End-of-Life Decisions for Socially Isolated Patients Under New York's Family Health Care Decisions Act

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ABSTRACT

The most challenging end-of-life cases involve patients who lack capacity and have no surrogate decision-makers. New York's Family Health Care Decisions Act provides alternative criteria for withdrawing or withholding treatment in such cases, including the requirement that the patient "will die imminently, even if the treatment is provided." This article clarifies the interpretation of "imminent" and offers recommendations to improve end-of-life policies, including greater reliance on Ethics Review Committees (ERCs).

Keywords: End-of-Life, Social Isolation, Medical Futility, Decision-making Capacity, Family Health Care Decisions Act

INTRODUCTION

Probably the most distressing end-of-life cases involve patients who lack capacity and who are socially isolated – that is, who do not have a health care agent, family member, or friend who knows them, cares about them, and will make decisions for them.[1] Health care professionals caring for these socially isolated patients struggle with exceedingly difficult professional, ethical, and legal issues.[2] Several states have enacted laws with standards and procedures for such decisions.[3] In New York, the Family Health Care Decisions Act (FHCDA) governs end-of-life decisions for most socially isolated patients.[4] This article examines the provisions for socially isolated patients in the FHCDA. While the FHCDA is just one state's statute, the clinical, ethical, policy, and even interpretive issues addressed here will be instructive to health care professionals and policymakers in other states as well.

Special attention is given to the FHCDA provision that requires, as a basis for withdrawing or withholding treatment from socially isolated patients, a finding that the patient "will die imminently, even if the

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treatment is provided."[5] That critical phrase is a source of uncertainty, both with respect to time period that qualifies as "imminently" and to the application of the phrase to DNR orders.[6] A clear, uniform understanding of the "will die imminently clause" will reduce both undertreatment and overtreatment of socially isolated patients at the end of life.

But an additional policy change is needed. This article recommends that, once standards for ethics review committees are strengthened, the FHCDA should be amended to allow the attending physician to decide to withhold or withdraw life-sustaining treatment for a socially isolated patient based on the standards that now apply to surrogate decisions, subject to approval by an ethics review committee. The FHCDA already allows decisions on this basis for socially isolated patients in hospice;[7] the approach should be broadened.

I. The Family Health Care Decisions Act

The FHCDA governs decisions for patients in hospitals, nursing homes, and hospices who lack capacity and who did not, prior to losing capacity, make the decision personally or appoint a health care agent.[8] The statute governs consent to treatment and decisions to withdraw or withhold life-sustaining treatment.

In general, the FHCDA provides for the designation of a surrogate decisionmaker from a priority list. The highest priority category on that list is a court-appointed guardian when there is one. After that, the list proceeds through levels of close relatives and ends with the category "close friend."[9]

a. A Surrogate Decision to Withdraw or Withhold Life-Sustaining Treatment

Under the FHCDA, a surrogate may decide to withhold or withdraw life-sustaining treatment from the adult patient who lacks decision-making capacity based on the patient's wishes, if known or ascertainable through reasonable efforts or when the patient's wishes are unknown and not reasonably ascertainable, on best interests. Whether the patient's wishes or the best interest standard is applied, certain clinical ethical standards must be met. For example, either:

> (i) treatment would be an extraordinary burden to the patient and the patient has an illness or injury which can be expected to cause death within six months, whether or not treatment is provided; or the patient is permanently unconscious; or
>
> (ii) the provision of treatment would involve such pain, suffering, or other burden that it would reasonably be deemed inhumane or extraordinarily burdensome under the circumstances, and the patient has an irreversible or incurable condition.[10]

This standard, referred to in this article as the "surrogate decision-making standard," does not require a finding that the patient is imminently dying.

b. FHCDA Provisions Regarding Socially Isolated Patients

FHCDA section 2994-g governs decisions for most incapable adult patients without surrogates. Subsections 5 and 5-a establish the three alternative bases for ordering the withdrawal or withholding of life-sustaining treatment for socially isolated adult patients. As explained further below, life-sustaining treatment can be withdrawn or withheld from a socially isolated patient based on:

1) judicial approval;
2) the "will die imminently" test; or
3) decisions regarding hospice care.

c. Judicial Approval

First, the FHCDA allows treatment to be withdrawn or withheld from a socially isolated patient if a court finds that the decision meets the surrogate decision-making standard (terminally ill, permanently unconscious, or extraordinary burden).[11] Prior to the FHCDA, a court had no such authority; it could approve the decision only if it found "clear and convincing evidence" of the patient's "firm and settled commitment" to forgo treatment under the circumstances.[12]

d. The "Will Die Imminently" Test

Second, treatment can be withdrawn or withheld from the socially isolated patient where:

> The attending practitioner, with independent concurrence of a second practitioner, determines to a reasonable degree of medical certainty that:
>
> (i) life-sustaining treatment offers the patient no medical benefit because the patient will die imminently, even if the treatment is provided; and
>
> (ii) the provision of life-sustaining treatment would violate accepted medical standards.[13]

As noted previously, there is uncertainty among clinicians and others regarding the meaning of "will die imminently"[14] — what does it mean and how long a time period is "imminently"? Or to use a legal lens: how would the phrase "will die imminently" be construed in an administrative or judicial legal proceeding?

As explained below, the phrase "imminently" clearly includes a period of hours or a few days, probably includes a week and perhaps two weeks, but probably does not include a month or more.

Administrative and Judicial Definition. There is no NYS Department of Health regulation or guidance that further defines the phrase "will die imminently."[15] Such state agency regulation or guidance would have been entitled to considerable deference if a court found that the interpretation required specialized knowledge or expertise.[16]

Moreover, no published judicial opinion interprets the meaning of "will die imminently" in the FHCDA, so there is no binding precedent.

The words "imminent" and "imminently" appear in several other New York state statutes. For example, under New York Mental Hygiene Law, confidential mental health information can be disclosed to an endangered individual based on the practitioner's determination that the patient presents "a serious and imminent danger" to the endangered individual.[17] The Family Court Act defines "neglected child" to mean a child "in imminent danger of becoming impaired...."[18] Several courts have interpreted those words for the purpose of those other statutes. In a child neglect case, the NYS Court of Appeals explained that "' imminent danger'" must be "near or impending, not merely possible."[19] However, the interpretation of "imminent" for the purpose of statutes other than the FHCDA is not dispositive of its meaning in the FHCDA.

The phrase "imminent death" is also used in Georgia and Vermont laws as a basis for a DNR order.[20] But the phrase is not defined in those statutes either.

Principles of Statutory Construction. In the absence of administrative guidance or judicial precedent, a court would define "will die imminently" by using familiar principles of statutory construction.[21] Initially it would look to the plain, customary meaning of the words as well as the statutory context. If the court needed further guidance, it would consider the legislative history and then possibly professional or scholarly

interpretations. A court would be mindful of policy implications, but it could not twist the plain meaning of the words to achieve policy ends.

Plain Meaning. Courts typically start with dictionary definitions "as guideposts to determine a word's ordinary and commonly understood meaning."[22] Webster's International Dictionary, Third Edition (1993) defines "imminent" to mean "Ready to take place; near at hand; impending; hanging threateningly over one's head; menacingly near."[23] The Oxford English Dictionary defines "imminent" to mean "Of an event (almost always of evil or danger): Impending threateningly, hanging over one's head ready to befall or overtake one close at hand in its incidence coming on shortly."[24] Merriam-Webster, a commonly used online reference, defines "imminent" as "ready to take place: happening soon."[25]

Not surprisingly, none of these definitions specify a time period; the term is intentionally imprecise. It is a qualitative, not quantitative, concept. But it unmistakably means "soon."

Statutory Context. Courts will also construe a statute as a whole and consider sections together with reference to each other.[26] In this instance, the statutory context is revealing: one of the other bases in the FHCDA for a surrogate decision to forgo life-sustaining treatment is that "the patient has an illness or injury which can be expected to cause death within six months...."[27] Accordingly, "imminently" must mean something sooner than "within six months." The Legislature would not have used different phrases for the same time period. Put differently, if the Legislature meant "within six months," it knew how to say it. It used "imminently" to mean something sooner.[28]

Legislative History. The legislative history of the phrase "will die imminently" is the most revealing guide to its meaning. The FHCDA was based on the 1992 report and recommendations of the New York State Task Force on Life and the Law, *When Others Must Choose – Deciding for Patients Who Lack Capacity*.[29] The Task Force recommended two bases for a decision to forgo treatment for socially isolated patient:

1) A decision by the attending physician to withhold or withdraw life-sustaining treatment, based on the standard that would apply to a surrogate, subject to ethics review committee approval; or
2) "health care without benefit" defined as follows:
    a. An attending physician determines, in accordance with accepted medical standards and to a reasonable degree of medical certainty, that the patient will die within a short time period despite the provision of treatment and that treatment should be withdrawn or withheld; and
    b. one other physician selected by the hospital concurs in this determination.[30]

The Task Force's proposed clause in paragraph (2), "will die within a short time period," is the direct forerunner to PHL 2994-g's "will die imminently" clause. Moreover, as discussed below, the Task Force regarded "a short time period" and "imminently" as having the same meaning.

The Task Force report devotes a full chapter to "Deciding for Adults Without Surrogates," with a section on "Treatment Without Medical Benefit." Its discussion in that chapter in support of the "will die within a short period" standard uses all of these phrases for the same concept:

- "during the final days and hours of the dying process"
- "the final days of their dying process"
- "at the end stage of their dying process"
- "will die within a short period even if treatment is provided"
- "patients who are imminently dying"

Ultimately, the NYS Legislature deleted the first option of allowing a decision for a socially isolated patient based on the surrogate decision-making standard subject to ethics review committee review proposed by the Task Force. Further below, this article recommends revisiting that option.

More to the point for present purposes, the Legislature modified the Task Force proposed phrase "will die within a short time period" to "will die imminently." But neither phrase is quantifiable and, as noted above, the Task Force used them interchangeably.

This article cannot provide an authoritative definition of the precise time period conveyed by the phrase "will die imminently." That would need to come from a court, the legislature or a state agency. But in the absence of such definition, principles of statutory construction indicate that "imminently" clearly includes a time period of hours or a few days, probably includes a week and perhaps two weeks, but probably does not include a month or more.

This conclusion may seem unremarkable. But it may help counter interpretations at opposite ends of the spectrum. If "imminently" is read to mean that the patient must be expected to die within minutes or hours for treatment to be withheld or withdrawn, clinicians may feel compelled to provide highly aggressive treatment to the dying socially isolated patient that most would regard as extraordinarily burdensome in light of minimal benefit. On the other hand, if "imminently" is read to mean that the patient will probably die sometime in the next few months but not the next few weeks, a decision to withhold or withdraw treatment from the socially isolated seems to involve more of a value judgment than a medical judgment.

e. DNR Orders

Applying the term "will die imminently" to DNR orders raises special issues. As explained below, the phrase, as applied to a DNR order means that a DNR order can be written based on a finding that in the event of cardiac arrest, the patient will die imminently even if the treatment is provided. The phrase does not require a finding that the patient is imminently dying at the time the DNR order is written.

A do-not-resuscitate (DNR) order directs the medical staff not to attempt cardiopulmonary resuscitation if and when, at some point in the future, the patient goes into cardiac arrest. New York's former DNR law, in effect from 1988 to 2010, created a process and standards for securing surrogate consent to a DNR order.[31] For socially isolated patients, it provided that a DNR order could be entered based on an attending physician and concurring physician determination that resuscitation would be "medically futile." Per the former statute, "medically futile" means that "cardiopulmonary resuscitation will be unsuccessful in restoring cardiac and respiratory function or that the patient will experience repeated arrest in a short time period before death occurs."[32]

Significantly, the standard to enter a DNR order for socially isolated patient did not require a finding about the patient's condition or life-expectancy at the time of writing the order; it just required a finding about whether, in the event of a future cardiac arrest, resuscitation would work.

The FHCDA was developed to extend the DNR Law to a broader range of life-sustaining treatments.[33] The Task Force and legislature, in proposing the FHCDA, adopted or adapted DNR Law provisions on, among other topics, determining incapacity, a surrogate priority list, clinical predicates to support a surrogate decision to forgo life-sustaining treatment, the patient's wishes or best interest standard, and the use of an ethics committee.

With respect to socially isolated patients, the FHCDA could not simply reproduce the DNR Law's provision on medical futility because the DNR Law provision was treatment-specific: it referred only to the effectiveness of cardiopulmonary resuscitation. The FHCDA needed to extend the DNR concept of medical futility to encompass decisions about ventilators, feeding tubes, dialysis, antibiotics, and more. Accordingly, the DNR provision on the futility of resuscitation, extended to other treatments, became in the Task Force's proposal a finding "that the patient will die within a short time period despite the provision of treatment." In the final FHCDA, that phrase was changed to a finding that "the patient will die imminently, even if the treatment is provided."

That background illuminates the meaning of the FHCDA term "will die imminently" as applied to a DNR order: It means that a DNR order can be written for a socially isolated patient based on a finding that in the event of cardiac arrest, the patient will die imminently, even if the treatment is provided.

The language of the provision supports the above conclusion. "Will die imminently even if the treatment is provided" ties the phrase "will die imminently" to the time the treatment, resuscitation (when the patient has a cardiac arrest), is provided.

Consider a socially isolated patient dying from cancer that has metastasized. The attending practitioner considering a DNR order may not be able to state with certainty that the patient "will die imminently." But the physician may well be able to say with certainty that when the disease finally causes the patient's heart to stop, the patient "will die imminently, even if the treatment is provided."

This is the standard that was in effect under the DNR Law from 1988 to 2010. Neither the Task Force nor the NYS Legislature intended to disturb that standard in proposing and enacting the FHCDA. As others have noted, "Although the law now uses different words, there are few, if any, cases in this ... category where a DNR order legally could have been issued before FHCDA but could not be issued under FHCDA."[34]

A NYS Bar Association website, "The Family Health Care Decisions Act Resource Center," endorses this view.[35] It includes an FAQ that states as follows:

> Health Care Decisions for Adult Patients Without Surrogates. N.Y. PHL § 2994-g
>
> Q – Under the former DNR law, a DNR order could be entered for an incapable patient who did not have a surrogate if the physician and a concurring physician determined that resuscitation would be "medically futile" (if CPR would "be unsuccessful in restoring cardiac and respiratory function or that the patient will experience repeated arrest in a short time period before death occurs"). Can a practitioner still do that?
>
> A – The language of the standard has changed, but it still ordinarily supports the entry of a DNR order if resuscitation would be "medically futile" as defined above. Under the FHCDA, the practitioner and a concurring practitioner would need to determine that (i) attempted resuscitation (in the event of arrest) would offer the patient no medical benefit because the patient will die imminently, even if the treatment is provided; and (ii) the attempt would violate accepted medical standards.

This NYS Bar Association FAQ, while not an authoritative source of law, was written, reviewed and approved by a broad range of experienced health lawyers and provides strong support for a facility or practitioner that follows this approach.

Moreover, an article by clinicians and bioethicists at the New York City Health + Hospitals, including bioethicist Nancy Dubler, adopted this position as well:

> Life-sustaining treatment decisions should be seen as situation-specific, as they depend on the treatment in question and on the medical condition and prognosis of the individual at the time the adverse event occurs, such as cardiopulmonary arrest. Based upon the dismal CPR survival data for nursing home residents with dementia, in the event of cardiac arrest, CPR likely will result in imminent death.[36]

The DNR laws in other states specify this temporal concept. For instance, a provision in Vermont's DNR law allows a physician to write a DNR order for any patient (not just isolated patients) upon a certification "that resuscitation would not prevent the imminent death of the patient, should the patient experience cardiopulmonary arrest. . . ."[37]

It would seem that the same conclusion can be reached for a do-not-intubate (DNI) order, a nursing home do-not-hospitalize order, or any other order that directs the withholding or withdrawal or life-sustaining treatment in the event of a future clinical contingency. Such orders are distinguishable from noncontingent orders meant to be carried out immediately, such as discontinuing a ventilator or feeding tube. But these treatments may raise different clinical and ethical issues. In any case, the clearest case, based on words and history, relates to DNR orders.

To be sure, it would have been preferable if the drafters of the FHCDA specified, as Vermont did, that for the purpose of a DNR order, the test is whether, in the event of cardiac arrest, the patient will die imminently, even if the treatment is provided. And it would be helpful if policymakers clarified this point now.[38] Legislative bills to accomplish this have been introduced repeatedly.[39] The state Department of Health could also accomplish such clarification by a "Dear CEO/Administrator Letter," [40] or by revising the MOLST checklist for adults without surrogates.[41] Such clarification would help decrease uncertainty and misunderstanding among health care professionals and their advisers and allow DNR decisions for socially isolated patients based on longstanding, ethically sound principles.

But even without an official pronouncement, the words and history of the "will die imminently" provision make clear what was meant.

As an aside, advances in resuscitative techniques, such as the increased deployment of Extracorporeal Membrane Oxygenation (ECMO), are increasing the duration of patient survival after resuscitation.[42] ECMO raises complex medical and ethical issues regarding, among other matters, whether a patient is a candidate for the procedure,[43] when to discontinue ECMO after it has commenced, and what a DNR order means as applied to a patient on ECMO.[44] These fraught issues are beyond the scope of this article. In any case, if and when ECMO becomes a standard of care response to an inpatient cardiac arrest, the FHCDA test for a "do not ECMO order" for a socially isolated patient would seem to be whether, in the event of cardiac arrest, the patient will die imminently even if ECMO is provided. This could lead to a different result than applying the standard to a non-ECMO resuscitation. But this rote application of the FHCDA test would not take into account the exceptionally scarce availability of ECMO equipment and staff, which compels distributive justice considerations, specifically resource allocation, well beyond those raised by CPR. It makes the treatment akin in many ways to decisions about scarce transplantable solid organs, or ventilators in a pandemic. So, there is an ethical argument for devoting ECMO to patients who have a prospect of post-ECMO life. Again, these are issues beyond the scope of this article.

f. Decisions Regarding Hospice Care

A 2015 amendment to the FHCDA added a third FHCDA basis for withdrawing or withholding treatment from a socially isolated patient.[45] It authorizes the attending practitioner to make "decisions regarding hospice care" for the patient, subject to several oversight requirements.[46] The decision must be made in consultation with staff directly responsible for the patient's care, with the concurrence of another practitioner, and – significantly — with the review and approval of an ethics review committee.[47]

The FHCDA defines "decisions regarding hospice care" to mean "the decision to enroll or disenroll in hospice, and consent to the hospice plan of care and modifications to that plan."[48] The reference to "plan of care" signifies that the attending is not simply making the hospice enrollment decision, but the treatment plan as well. The provision requires the practitioner to base his or her decisions regarding hospice care for the socially isolated patient on the principles that would apply to surrogate decisions, including the surrogate decision-making standard for end-of-life decisions.[49] That standard does not require a finding that the patient "will die imminently."

Data is not available to the extent to which New York hospitals, nursing homes, and practitioners are invoking or even aware of this hospice-related provision as a basis for decisions for socially isolated patients. But by referring to the surrogate decision-making standard, as opposed to the "will die imminently" standard, the provision gives the practitioner and ethics committee a role akin to that of a joint surrogate for the hospice-eligible socially isolated patient. In fact, it approximates the Task Force's original proposal, which would have allowed the withdrawal or withholding of life-sustaining treatment from an isolated patient based: a decision by the attending physician applying the standard that would apply to a surrogate, subject to ethics review committee approval.[50]

II. Policy Recommendation

This paper proposes to strengthen ethics review committee standards, then allow the attending practitioner to make end-of-life decisions for a socially isolated patient based on the surrogate decision-making standard, subject to ethics review committee approval.

Clarifying the "will die imminently standard" will improve the quality of care for dying socially isolated patients. But will not remedy another gap – the need to allow carefully considered end-of-life decisions for socially isolated patients who are not expected to die imminently, but who meet the criteria described in the surrogate decision-making standard (a decision based on the patient's wishes or, if those are not reasonably known, the patient's best interests and, summarized, a finding that the patient is terminally ill or permanently unconscious, or the proposed treatment would impose an extraordinary burden on the patient).[51]

The Task Force's original 1992 proposal would have addressed this gap by allowing a decision by the attending physician to withhold or withdraw life-sustaining treatment for an isolated patient based on the surrogate decision-making standard, subject to ethics review committee approval.[52] This option would allow for humane, patient-centered, comfort care-oriented end-of-life decisions for socially isolated patients in cases that are not in the "will die imminently" category.

Moreover, this option dovetails well with the "will die imminently" option: The physician/ERC option addresses cases that include prominent ethical or nonmedical questions. For example, what are this socially isolated patient's wishes or best interests? What are the benefits and burdens of the treatment? These questions make it necessary and appropriate to convene an ERC to review and possibly approve a decision.

In contrast, the "will die imminently" basis is primarily a medical question (will the treatment work?). An ERC has no apparent role in that determination unless there is a dispute.[53]

Indeed, allowing the physician/ERC option may reduce concerns about the meaning of "will die imminently" and the reliability of a prognosis that the patient will die imminently. If the attending practitioner is uncertain about whether the patient "will die imminently" but believes comfort care is appropriate for the patient, she or he would be able to refer the recommended course of treatment to the ERC.

Reliance on institutional ethics committee approval for end-of-life decisions for isolated patients is a hardly novel idea.[54] The FHCDA itself already relies upon an ERC to approve the practitioner's decision about hospice, including a hospice plan of care.[55] It also makes three other types of end-of-life decisions that are subject to ERC approval.[56] Moreover, some New York hospitals or nursing homes require ERC approval for end-of-life decisions even when applying the "will die imminently" standard.[57]

Elsewhere, some state's laws recognize a role for ethics committees in decisions for socially isolated patients (Alabama, Arkansas, Georgia, and Tennessee place ethics committees into the priority list of default surrogates) and in other states, hospitals rely upon ethics committees for such decisions without statutory authority.[58]

There is a strong case in New York for allowing end-of-life decisions for socially isolated patients who do not meet the "imminently dying" criteria based on a practitioner applying the FHCDA's surrogate decision-making standard, subject to ERC approval.

III. Criticism of Reliance on Ethics Review Committees

This proposal will encounter serious substantive criticisms, particularly regarding the role of the ERC.[59]

The foremost criticism is a concern that, in some cases, the attending physician and ERC may make decisions that undervalue the life of the socially isolated patient who is severely and irreversibly ill but not imminently dying. That risk is even greater for socially isolated patients who face health system discrimination for other reasons: people with physical, mental, or developmental disabilities, poor patients, minority patients, patients with substance abuse-related conditions, prisoners, and very elderly patients.

That concern is very real. But the remedy should not be to compel aggressive treatment in all such cases; that approach fails to consider the particulars of each case and can also cause terrible harm to socially isolated patients. The option of involving a court—apart from the delay and expense—does not really address the concern: it transfers decision-making to a judge who is apt to be inexperienced in these matters and may exhibit the same bias.

One argument for referring such cases to courts is that courts, unlike ERCs, will apply procedural due process in reaching a decision.[60] Typical due process elements are written notice, hearing, legal representation, right to present evidence, rules about the admissibility of evidence, an impartial decisionmaker, written decision, or appeal rights. But these principles are designed to ensure fairness in adversarial procedures. There is a strong case to apply them when the ERC hears and is empowered to resolve a dispute. However, the ERC role envisioned here does not involve dispute resolution. It involves reviewing a decision made on behalf of a socially isolated, incapable, non-objecting patient, based on the patient's wishes, if known, or else the patient's best interests. This is a part-medical and part-ethical inquiry. It is emphatically not an adversarial procedure seeking to deprive the patient of rights.

To be sure, procedural due process is intended to achieve fairness and thoroughness, and some elements of due process would enhance any formal review, including an ERC review. Moreover, if any person connected with the case brings an action to challenge or block an ERC decision, far more processes will be due. The full panoply of judicial-type due process elements should not be grafted onto a physician and ERC's non-adversarial review of a decision on behalf of the socially isolated patient.

There is another persuasive argument for caution: FHCDA ethics review committees have existed in New York since 2010, yet there is little to no information on how well they work in their statutory role. Who is on them? Do they have significant conflicts of interest? What are their credentials? Do they have training in the legal and ethical principles they should follow? How do they collect information about patient wishes and values? Particularly little is known about their current role in approving end-of-life decisions for socially isolated patients in hospice.

Researchers at Massachusetts General Hospital conducted a retrospective cohort study of ethics committee consultations involving decision-making about life-sustaining treatment for socially isolated patients from 2007 to 2013.[61] They recommended caution before endorsing ethics committees as final decision maker for socially isolated patients.

Another prominent study surveyed hospitals regarding ethics consultants and ethics consulting.[62] It does not address the role of the ethics committee in making decisions for socially isolated patients. However, some of its inquiries would also be relevant to ethics committees with decision-making authority, including: Is their financial support adequate? How do they gather information? What records do they keep? How are they evaluated?

Before expanding the role of ERCs to include end-of-life decisions for socially isolated patients, there is a need for further study. (As of this writing, the Empire State Bioethics Consortium[63] is undertaking just such study.) Depending in part on the findings of a study, consideration must also be given to improving the ERC structure and practices. For instance, hospitals and ERCs could be encouraged, or even required, to follow model policies regarding:

- Addressing conflicts of interest;
- Addressing bias against patient subpopulations;
- Training in relevant principles of medical ethics and law;
- Procedural steps to follow in end-of-life decision cases, including steps to ascertain patient wishes; Institutional retrospective review of ERC decisions in end-of-life cases (e.g., by the hospital quality assurance committee or other body);
- Data collection, subject to QA confidentiality and privilege protections.

In short, ERCs need to adopt some of the formalities that apply to institutional review boards.[64]

With additional rules and safeguards, and with increased professionalism of ERCS, end-of-life decisions for socially isolated patients could be based on a physician applying the surrogate decision-making standard, subject to ERC approval.

Additional rules and safeguards, informed by data from studies, will enhance the professionalism of ERCs and the quality of their decision-making. After that step, the FHCDA should be amended to add a fourth basis for an end-of-life socially isolated patient: a decision by the attending physician based on the surrogate decision-making standard, subject to ERC approval. This would allow for patient-centered end-of-life care for the socially isolated patient.

CONCLUSION

New York's Family Health Care Decisions Act authorizes the withdrawal or withholding of life-sustaining treatment from an incapable, socially isolated patient, among other instances, if the attending practitioner finds that the patient "will die imminently, even if treatment is provided." That phrase is a source of uncertainty, both with respect to time period that qualifies as "imminent" and to the application of the phrase to DNR orders. This study of the phrase, particularly the legislative history of the phrase, indicates that the term "imminently" clearly includes a time period of hours or a few days, probably includes a week and perhaps two weeks, but probably does not include a month or more.

Moreover, with respect to DNR orders, a study of the phrase and its legislative history indicates that a DNR order can be written for a socially isolated patient based on a finding that in the event of cardiac arrest, the patient will die imminently even if the treatment is provided. The clause does not require a finding that the patient is imminently dying at the time the DNR order is written.

Clarifying the "will die imminently standard" will improve the quality of care for dying socially isolated patients, but it will not allow carefully considered end-of-life decisions for socially isolated patients who are not imminently dying, but who meet the criteria described in the surrogate decision-making standard. Policymakers should consider strengthening the standards for ethics review committees to make them more professional. With such changes, the FHCDA should be amended to authorize the attending physician to make an end-of-life decision for an incapable isolated patient based on the same standards that would apply to a surrogate (not the "imminently dying" standard), subject to ERC review and approval. This change will result in more humane, patient-centered end-of-life decisions for socially isolated patients in New York.

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[1] *N. Karp and E. Wood, Incapacitated and Alone: Health Care Decision-making for Unbefriended Older People. (American Bar Association, Commission on Law and Aging. 2003 Washington, D.C.).*

[2] *See e.g., H. Kaplan, "Representing Unrepresented Patients," (Letter from the Editor) AMA Journal of Ethics 21:7:549 (2019) https://journalofethics.ama-assn.org/article/representing-unrepresented-patients/2019-07; T. Dempsey and E.S. DeMartino, "How Should Clinicians Navigate Decision Making for Unrepresented Patients?" AMA Journal of Ethics, Case and Commentary. 21:7:559 (2019); N. Sharadin, "Should Aggregate Patient Preference Data Be Used to Make Decisions on Behalf of Unrepresented Patients?", AMA Journal of Ethics, Case and Commentary.21:7:566 (2019)* https://journalofethics.ama-assn.org/article/should-aggregate-patient-preference-data-be-used-make-decisions-behalf-unrepresented-patients/2019-07; *D. Ozar, "Who Are "Unrepresented Patients" And What Counts As "Important" Medical Decisions for Them?" AMA Journal of Ethics, Medicine and Society, 21:7:611 (2019) https://journalofethics.ama-assn.org/article/who-are-unrepresented-patients-and-what-count-important-medical-decisions-them/2019-07; T. Pope, "Five Things Clinicians Should Know When Caring for Unrepresented Patients." AMA Journal of Ethics 21:7:582 (2019)* https://journalofethics.ama-assn.org/article/five-things-clinicians-should-know-when-caring-unrepresented-patients/2019-07.

[3] *Meisel, A., K.L. Cerminara and T.M. Pope, Right to Die: The Law of End-of-Life Decision-making (Third Edition 2004.) §8.05; T. Pope, 2017.*

[4] N.Y. Public Health Law Art. 29-CC. https://www.nysenate.gov/legislation/laws/PBH/2994-D. The FHCDA does not govern (i) end-of-life decisions for people with developmental disabilities; those are governed by NY Surrogate's Court Procedure Act §1750-b; or (ii) certain health care decisions for people in mental health hospitals or units, which are governed by Office of Mental Health regulations. Decisions for isolated patients who have a developmental disability or mental illness can be made by a Surrogate Decision Making Committee (SDMC) established by N.Y. Mental Hygiene Law Article 80.

[5] N.Y. Public Health Law § 2994-g.5(b). https://www.nysenate.gov/legislation/laws/PBH/2994-G

[6] This statement is largely based on my experience as counsel to a health care system, my participation in professional conferences on this issue, and my discussions with clinicians, bioethics professionals, and health care attorneys. But also, compare e.g., Howard J. Finger, James Zisfein, Khoi Luong, Cheryl A. Dury, Ravindra Amin, Steven Hahn, Albina Shkolnik, and Nancy Neveloff Dubler, "Life-Sustaining Treatment Decisions for Unbefriended Nursing Home Resident: Application of a Clinical Ethics Algorithm," *NYSBA Health Law J*, Fall 2018 at p.81 https://nysba.org/NYSBA/Publications/Section%20Publications/Health/PastIssues1996present/2018/HealthLawJournal-Fall2018.pdf#page=82 ("imminently" is longer than "immediately" but should be no longer than a few weeks or months") with Robert S. Olick, K. Faber-Langendoen, "Caring for Patients without Surrogates Under the Family Health Care Decisions Act," https://www.upstate.edu/bioinbrief/articles/2011/2011-03-case-study-patients-without.php ("likely to die within a matter of days to weeks (not weeks to months)"). With respect to confusion about the application of the FHCDA standard to DNR orders, see Elizabeth Dzeng, Thomas Bein, and J Randall Curtis, "The Role of Policy and Law in Shaping the Ethics and Quality of End-of-life Care in Intensive Care," Intensive Care Med. 2022 Mar; 48(3): 352-354 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8883558/

[7] N.Y. Public Health Law § 2994-g.5-a. https://www.nysenate.gov/legislation/laws/PBH/2994-G

[8] R. Swidler, "New York's Family Health Care Decisions Act: The Legal and Political Background, Key Provisions and Emerging Issues," *New York State Bar Journal,* June 2010. https://nysba.org/NYSBA/Public%20Resources/Family%20Healthcare%20Decisions%20Act%20Resource%20Center/FHDAC%20Files/SwidlerHealthJournSpr10.pdf Life-sustaining treatment decisions for patients with intellectual or developmental disabilities are governed by separate laws: the "Health Care Decisions Act for People with Intellectual or Developmental Disabilities" N.Y. Surrogate's Court Procedure Act § 1750-b and, for isolated patients with mental disabilities, N.Y. Mental Hygiene Law Article 80 Surrogate Decision-making Committees.

[9] N.Y. Public Health Law §2994-d.1. https://www.nysenate.gov/legislation/laws/PBH/2994-D

[10] N.Y. Public Health Law §2994-d.5. https://www.nysenate.gov/legislation/laws/PBH/2994-D

[11] N.Y. Public Health Law §2994-g.5(a). https://www.nysenate.gov/legislation/laws/PBH/2994-D

[12] *Matter of O'Connor (Westchester County Med. Ctr.*), 72 N.Y.2d 517 (1988) https://casetext.com/case/matter-of-oconnor-40; *Matter of Storar and Matter of Eichner v Dillon*, 52 N.Y.2d 363 (1981) https://casetext.com/case/matter-of-eichner-fox, https://casetext.com/case/matter-of-storar-2

[13] N.Y. Public Health Law § 2994-g.5(b). https://www.nysenate.gov/legislation/laws/PBH/2994-G

[14] See note 7 supra. Most of the language in the provision is not problematic. The meaning of "no medical benefit" is clear because the clause itself supplies the definition: it means that "the patient will die imminently, even if the treatment is provided." With respect to the requirement that "the provision of life-sustaining treatment would violate accepted medical standards," if the patient will die imminently, even if the treatment is provided, the treatment has no medical benefit. Providing a treatment that has no medical benefit is not consistent with accepted medical standards. American Medical Association Code of Ethics 2024, § 5.5. https://code-medical-ethics.ama-assn.org/ethics-opinions/medically-ineffective-interventions (Although, despite medical standards, treatment is sometimes provided toward the end-of-life for non-medical reasons, such as acceding to patient or family requests, or to avoid real or perceived legal risk. See New York State Task Force on Life and the Law 1992, supra note 7, p.169.)

Finally, the requirement that the determination must be made with "a reasonable degree of medical certainty," employs a phrase that is commonly used in the FHCDA and other New York health laws. E.g., N.Y. PHL § 2994-c (determination of incapacity); N.Y. PHL §2994-d.5 (surrogate decision-making standard).

As an aside, a recent study provides reassurance that clinicians are generally accurate at identifying patients who are expected to die within 60 days and particularly good at identifying patients who are likely to die within 14 days. M. Orlovic, et al., "Accuracy of Clinical Predictions of Prognosis at The End-Of-Life: Evidence from Routinely Collected Data in Urgent Care Records," 2023, *BMC Palliative Care* 22:51 (2023) https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-023-01155-y.

[15] The NYS Department of Health approved a Medical Orders for Life-Sustaining Treatment (MOLST) form and posted it on its website. https://www.health.ny.gov/professionals/patients/patient_rights/molst/. That site includes Checklist 4 for "Adult without FHCDA Surrogate." But the checklist simply recites the "imminently dying" test without further guidance.

[16] *Wang v. James*, 40 N.Y.2d 497 (2023). https://law.justia.com/cases/new-york/court-of-appeals/1976/40-n-y-2d-814-0.html A recent decision of the United States Supreme Court struck down the "Chevron Doctrine" whereby courts had been directed to defer to an agency's interpretation of statutes the agency administers. *Loper Bright Enterprises v. Raimondo,* U.S. S.Ct. Slip Op. 22-451 (June 28, 2024.) But that decision does not affect the deference state courts accord to state agency interpretations of state statutes.

[17] N.Y. Mental Hygiene Law §33.13(c)(6) https://www.nysenate.gov/legislation/laws/MHY/33.13

[18] N.Y. Family Court Act § 1012(f)(i). https://www.nysenate.gov/legislation/laws/FCT/A10P1

[19] *Nicholson v. Scoppetta*, 3 N.Y. 3d 357, 368, (2004). https://www.nycourts.gov/LegacyPDFS/IP/cwcip/Training_Materials/FP_Training/Nicholson_V_Scoppetta-3N.Y.3D357.pdf

[20] O.C.G.A. §31-39-1.1 (Georgia) https://law.justia.com/codes/georgia/title-31/chapter-39/; 18 V.S.A. §9708(d)(3)(B) (Vermont) https://legislature.vermont.gov/statutes/section/18/231/09708.

[21] *People v. Williams*, 37 N.Y.2d 314 (2021). https://case-law.vlex.com/vid/broughton-v-state-no-887340191

[22] People v. *Williams*, 2021.

[23] Webster's Third New International Dictionary of The English Language, Unabridged (1993).

[24] Oxford English Dictionary, Second Edition (1989) Oxford, U.K.

[25] *Merriam-Webster online*. https://www.merriam-webster.com/dictionary/imminent.

[26] *Peyton v. NYC Board of Standards and Appeals*, 36 N.Y.3d 271 (2020). https://casetext.com/case/hoffman-v-nyc-bd-of-standards-appeals-in-re-peyton-ex-rel-peyton

[27] N.Y. Public Health Law §2994-d.5(a)(i). https://www.nysenate.gov/legislation/laws/PBH/2994-D

[28] H.G. Finger, C.A. Dury, G.R. Sansone, R.N. Rao, N.N. Dubler. "An Interdisciplinary Ethics Panel Approach to End-of-Life Decision Making." *Journal of Clinical Ethics*. 33:2 (2022).

[29] New York State Task Force on Life and the Law, *When Others Must Choose: Deciding for Patients Without Capacity.* 1992. Albany, NY. ISBN: 1881268004. https://purl.nysed.gov/nysl/27683657. For a description of the Task Force, its background and reports, see https://en.wikipedia.org/wiki/New_York_State_Task_Force_on_Life_and_the_Law. I was Staff Counsel to the Task Force from 1985 – 90, and a member of the Task Force from 2011 to the present but was not affiliated with the Task Force at the time it issued this report. I also authored the Wikipedia article cited in this note.

[30] New York State Task Force on Life and the Law, pp. 259-60 (Emphasis added). https://purl.nysed.gov/nysl/27683657

[31] N.Y. Public Health Law Article 29-B, repealed by NY Laws of 2023, Chapter 23. https://www.nysenate.gov/legislation/bills/2023/S8059

[32] Former New York Public Health Law § 2962.12. https://www.nysenate.gov/legislation/laws/PBH/12

[33] New York State Task Force on Life and the Law 1992, Preface and Chapter 12. https://purl.nysed.gov/nysl/27683657

[34] K. Lipson and J. Karmel, "Honoring Patient Preference at The End of Life: The MOLST Process and the Family Health Care Decisions Act," *NYSBA Health Law Journal* 16:1 (2011). https://molst.org/wp-content/uploads/2018/11/Lipson.Karmel.HealthLawJournal.MOLST_.2011.pdf. But see Dzeng, 2022 (the FHCDA standard for DNR futility is being interpreted as narrower than the former DNR Law standard for futility).

[35] New York State Bar Association (2020) *Family Health Care Decisions Act Resource Center*. https://nysba.org/fhcda-resource-center. I was the principal author of the FAQ cited above, but all the FAQs were reviewed and approved by seven other editorial board members.

[36] Finger, 2022.

[37] 18 V.S.A. § 9708(c)(3)(B) https://legislature.vermont.gov/statutes/section/18/231/09708; O.C.G.A. §31-39-1 et. seq. https://law.justia.com/codes/georgia/title-31/chapter-39/

[38] J.J. Fins, and R.N. Swidler, "A Proposal to Restore Medical Futility as A Clinical Basis for A DNR Order Under New York Law," *NYSBA Health Law Journal* 22:1 (2017).

[39] The most recent versions are (NY Senate Bill 2894 (Rivera) (2023) and NY Assembly Bill 7178 (Dinowitz) (2023).

[40] NYS Department of Health – Dear Chief Executive Letters https://www.health.ny.gov/professionals/hospital_administrator/letters/.

[41] https://www.health.ny.gov/professionals/patients/patient_rights/molst/docs/checklist_4.pdf.

[42] H. Ouyang, "The Race to Reinvent CPR," *NY Times*, March 27, 2024, NY Times online https://www.nytimes.com/2024/03/27/magazine/ecpr-cardiac-arrest-cpr.html.

[43] I. Wolfe, "On Not Recommending ECMO, *Hastings Center Report*," September-October 2020 https://onlinelibrary.wiley.com/doi/full/10.1002/hast.1177.

[44] E.C. Metzer, N.S. Ivascu and J.J. Fins, "DNR and ECMO: A Paradox Worth Exploring," *Journal of Clinical Ethics* 25, note 1 (Spring 2014):13-9 https://pubmed.ncbi.nlm.nih.gov/24779313/.

[45] Chapter 107, New York Laws of 2015, enacting Public Health Law § 2994-g.5-a. https://www.nysenate.gov/legislation/laws/PBH/2994-G

[46] T. Kirk and R. Seigel, "Decisions Regarding Hospice Care for Isolated Patients: A Guide to the 2015 Amendment of The Family Health Care Decisions Act", *NYS Bar Association Health Law Journal* 21:3 (2016) https://philpapers.org/rec/KIRDRH; A. Hulkower, G. Garijo-Garde and L. Flicker, "Should Dialysis Be Stopped for An Unrepresented Patient with Metastatic Cancer? *American Medical Association Journal of Ethics* 21:7, 575 (2019) at 588 https://journalofethics.ama-assn.org/article/should-dialysis-be-stopped-unrepresented-patient-metastatic-cancer/2019-07.

[47] N.Y. Public Health Law § 2994-g.5-a. https://www.nysenate.gov/legislation/laws/PBH/2994-G

[48] N.Y. Public Health Law §2994-a.5-a. https://www.nysenate.gov/legislation/laws/PBH/2994-A

[49] N.Y. Public Health Law §2994-g.5-a. https://www.nysenate.gov/legislation/laws/PBH/2994-G

[50] New York State Task Force on Life and the Law, https://purl.nysed.gov/nysl/27683657

[51] Under the surrogate decision-making standard, life-sustaining treatment can be withdrawn or withheld when: (i) treatment would be an extraordinary burden to the patient and the patient has an illness or injury which can be expected to cause death within six months, whether or not treatment is provided; or the patient is permanently unconscious; or (ii) the provision of treatment would involve such pain, suffering or other burden that it would reasonably be deemed inhumane or extraordinarily burdensome under the circumstances; and the patient has an irreversible or incurable condition. N.Y. Public Health Law §2994-d.5. https://www.nysenate.gov/legislation/laws/PBH/2994-D

[52] New York State Task Force on Life and the Law, pp 259-60. https://purl.nysed.gov/nysl/27683657

[53] New York State Task Force on Life and the Law, pp 259-60. https://purl.nysed.gov/nysl/27683657

[54] F. Rosner, "Hospital Medical Ethics Committees: A Review of Their Development," *Journal of the American Medical Association* 253(18); (1985) 2693-97.

[55] N.Y. Public Health Law § 2994-g.5-a. https://www.nysenate.gov/legislation/laws/PBH/2994-G

[56] Specifically: in a nursing home, ERC approval is required for a surrogate decision to withdraw or withhold life-sustaining treatment from a patient who is not terminally ill or permanently unconscious (based on extraordinary burden. PHL §2994-d.8(b); In a general hospital, ERC approval is required for the withdrawal or withholding of artificial nutrition and hydration if the attending practitioner objects to such decision by a surrogate. PHL §2994-d.8(c); ERC approval is required for a decision to withdraw or withhold life sustaining treatment from an emancipated minor Public Health Law §2994-3.(3)(a). https://www.nysenate.gov/legislation/laws/PBH/2994-D

[57] Finger,2022.

[58] Pope, 2019.

[59] ERCs will also be denounced by some as "death panels." This article focuses on substantive ethical and policy criticisms but recognizes that there is a volatile political dimension to this as well.

[60] T. Pope, "The Growing Power and Healthcare Ethics Committees Heightens Due Process Concerns," *Cardozo Journal of Conflict Resolution* 15:425 (2014) https://open.mitchellhamline.edu/cgi/viewcontent.cgi?article=1278&context=facsch.

[61] A.M. Courtwright, J. Abrams and E. Robinson. "The Role of a Hospital Ethics Consultation Service in Decision Making for Unrepresented Patients." *Journal of Bioethics Inquiry* 14(2): 241-250 (2017).

[62] Ellen Fox, Marion Danis, Anita J. Tarzian & Christopher C. Duke, "Ethics Consultation in U.S. Hospitals: A National Follow-Up Study, The American Journal of Bioethics, 22:4, 5-18, DOI: 10.1080/15265161.2021.1893547. https://doi.org/10.1080/15265161.2021.1893547. However, while the article describes the prevalence of ethics review committees, it does not address their role as decisionmakers at the end of life.

[63] See http://www.empirestatebioethics.org. The author was a founding member of and a current director of the Empire State Bioethics Consortium, as well as a member of the ESBC team conducting the survey of ethics review committees.

[64] Institutional Review Boards, 21 Code of Federal Regulations Part 56, https://www.ecfr.gov/current/title-21/chapter-I/subchapter-A/part-56.