualty program, or its fire and internal disaster program.[20]	"A health care provider or health care institution acting in good faith and in accordance with generally accepted health care standards applicable to the health care provider or institution is not subject to civil or criminal liability or to discipline for unprofessional conduct for any actions in compliance with this division, including, but not limited to, any of the following conduct: (a) Complying with a health care decision of a person that the health care provider or health care institution believes in good faith has the authority to make a health care decision for a patient, including a decision to withhold or withdraw health care. (b) Declining to comply with a health care decision of a person based on a belief that the person then lacked authority. (c) Complying with an advance health care directive and assuming that the directive was valid when made and has not been revoked or terminated."[21]