Title: New York State's 2010 Family Healthcare Decisions Act (FHCDA): What NY ACP Members Need to Know About Withholding and Withdrawing Life Sustaining Therapies for Adult Patients Without Capacity

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Executive Summary:

Medical decision-making on behalf of adult, incapacitated patients can be challenging for physicians. This article reviews medical decision-making when patients lack capacity, and the 2010 New York State Family Healthcare Decisions Act (FHCDA), a law that governs surrogate decision-making in hospitals as well as nursing homes in the state of New York. In addition, it provides information about a 2015 amendment to this law that allows physicians to provide hospice-eligible, incapacitated patients with no surrogate hospice care in a way that was not previously permissible under the FHCDA, providing details on the steps that must be taken. The Committee's guidance is offered here for NY ACP Members.

Medical decision-making on behalf of adult, incapacitated patients can be challenging for physicians. Irrespective of whether it's helping a grieving family member make a difficult end-of-life decision or, in cases when there is no surrogate, physicians being tasked with making decisions on behalf of incapacitated patients, surrogate decision-making presents significant ethical and legal questions.

Consider the following clinical case: A 75 year-old man with moderate dementia, metastatic liver cancer, and no family members or friends is admitted to the hospital from a nursing home for worsening pain, encephalopathy, nausea and vomiting. The nursing home reports that the patient declined considerably over the past month, with difficult to control cancer related symptoms. A CT scan reveals that there has been progression of disease, and his mental status does not improve with treatment of the encephalopathy. No one at the facility has knowledge of his prior wishes with respect to end-of-life care. Even before he became acutely ill, the patient was unable to demonstrate decisional capacity due to both dementia and encephalopathy. An oncologist estimates that the patient will probably live for a few weeks, but not months. All medical providers agree that it would be in the patient's best interest if he dies comfortably and without suffering from added interventions that would not cure his underlying disease. The clinical team is unsure how to proceed.

In the absence of a surrogate decision-maker, what end-of-life decisions can be made, and who has the authority to make them? Because over 50% of adults who are hospitalized or living in nursing homes cannot make their own medical decisions, these are clinical questions that many internists commonly face. (Vig. *J Gen Intern Med.* 2007;22(9):1274-1279. Wendler. *Ann Intern Med.* 2011;154(5):336-346.)

Accordingly, members of the Ethics and Professionalism Committee of the New York State Chapter of the American College of Physicians convened to discuss the 2010 New York State Family Healthcare Decisions Act (FHCDA), a law that governs surrogate decision-making in hospitals as well as nursing homes in the state of New York. The Committee's guidance is offered here for NY ACP Members.

FHCDA: When patients lack capacity, who decides?

The Public Health Law establishes "a procedure for making health-care decisions for adult patients who have *no* available family member or friend to act as a surrogate." (Swidler. NYSBA Health Law Journal, Spring 2010:Vol. 15, No.1)

To summarize, surrogate medical decision-making under the FHCDA applies only when an adult patient lacks capacity and did not previously appoint a healthcare agent by completing a health care proxy form. (Separate laws govern end-of-life decision-making for incapacitated patients who have an intellectual disability or who are in a psychiatric hospital or unit, which are beyond the scope of this article.) There is an order of priority for determining who serves as surrogate when the patient has not previously named one. (See Table Below.) At the top of the hierarchy is a court-appointed guardian, if the patient has one. Next is the patient's spouse or domestic partner, regardless of gender, followed by adult children (all with equal standing), parent, sibling, and then a close friend or any other more distant relative who can attest to having a relationship with the patient.

Adult Surrogate Decision Making Hierarchy

Court Appointed Guardian
Spouse/ Domestic Partner (Same or Opposite Sex)
Adult Child (Over 18 years-old all with equal standing)
Parent
Sibling
Close Friend or Distant Relative

FHCDA: What decisions can surrogates make?

The FHCDA allows for a surrogate to consent to all medical treatments (diagnostic and therapeutic) on behalf of the incapacitated patient. In addition, the surrogate may consent to withholding and withdrawing life sustaining therapies (LST), including inotropes, mechanical ventilation, cardiopulmonary resuscitation (CPR), and artificial nutrition and hydration. It serves to provide surrogates with more authority to make end-of-life decisions than they had prior to its enactment. However, a careful system of checks and balances remains in place to ensure that decisions are made thoughtfully, within clinically

appropriate boundaries, and with the utmost regard for the patient's preferences and best interest.

If a patient previously, when capacitated, made the decision to forgo LST and expressed this, either orally before two witnesses or in writing, this choice should be honored. In the absence of any such advance directive, the law provides guidance for how surrogates should approach medical decision-making. As set forth in *Public Health Law Section 2994(d)(4),* surrogates should make decisions that reflect the patient's prior expressed wishes and preferences for medical care, when reasonably known (there is no requirement of "clear and convincing evidence").

In the absence of any reasonably known wishes, then the surrogate should make decisions based on the patient's "*best interest.*"

With respect to withholding or withdrawing LST for an incapacitated patient who did not previously let his or her wishes be known in any way, surrogates are authorized to do so only when an attending physician, and another concurring physician, attest that the patient meets one of the following clinical criteria set forth in *Public Health Law Section 2994(d)(5)*:

1. The patient has an illness or injury which can be expected to result in death in less than 6 months whether or not treatment is provided, and treatment would pose an extraordinary burden to the patient;
2. Patient is permanently unconscious;
3. Clinical condition is irreversible or incurable, and provision of treatment would involve such pain and suffering that it is deemed inhumane or extraordinarily burdensome.

FHCDA: When an incapacitated patient has no surrogate

Decision-making when there is no surrogate is uniquely complicated, for in these situations physicians are asked to serve as surrogates and make decisions on behalf of the incapacitated patient. It should be noted that if an incapacitated patient is admitted to the hospital, a good-faith effort should be made to locate a surrogate, and this search should be documented in the patient's medical record. If no such individual can be located, the hospital should try to obtain additional information about the patient's known wishes, values and religious or moral beliefs, and document any pertinent findings in the medical record to help guide future decision-making.

While an attending physician is authorized to decide about routine medical treatment for a hospitalized, incapacitated patient with no surrogate, there are more stringent requirements in the FHCDA when making major medical decisions for incapacitated hospitalized patients, such as a decision to pursue surgery, procedures or treatments with significant risk, the administration of general anesthesia, the use of physical restraints (except in emergency), and the administration of psychoactive medications (except when used in an emergency, acutely, or in the post-operative period). In these cases an attending physician must be supported by a second, concurring physician who independently attests to the

appropriateness of the treatment. If a major medical decision is to be made for a patient in a nursing home, then the concurring physician must be the medical director of the facility or his/her designee.

Similarly, decisions to withhold or withdraw LST from an incapacitated patient with no surrogate are held to a much narrower clinical standard under the FHCDA. As noted previously, surrogates can elect to withhold or withdraw LST if the patient meets one of three clinical criteria (see page 3 above); decisions for the incapacitated patient with no surrogate, however, need to occur when the patient is imminently dying. According to *Public Health Law Section 2994(g)(5)*, when there is no surrogate, withholding or withdrawal can only occur if the attending physician and a concurring physician can attest that, "I have determined that life-sustaining treatment offers the patient no medical benefit because the patient will die imminently even if the treatment is provided; and the provision of life-sustaining treatment would violate accepted medical standards" *or* with a court order requested based on the surrogate standard. For many of us on the Ethics and Professionalism Committee this section of law, perhaps intentionally left vague by those who crafted it, generates some degree of confusion in practice.

For instance, the phrase "die imminently" is subject to interpretation; it could refer to hours, days or weeks. How far in advance can we reasonably make this prognostication and designate the patient do not resuscitate (DNR)? Should the patient be in a peri-arrest phase, likely to die in the next 24-hours? Or do we, as physicians, have some latitude, and authority, to establish DNR status in advance of such extreme situations? Certainly a broader interpretation of imminently dying would serve to ensure that incapacitated patients with a terminal condition, yet not nearing cardiac or pulmonary arrest, are spared the incremental harms of CPR and other measures before death.

Joseph J. Fins, M.D., M.A.C.P and former NYACP Governor, and Robert N. Swidler, J.D., Vice President of Legal Services for St. Peter's Health Partners and former Assistant Counsel to the Governor, explore this issue in a recent paper and similarly support this position. (Fins and Swidler. NYSBA Health Law Journal, Spring 2017:Vol. 22, No.1) They conclude that, the law "should be read to mean, as applied to a DNR decision, that doctors must find that the patient will die imminently *if and when the patient has a cardiac arrest*—which is the moment that the treatment will be withheld."

It must be noted, however, that permitting too much physician autonomy could be risky, particularly if orders to limit LST are implemented too early in a patient's disease course, when a diagnosis or prognosis is uncertain. The abuse of such authority could deny a vulnerable individual beneficial medical care.

What about withholding other LSTs, such as artificial nutrition and hydration? The patient may not "die imminently" by withholding or withdrawing these, yet their provision in certain end-of-life clinical situations may violate accepted medical standards and potentially cause harm, either by prolonging the dying process or by causing additional symptoms, such as diarrhea, respiratory distress and anasarca. In this way, providing

artificial nutrition and hydration can make a patient's death more burdensome. These types of interventions might even accelerate death by precipitating an aspiration pneumonia.

These questions, which are not easy to answer, often prompt animated discussions with significant variance in thoughts and opinions. Because of this tension, the legislature, with the support of the Hospice and Palliative Care Association of New York, amended the FHCDA to address the question of access to hospice services for incapacitated patients without surrogates.

FHCDA: Hospice Amendment

Public Health Law Section 2994 (g) (5-a) authorizes an attending physician to make decisions regarding hospice care for eligible patients who are incapacitated and have no surrogate. It states, "The attending physician shall make decisions under this section in consultation with staff directly responsible for the patient's care, and shall base his or her decision on the standards for surrogate decision-making set forth in *Public Health Law Section 2994 (d)(4)-(5)*".

This 2015 amendment allows physicians to provide hospice-eligible incapacitated patients with no surrogate hospice care in a way that was not previously permissible under the FHCDA. Now patients who are not "imminently dying" can receive hospice benefits if they meet one of three clinical criteria (see page 3 above) and otherwise qualify for hospice in terms of overall prognosis. As with other major medical decisions, there must be a concurring opinion: for hospitalized patients, another physician must independently concur, while for nursing home patients the facility medical director or his/her designee must agree.

There is then a third step in this process. An Ethics Review Committee (ERC), or a court of competent jurisdiction, must convene, and also confirm, that the decision is consistent with standards set forth for surrogate decision-making. Depending on the patient's location, this will be the ERC of the hospital, nursing home, or hospice.

What is an Ethics Review Committee?

As detailed in *Public Health Law Section 2994 (m)*, an ERC is an interdisciplinary group that includes, "at least five members who have demonstrated an interest in or commitment to patient's rights or to the medical, public health, or social needs of those who are ill. At least three ethics review committee members must be health or social services practitioners, at least one of whom must be a registered nurse and one of whom must be a physician. At least one member must be a person without any governance, employment or contractual relationship with the hospital."

The patient's treating physician may not concurrently serve as an ERC physician, as there must be an unbiased, and independent evaluation of each case. In residential health care facilities, the residents' council of the facility may appoint up to two individuals (neither residents nor residents' family members) who "have expertise in or a demonstrated

commitment to patient rights or to the care and treatment of the elderly or nursing home residents through professional or community activities, other than activities performed as a health care provider" to serve on the ERC. Finally, it should be noted that when the ERC is summoned to discuss decisions regarding hospice care for incapacitated patients with no surrogate, the committee "shall invite a representative from hospice" to participate.

What does this mean for clinical care?

Once two attending physicians and the ERC agree that an incapacitated patient with no surrogate meets eligibility criteria for hospice, a note documenting the determination should be entered into the patient's medical record. If the decision is made to elect hospice, the question arises: what does a hospice designation actually mean for clinical care? According to Mr. Swidler, the amendment to the law is clear that once the decision is made that the patient is hospice-eligible, "the attending and concurring physician, along with the ERC, can approve a plan of care that may include DNR and other withholding or withdrawal of LST based on the surrogate standards." He points first to the text of *Public Health Law Section 2994 (g) (5-a),* noting, "it states that after following the steps in *5-a*, the attending physician is directed to make decisions about the plan of care in accordance with the standards surrogates must follow, including the standards for decisions to withdraw or withhold life sustaining treatment." He also points to even more direct language in the Bill Memos that accompanied the 2015 bills that enacted *5-a*, in which each sponsor (the respective Health Committee chairs) wrote:

> The physician may also include in the hospice plan of care provisions for the withdrawal or withholding of life-sustaining treatment (e.g., a DNR order), in accordance with the clinical and decision-making standards that would apply to a surrogate decision under the FHCDA. Such orders are often consistent with the hospice election.

Let's return to our case, a 75 year-old man who is incapacitated with metastatic liver cancer, has no surrogate, and has weeks or perhaps a month to live. Imagine all clinicians agree that this patient is eligible for hospice, and the ERC concurs. Now, the attending physician can complete a *Hospice Benefit Election Form for an Isolated Patient* (http://www.hpcanys.org), and consent to the admission of the patient to hospice. How this determination should affect specific aspects of clinical care?. Should we now designate this patient DNR? What if he develops respiratory failure, should we forgo intubation and mechanical ventilation?

Although we teach that there is no ethical or legal distinction between withholding and withdrawing LST, we know that for clinicians in practice there can be a chasm between those two actions. Many physicians are more comfortable placing a DNR order than extubating a terminal patient, particularly when there is no surrogate and the decision falls on the provider. We suggest that physicians faced with these difficult questions consider an ethics consultation, or solicit the input of the ERC, when deciding how to proceed

clinically. We offer the following guidance to our colleagues as a starting point for the discussion.

If an incapacitated patient with no surrogate is determined to be hospice eligible and is *not* currently intubated, the decision about DNR/DNI should first be viewed in light of the patient's reasonably known wishes, i.e., the first standard that a surrogate would apply. If the patient's wishes are not known, and the best interests test is reached, then it would seem that the patient should be designated DNR/DNI (no cardiopulmonary resuscitation and no intubation). In addition, other LST such as intravenous inotropes, dialysis, and artificial nutrition or hydration should not be initiated or increased, unless there is a comfort-based rationale. For in this context, the goal of the hospice designation is to maximize palliation, and to prevent any harms or burden that might arise from escalating medical interventions and "over treatment".

If an incapacitated patient with no surrogate is determined to be hospice eligible and *is* currently intubated and/or receiving other LST, we suggest that, unless the patients known wishes indicate otherwise, the patient should be designated DNR. Regarding whether to continue the current level of life support, we suggest that the treating physicians, in conjunction with the ERC, explore whether continuing LST would be burdensome and/or violate accepted medical standards. Furthermore, given the complexity and ramifications of this kind of situation, legal advice may be appropriate before removing LST from a patient who lacks a surrogate.

Conclusion

Medical decision-making on behalf of adult, incapacitated patients is challenging for physicians. In this context, the 2010 FHCDA and the 2015 Hospice Amendment provide legal guidance through this process. When conflict or confusion arises, however, physicians should not be left to make decisions alone, unsupported. Depending on the practitioner's institution, the Ethics Committee, the Ethics Review Committee, or Legal Affairs should be consulted for guidance when needed.

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Additional Resources

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