Refusing Artificial Nutrition and Hydration: Does Statutory Law Send the Wrong Message?

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Ethical consensus and appellate court decisions view artificial nutrition and hydration (ANH) as medical treatment that can be refused like other treatments. However, advance directive statutes may produce obstacles for refusal of ANH, as distinct from other life-sustaining treatments, in patients who lack capacity.

This paper reviews state statutes and appellate case law regarding medical decision making for patients who lack decisional capacity. Twenty states (39%) have one or more explicit statutory provisions delineating a separate and more stringent standard for ANH refusal. These standards include higher evidentiary standard; requirement for specific preauthorization, qualifying medical conditions, second medical opinion, or judicial review; refusal not permitted; refusal not permitted if death would result from “starvation” or “dehydration”; and previous law with higher standard applies to old documents. In 11 of these states and in eight others, statutory law contains language that could be misinterpreted, implying, but not rising to, an explicitly higher standard. Four appellate decisions departed from the judicial consensus that ANH can be refused like other treatments, but subsequent court decisions or legislative enactments reduced or eliminated their impact.

Legislators and the courts should ask whether higher standards for ANH refusal are appropriate in light of case law authority that ANH should not be treated differently and in light of statutory language that preserves those common law rights. These higher standards may make it more difficult in certain states to refuse ANH for patients who lack capacity or place a burden on good practice by making providers fearful of the law. J Am Geriatr Soc 50: 544–550, 2002.

Key words: advance directives; enteral nutrition; legislation; mental competency; nutritional support

The use of artificial nutrition and hydration (ANH) at the end of life has long been an issue of controversy.1–7 Although some commentators continue to consider ANH “ordinary care” that cannot be forgone, an ethical and judicial consensus has emerged that ANH may be refused like any other medical treatment.8–14 Despite this, advance directive legislation in certain states contains separate and more stringent standards with regard to forgoing ANH than for other treatments.

Reasons for this disparate treatment of ANH under the law are probably diverse but could be related to misunderstanding about the medical aspects of ANH and the consequences of forgoing it.15,16 Several studies have documented a greater reluctance on the part of patients, surrogates, and physicians to forgo, withhold, or withdraw ANH at the end of life compared with other treatments.17–21 Furthermore, moral objections have been articulated by a number of commentators with regard to the withholding or withdrawal of ANH.2–6

The purpose of this paper is to describe the extent to which state statutes carve out separate and more-stringent standards of decision making with regard to ANH. This information should help to focus the debate about whether such statutory provisions are legally valid and clinically appropriate.

METHODS

We reviewed laws in 50 states and the District of Columbia that govern advance directives and medical decision making for patients who lack decisional capacity. Statutory laws (living will, medical power of attorney, and surrogate decision-making provisions) enacted through December 31, 2000, were reviewed. Attention was specifically given to whether provisions governing refusal of ANH differed from or were more stringent than those governing other life-sustaining or potentially life-sustaining treatments. In addition, attention was given to language regarding ANH that might be confusing or misleading but did not consti-
tute an explicit, higher standard. Finally, we reviewed all pertinent case law. Pertinent cases were those decided at the state or federal appellate level that specifically addressed the issue of forgoing ANH. Attention was specifically given to whether the decision established or affirmed separate standards for refusal of ANH. Cases were selected for review from a quarterly compilation of case law. This compilation represents a quarterly survey of Westlaw and Lexis (legal data bases), professional publications, and news sources.

**Terminology**

_**Living Will**_ (also commonly known as a “declaration”) refers to written instructions, by a person with capacity, outlining his or her wishes regarding end-of-life care in the event of future loss of capacity. _**Medical Power of Attorney**_ (also referred to as a healthcare proxy or durable power of attorney for health care) is the document that permits a person with capacity to appoint an individual to make medical treatment decisions on his or her behalf, in the event of future loss of capacity. _**Surrogate Decision Maker**_ refers to an individual designated by law to act in the absence of a living will or proxy appointment. _**Health Care Decision Act**_ refers to a comprehensive statute combining living will, medical power of attorney, and surrogate decision-making provisions. A _**qualifying condition**_ is a specific medical condition, such as “terminally ill” or “persistent vegetative state,” required by statute to exist before refusal of medical treatment from a patient who lacks decision-making capacity.

**More Stringent Standard**

A separate and more stringent standard was deemed to exist for ANH if one or more of the following provisions existed in the law that did not apply for other medical treatments.

1. The patient or surrogate cannot authorize withholding or withdrawal of ANH.
2. Specific authorization by the previously competent patient is required for ANH to be forgone, for example, by so indicating on the advance directive form.
3. A higher evidentiary standard of the previously competent patient’s wishes regarding ANH (other than noted in #2 above) must be met.
4. A patient must have specific medical conditions (qualifying conditions) that are not required for refusal of other medical treatments.
5. An additional attending physician or specialist, such as a neurologist, must certify pertinent aspects of the patient’s medical condition.
6. A life-sustaining treatment cannot be withheld or withdrawn if doing so would cause death by “starvation or dehydration.”
7. Advance directives executed before revised law are to be interpreted in accordance with previous, more-stringent standards.
8. Judicial review of the decision is required.

If the statute was silent with regard to ANH, we assumed that ANH was considered equivalent to other life-sustaining treatments and therefore that there was no separate standard.

In the context of qualifying medical conditions, a persistent vegetative state (PVS) was considered to be different from advanced dementia. The terms “permanent unconsciousness,” and “irreversible coma,” were considered to be equivalent to PVS unless language specifically stated otherwise and were likewise considered to be different from advanced dementia.

Qualifying medical conditions that might exclude patients from forgoing ANH were not considered to constitute a separate standard if that condition would also exclude other life-sustaining treatments under certain circumstances. For example, “terminal illness” as a qualifying condition is sometimes defined as death expected to occur “even if” life-sustaining treatment is given; this might exclude forgoing tube feeding in advanced dementia or PVS, but might also exclude mechanical ventilation in a respirator-dependent patient with end-stage emphysema. “Terminal illness” is also sometimes defined in vague language that is unclear, such as “death . . . in a short time,” but this lack of clarity would extend to any life-sustaining treatment.

**Confusing or Misleading Language**

In some states, the statutory language may imply that it is more difficult to forgo ANH or may raise confusion regarding the consequences of forgoing it but does not rise to an explicitly higher standard. The practical consequences might include inaccurate clinical decisions or choices by patients that are inconsistent with their intent. This language or these provisions were noted separately and included one or more of the following.

1. The suggested or mandatory advance directive form contains a specific check-off or space to indicate refusal of ANH (and no such space for any other individual life-sustaining treatment), but separate authorization is not required in the language of the statute.
2. A provision indicates that ANH must be given for “comfort care,” but the language otherwise permits refusal of ANH. This language was considered problematic because there is no convincing evidence that the provision of ANH, in and of itself, provides symptomatic relief in dying patients, or that forgoing ANH leads to a painful death.
3. The recommended or required advance directive form contains language that could cause a patient unnecessary concern that forgoing tube feeding might lead to a “bad death,” for example, by causing death by “malnutrition” or “starvation.”
4. A series of stipulations must be satisfied before ANH can be forgone; these stipulations appear broad and inclusive, but their lengthiness or complexity sets ANH apart from other life-sustaining treatments, implying a higher standard, or the provisions may be confusing, implying a higher standard.

**RESULTS**

Twenty states (39.2% of 50 states and the District of Columbia) have one or more explicit provisions in which there is a separate and higher standard for the refusal of ANH than for other medical treatments. These states, the type of standard, and the instrument in which the provision exists, are given in Table 1. There were no other med-
ical treatments for which a separate and more-stringent standard existed. In 11 of the 20 states and in eight additional ones, there was language that might imply that it was more difficult to forgo tube feeding or that might create confusion regarding the consequences of forgoing ANH (see Table 2). Statutory citations are given in Appendix 1.

Review of case law revealed overall judicial consensus that ANH is a medical treatment that can be forgone like any other treatment. Although one Ohio decision restricted a guardian’s ability to make decisions regarding ANH, this case was expressly superseded by subsequent legislation. Three other decisions departing from the consensus were also followed by court decisions or legislative enactments that reduced or eliminated their impact; in Missouri, the state supreme court argued that ANH did not constitute medical treatment, but, upon appeal, the decision was not supported by the United States Supreme Court.

A different type of confusion exists in the Oregon statute, where provisions added to clarify the permissibility of refusing ANH under certain circumstances might have the opposite effect. The law provides an exhaustive list of circumstances under which refusal could occur. However, although these circumstances appeared to include any likely clinical situation, the complexity of the provisions could create the impression that it was more difficult to forgo ANH than other treatments.

Our review of case law revealed virtual judicial consensus that ANH is a medical treatment that can be for- gone like any other treatment. Objections that ANH did

### Table 1. Statutes with Separate and More-Stringent Standards for Refusal of Artificial Nutrition and Hydration

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<tr>
<th>State</th>
<th>Refusal Not Permitted</th>
<th>Preauthorization Required</th>
<th>Other Higher Evidentiary Standards</th>
<th>Specific Medical Conditions Required</th>
<th>Second Opinion Required</th>
<th>Refusal Not Permitted if Death Would Result From “Starvation” or “Dehydration”</th>
<th>Previous Law With Higher Standard Applies to Old Documents</th>
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LW = living will; MPA = medical power of attorney; S = statutory surrogate decision making; HCD = health care decisions (comprehensive statute combining living will, medical power of attorney, and surrogate decision making provisions).

*In addition to other limitations, a decision to withdraw artificial nutrition and hydration must be approved by the probate court in the county in which the patient is located.

In addition, many statutes contain language that could create confusion regarding the permissibility of forgoing ANH under certain circumstances or could generate concern about the consequences of doing so. Although these provisions were not considered to constitute a higher legal standard, such language was not used for other life-sustaining treatments. In Idaho, for example, the recommended advance directive form—but not the body of the statute—states, “Nutrition and hydration shall not be withheld or withdrawn from me if I would die from malnutrition or dehydration rather than from my injury, disease, illness or condition.” A person completing such a form might be misled by the language and become unduly concerned that dying without ANH would be unnatural or painful. In addition to creating confusion about what a law actually permits, as in this case, language that is clinically imprecise, or unnecessarily alarming, poses a barrier to informed decision making.

A different type of confusion exists in the Oregon statute, where provisions added to clarify the permissibility of refusing ANH might have the opposite effect. The law provides an exhaustive list of circumstances under which refusal could occur. However, although these circumstances appeared to include any likely clinical situation, the complexity of the provisions could create the impression that it was more difficult to forgo ANH than other treatments.

Our review of case law revealed virtual judicial consensus that ANH is a medical treatment that can be forgone like any other treatment. Objections that ANH did
not constitute medical treatment and that forgoing ANH required judicial oversight departed from this consensus, but subsequent holdings by the United States Supreme Court and legislative enactments have reduced or eliminated the impact of these decisions, respectively.

The Uniform Health Care Decisions Act is consistent with the judicial consensus. This comprehensive model statute was crafted to provide guidance to states when developing advance directive legislation and does not include any restrictive provisions regarding ANH.

Although this review has highlighted statutory and case law, interpretive opinions by attorneys general also provide guidance as to the legal validity of decisions to forgo ANH. Attorneys’ general opinions do not have the force and effect of law but may provide guidance as to the role of advance directive legislation and does not include any restrictive provisions regarding ANH.

A focus on statutory law is valuable. In our experience, advance directive legislation is often mistakenly perceived as establishing the only legally permissible mechanism for determining decision-making standards and procedures. This may be because of the seeming straightforwardness of the statutes and the promise of provider immunity. However, most advance directive statutes, and decisions by some courts, clarify that these statutory provisions are cumulative with existing law and should not preempt common law rights and prerogatives. As such, constitutional and common law authority should provide an equally valid legal basis for decisions to refuse ANH.

Unfortunately, it is likely that healthcare providers and even many attorneys do not completely understand the intricacies of the law in certain states.

A limitation of this study is the inability to determine how these legal standards affect clinical care. Application of the law is likely to vary depending on the provider, attorney, healthcare setting, or degree of advocacy for a particular patient. Specific providers may fail to understand the law or decide to ignore it. The practice setting (home, hospital, nursing home) could also affect whether the standards are correctly applied, because legal oversight might be greater in one setting than another. Healthcare providers may misunderstand the medical indications for ANH and incorrectly explain the clinical situation to patients or surrogates. Recent reviews attempting to clarify these misunderstandings emanated from this concern.

There are possible explanations for the finding that ANH is viewed differently under the law. First, lawmakers may misunderstand the clinical aspects of ANH, specific diseases, or the profound defects that exist in advanced dementia. A commonly misunderstood issue is the nature of dying without ANH. The Illinois living will statute excludes refusal of ANH if this “would result in death solely from dehydration or starvation rather than from the existing terminal illness,” and similar language sometimes occurs on advance directive forms or instructions. Use of the term “starvation” can be emotionally laden and likely to imply that forgoing ANH leads to a painful death. It is never possible to know with certainty what a dying person experiences if he or she is unable to communicate, but there is no evidence that dying without ANH is painful. Laws in some states prohibit forgoing ANH if it is necessary for “comfort care,” implying that ANH may be important for symptom relief in dying patients. Although

<table>
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<tr>
<th>State</th>
<th>Specific Check-Off on Advance Directive Form To Refuse ANH</th>
<th>Implies ANH Might Be Needed for Comfort Care</th>
<th>Contains “Malnutrition” or “Starvation” Language</th>
<th>Complex or Confusing Provisions</th>
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A limitation of this study is the inability to determine how these legal standards affect clinical care. Application of the law is likely to vary depending on the provider, attorney, healthcare setting, or degree of advocacy for a particular patient. Specific providers may fail to understand the law or decide to ignore it. The practice setting (home, hospital, nursing home) could also affect whether the standards are correctly applied, because legal oversight might be greater in one setting than another. Healthcare providers may misunderstand the medical indications for ANH and incorrectly explain the clinical situation to patients or surrogates. Recent reviews attempting to clarify these misunderstandings emanated from this concern.

There are possible explanations for the finding that ANH is viewed differently under the law. First, lawmakers may misunderstand the clinical aspects of ANH, specific diseases, or the profound defects that exist in advanced dementia. A commonly misunderstood issue is the nature of dying without ANH. The Illinois living will statute excludes refusal of ANH if this “would result in death solely from dehydration or starvation rather than from the existing terminal illness,” and similar language sometimes occurs on advance directive forms or instructions. Use of the term “starvation” can be emotionally laden and likely to imply that forgoing ANH leads to a painful death. It is never possible to know with certainty what a dying person experiences if he or she is unable to communicate, but there is no evidence that dying without ANH is painful. Laws in some states prohibit forgoing ANH if it is necessary for “comfort care,” implying that ANH may be important for symptom relief in dying patients. Although
some statutes did refer to “comfort care” with regard to any medical treatment. ANH was the only treatment to which this standard was specifically applied (Table 2). Several authors have critically reviewed the question of whether ANH is ever palliative and have failed to find any evidence that ANH contributes to comfort in dying patients. To the contrary, ANH may reduce comfort significantly.

Individual attitudes based on religious or other personal beliefs may also play a role in the development of separate legal standards by lawmakers, just as attitudes may affect decisions by any individual. Examples of these beliefs include that feeding by tube is “ordinary care,” like providing food and water, or that forgoing artificial feeding amounts to “killing the patient” as opposed to allowing the person to die by a natural process. Advance directives provide an opportunity to make individual choices about specific treatments, such as ANH, blood transfusions, mechanical ventilation, antibiotics, or others, and the law must clearly enable individual beliefs to be represented. However, ANH is the only life-sustaining treatment singled out by some state statutes with more-stringent standards for refusal. This may unduly burden or disregard the belief of those who believe that such refusal is morally and ethically permissible.

CONCLUSION

Despite judicial and ethical consensus that ANH is equivalent to other life-sustaining treatments, statutory provisions in certain states may make it more difficult to refuse this treatment on behalf of patients who lack capacity. Likewise, such provisions may place a burden on good practice by making providers fearful of the law. It is important that legislation crafted to protect incapacitated persons not be based on misconceptions regarding the medical aspects of ANH. Likewise, legislation that gives voice to those who feel ANH must always be given must not at the same time unduly burden those who believe that such refusal is morally and ethically permissible. Finally, legislators and the courts should ask whether statutory provisions that delineate higher standards for refusing ANH are appropriate in light of case law authority that ANH not be treated differently and in light of statutory language that preserves those common law rights.

REFERENCES

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42. The Right To Die: A challenge to our values. Fourth Quarter, 2000.
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46. Ciocon JO, Silverstone FA, Graver M et al. Tube feeding in elderly patients: Investigation of a practice by making providers fearful of the law. It is important that legislation crafted to protect incapacitated persons not be based on misconceptions regarding the medical aspects of ANH. Likewise, legislation that gives voice to those who feel ANH must always be given must not at the same time unduly burden those who believe that such refusal is morally and ethically permissible. Finally, legislators and the courts should ask whether statutory provisions that delineate higher standards for refusing ANH are appropriate in light of case law authority that ANH not be treated differently and in light of statutory language that preserves those common law rights.
Appendix 1. Statute Citations

Alabama
Durable Power of Attorney Act, Ala. Code § 26–1–2

Alaska
Rights of Terminally Ill Act, Alaska Stat. §§ 18.12.010 to 18.12.100

Arizona

Arkansas
Durable Power of Attorney for Health Care Act (H.B. 1331, Effective 4/15/99)

Colorado
Medical Treatment Decision Act, Colo. Rev. Stat. §§ 15–18–101 to 15–18–113

Delaware
Health-Care Decisions Act, Del. Code Ann. tit. 16, §§ 2501 to 2518

Georgia

Hawaii
Uniform Health-Care Decisions Act, (H.B. 171, Effective 7/1/99)

Idaho
Natural Death Act, Idaho Code §§ 39–4501 to 39–4509

Illinois

Indiana

Kentucky

Minnesota

Missouri

Appendix 1. Statute Citations (Continued)

Nevada

New Hampshire

New Mexico

New York
Health Care Proxy Act, N.Y. Pub. Health Law §§ 2980 to 2994

North Dakota
Uniform Rights of the Terminally Ill Act, N.D. Cent. Code §§ 23–06.4–01 to 23–06.4–14
Durable Powers of Attorney for Health Care Act, N.D. Cent. Code §§ 23–06.5–01 to 23–06.5–18

Ohio
Modified Uniform Rights of the Terminally Ill Act, Ohio Rev. Code Ann. §§ 2133.01 to 2133.15
Power of Attorney for Health Care Act, Ohio Rev. Code Ann. §§ 1337.11 to 1337.17

Oregon
Health Care Decisions Act, Or Rev. Stat. §§ 127.505 to 127.640

Rhode Island
Rights of the Terminally Ill Act, R.I. Gen. Laws §§ 23–4.11–1 to 23–4.11–14

South Carolina

South Dakota
Living Will Act, S.D. Codified Laws §§ 34–12D-1 to 34–12D-22

Tennessee

Washington
Natural Death Act, Wash. Rev. Code Ann. §§ 70.122.010 to 70.122.920
Durable Power of Attorney Act, Wash Rev. Code Ann. §§ 11.94.010

Wisconsin
Declaration to Physicians and Do-Not-Resuscitate Orders Act, Wis. Stat. Ann. §§ 154.01 to 154.29

(continued)
Appendix 1. Statute Citations (Continued)


Appellate Case Citations

Arizona

California

Connecticut

Delaware
- In re Tavel, 661 A.2d 1061 (Del. 1995).

Florida
- In re Guardianship of Browning, 568 So. 2d 4 (Fla. 1990).

Georgia

Illinois
- In re Estate of Longeway, 133 Ill. 2d 33, 549 N.E.2d 292 (1989).

Indiana

Kentucky
- DeGrella v. Elston, 858 S.W.2d 698 (Ky. 1993).

Maine
- In re Chad Eric Swan, 569 A.2d 1202 (Me. 1990).
- In re Gardner, 534 A.2d 947 (Me. 1987).

Maryland

Massachusetts

Michigan

Missouri
- Cruzan v. Harmon, 760 S.W.2d 408 (Mo. 1989).

Appendix 2. Appellate Case Citations

New Jersey

New York
- In re Westchester County Medical Center (O'Connor), 72 N.Y.2d 517, 534 N.Y.S.2d 886, 531 N.E.2d 607 (1988).
- Delio v. Westchester County Medical Center, 129 A.D.2d 1, 516 N.Y.S.2d 677 (2d Dep't 1987).

North Carolina

Ohio

Pennsylvania

Virginia

Washington

Wisconsin

United States