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|               |                                                                                                   |
|---------------|---------------------------------------------------------------------------------------------------|
| Item Type     | Article                                                                                           |
| Authors       | Welie, Jos V M                                                                                    |
| Publisher     | The Online Journal of Health Ethics                                                               |
| Rights        | With permission of the license/copyright holder                                                   |
| Download date | 2026-09-16 15:02:23                                                                               |
| Link to Item  | <a href="http://hdl.handle.net/20.500.12424/176389">http://hdl.handle.net/20.500.12424/176389</a> |

# Pitfalls of Legal Regulation to Improve End-of-Life Care. The Example of Artificial Nutrition and Hydration

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## Abstract

Biomedical advances nowadays enable physicians to keep patients hovering at the brink of death for many years. These new technologies have evoked challenging ethical dilemmas that test society's moral resources. But some have been unwilling to patiently search for new moral wisdom, believing a bold stance is required and they are using legal means to achieve their goal. Attempts to legalize physician assisted suicide and euthanasia are one example, and the literature is replete with analyses of these practices. Far less attention has been paid to opposite attempts at legally enforcing life-sustaining medical interventions. In the mid 1990s, a group called "Nebraskans for Humane Care" sought to amend the Nebraska Constitution to require that nutrition and hydration is administered to any person and with any means available. In this article, the history behind and the text of the proposed amendment is critically analyzed, revealing the serious consequences that adoption of such legal regulation of medical treatment can have.

### **Pitfalls of Legal Regulations to Improve End-of-Life Care**

Never before in the history of mankind have advanced societies been able to keep people hovering at the brink of death for many years, even decades, unable to sustain themselves, kept alive only by advanced medical technologies. These new technologies have evoked very complex and challenging ethical dilemmas that test society's moral resources. With it, the ethical question has arisen whether the fact that one can do so, also means that one morally must do so. This is a most challenging ethical question, which has put society's moral resources to the test. Thus, many contemporary patients, their physicians, family members and care givers are searching for moral truth, planning, pondering, and praying.

But some have been unwilling to seek patiently, believing a bold stance is required. There are those who argue that physicians, having created the problem of patients hovering between life and death, should provide patients with an expedient way out, either by assisting in patients' suicides or by assuming final responsibility and actually ending patients' lives. The states of Oregon and Washington have legalized physician assisted suicide (PAS), Belgium legalized euthanasia, and the Netherlands decriminalized both. Then there are those who believe this answer is contrary to the fundamental dignity and sacredness of human life. They do not believe human life is ever *not* worth living, shun discussions about forgoing life-sustaining medical treatments, and have, likewise, resorted to the law to propel their perspective. In the case of Terri Schiavo, her parents managed to continue the provision of medically administered nutrition and hydration for approximately seven years by fighting its withdrawal in court (Cerminara & Goodman, 2006). In the second half of this decade, a group called "Nebraskans for Humane Care Committee" sought to amend the constitution of the State of Nebraska, requiring, by force of law, that nutrition and hydration in principle is administered to any person and with any means available.

This article reviews the Nebraska proposal, submitting both the text of the amendment and the political process that surrounded this event to close scrutiny. This amendment was admittedly a rather local initiative, concerning only the 1.7 million inhabitants of the State of Nebraska. Moreover, in the end, it did not become positive law. However, the ethical discussion of that initiative serves two larger purposes. First, the examination of the amendment text itself shows that it is truly difficult to write good laws about end-of-life medical care. Although this author – and everybody else known to this author – has failed to gain first-hand insight in the intentions of the individuals who wrote this particular amendment, for they have steadfastly refused to answer all inquiries, there is no reason to believe that they intended the potential harms entailed in this amendment. Instead, these dangers are largely the result of the limitations of the legislative endeavor itself.

Second, this review of the legislative process will show that this amendment was not a peculiarly Nebraskan idiosyncrasy. Instead, it appears that Nebraska was simply a testing ground for a political experiment, conceived of and operationalized by individuals and agencies, none of which were Nebraskan. The analysis serves to underscore the more general caveat against relying on legal means to resolve urgent and complex medical-ethical quandaries, such as those evoked by emerging medical treatments and life-sustaining technologies.

As mentioned, the proponents of this Nebraskan initiative refused to engage in public or private discussions about the proposed amendment. Consequently, the analyses of this HCA presented here are inevitably biased by the perspectives that have been voiced in a variety of media by opponents of the amendment. The virtual absence of public comments and explanations by those individuals who have first-hand knowledge about this initiative has also rendered it difficult to provide a complete and verifiable rendering of the facts.

### **The 2006 Petition Drive**

In the summer of 2006, a large number of signature collectors went in search of registered voters who might be willing to support a proposal to amend the Constitution of the State of Nebraska. Specifically, the amendment would add a new section 30 entitled “Humane Care.” The goal was to collect sufficient signatures to have the Humane Care Amendment (HCA) included on the ballot for the elections slated for November of that same year.

The HCA’s full title, “To Amend Article I of the Constitution of Nebraska by adding a new section 30: Humane Care,” probably sufficed to sway a good number of Nebraskans. After all, who is *against* humane care? It is unknown what additional explanation the signature collectors would give next to persuade the hesitant citizen. However, the text of the official “object clause” that was printed right below the amendment’s title is as follows:

This measure would humanely protect any person, regardless of race, religion or ethnicity, age, disability or gender, from the withholding of food or water by any institution with a legal duty of care (such as a hospital, orphanage, prison or nursing home) if the withholding of that nourishment could reasonably result in death from dehydration or starvation. This measure allows for honoring the will of any person who has expressly requested withholding food and water under specific conditions or delegated to relatives that decision, by means of a valid advance directive given previous. (Nebraskans for Humane Care Committee 2006b)

The object clause contains two sentences. The first describes what the amendment would require if accepted. When reduced to its essence, this sentence reads: “This measure would humanely protect any person .... from the withholding of food or water .... if the withholding ... could reasonably result in death from dehydration or starvation.”

The supposed “humaneness” of the amendment is underscored once more by the fourth word, immediately followed by the claim that the amendment actually “protects” people from some sort of harm. The harm turns out to be a deprivation (“withholding”) of a good, indeed a very basic good (i.e., food and water). Apparently – for otherwise there would not have been a need to amend the Constitution – health care providers in the State of

Nebraska so often deprive patients from these basic goods that a most forceful measure is in order, that is, a constitutional amendment. Fear is sown. The sentence ends by adding more fuel to the flame: If the petition fails, people may end up dying “from dehydration or starvation.” The same frightening language (and worse) surfaced on the website of the Nebraskans for Humane Care Committee (NHCC) which sponsored the amendment (Nebraskans for Humane Care Committee 2006b).

The second sentence of the object clause, in contrast, appeals to the value of individual freedom of choice, a building block of American culture that is particularly dear to many citizens of the State of Nebraska. The object clause assures those voters who are suspicious of any government interference with their own health care that their choices will be respected, including a refusal of food and water.

The combination of the title, object clause, and any explanation added by the signature collectors themselves is likely to have been sufficient to persuade most of the 137,000 signatories. Few people would have read the full text of the HCA, which is a dense and potentially confounding piece of legal writing:

The fundamental human right to food and water should not be denied to any person, regardless of race, religion, ethnicity, nativity, disability, age, state of health, gender or other characteristic: No entity with a legal duty of care for a person within its custody (including a hospital, orphanage, foster home, nursing home, sanitarium, skilled nursing facility, prison, jail, detainment center, corporation, business, institution or individual) may refuse, deny, or fail to provide food and water sustenance and nourishment, however delivered, to any such person if death or grave physical harm could reasonably result from such withholding and the person at risk can metabolize. Any such person so threatened with dehydration or starvation, any relative of such person, such person's legal guardian or surrogate, any public official with appropriate jurisdiction, or any protection and advocacy or ombudsman agency shall have legal standing to bring an action for injunctive relief, damages and reasonable attorney's fees to uphold this standard of humane care. This section does not prohibit honoring the will of any person who, by means of a valid advance directive record, has fully, expressly, and personally either authorized the withholding of food or water from himself or herself under specific conditions, or delegated that decision, under specific conditions, to one or more relatives or to another person unrelated to the entity with a legal duty of care.

What is worse, the actual amendment does not quite live up to the assurances included in the object clause. As will be shown shortly, instead of the benefits guaranteed by the first sentence of the object clause, the text of the amendment actually entails many harms. And the respect for patient's autonomy promised in the second sentence is severely restricted by the amendment itself. And yet it is the amendment, not the object clause, that would have become law if adopted.

### **Ethical Analysis of the Proposed Amendment**

The 226 word HCA consists of three sentences only, each delineating a distinct part of the HCA. The first part describes the specific behavior that is to be prohibited. The second part enumerates who has the power to seek enforcement of that prohibition. And the third part lists some exceptions to the prohibition. This analysis commences with Part 2 because it is largely procedural in nature and, as such, the least controversial of the three. Subsequently, Part 1 will be examined, which is ethically the most problematic. Finally, it will be shown that patients' freedom of choice ultimately is much more limited than Part 3 appears to promise.

#### *Part 2: Legal Force*

The middle sentence of the HCA in essence outlines who is authorized to take legal action to enforce the proscribed behavior, or to seek damages if it has been violated:

Any such person so threatened with dehydration or starvation, any relative of such person, such person's legal guardian or surrogate, any public official with appropriate jurisdiction, or any protection and advocacy or ombudsman agency shall have legal standing to bring an action for injunctive relief, damages and reasonable attorney's fees to uphold this standard of humane care.

Expectedly, the first person included in this list is the patient. It is equally reasonable to include in this list "such person's legal guardian or surrogate," in case the patient has

become incompetent and is no longer able to protect his or her rights. Whereas this legal representative could be a family member, it does not have to be one.

But the amendment actually allows any patient relative to act as a self-appointed advocate. This is consistent with the absence in Nebraska end-of-care law of a so-called “familial consent” statute that would have regulated the order in which relatives may decide on behalf of incompetent family members in the absence of a legally appointed surrogate. At odds with Nebraska law, however, is the HCA’s allowing such a relative, even a very distant one, to intervene while the patient is still perfectly competent to make health care decisions. Or if the patient has become incompetent, this relative may come forward to contradict the patient’s legally appointed surrogate. The fact that *any* relative of such person is so authorized can easily result in a single relative upsetting a carefully negotiated palliative care plan for grandmother, even if it happens to be a distant cousin with an ax to grind against one of the other family members, or the estranged son who now converts his deep sense of guilt into a dramatic demand that every life-sustaining treatment is tried. This increases the chance of family in-fighting and communication breakdowns, already a prevalent problem in end-of-life care planning (Lang & Quill, 2004; Swetz, Crowley, Hook & Mueller, 2007; Winter & Parks, 2008).

To this already expansive list of authorized individuals are added three groups of “third persons.” Mentioned first is (a) “any public official with appropriate jurisdiction”. The state most certainly has a justifiable interest in human life and must pay particular attention to the protection of vulnerable individuals who are unable to safeguard their own rights. Unfortunately, there are also ample examples of state officials, such as attorneys general, having intervened in the decision-making processes surrounding patients’ end-of-life care, insisting on the continued artificial nutrition and hydration (AN&H) regardless whether such continuation was medically indicated or even if it caused the patient “grotesque harm”

according to the physicians involved, as happened in the case of Sheila Pouliot (Ouellette, 2004).

Whereas the first category of individuals empowered by the HCA to intervene is restricted by the limiting clause “with appropriate jurisdiction,” the second and third categories are very broadly defined, giving license to (b) any protection and advocacy agency and (c) any ombudsman agency. Because the HCA does not define what justifies such a label, a small group of vitalist crusaders that calls itself a protection agency could qualify or even the company that manufactures the machinery for artificial nutrition could qualify when it presents itself as an advocacy agency.

Part 2 is also problematic for a very different reason, that is, the language used. The HCA references the person “*so threatened with dehydration or starvation.*” As pointed out earlier in the discussion of the object clause, these are all very negative terms. The word “threat” suggests a serious danger. “Dehydration” and, even more so, “starvation” connotes severe suffering. Because of that connotation, it is impossible to argue against it. Physicians cannot defend their proposal to stop artificial nutrition in terms of “I favor starving your mother”. What needs to be determined in any given case is whether such a withdrawal of the AN&H does indeed equate to starvation as that process is commonly understood. If it is, it is necessarily immoral. But if it is not, it may well be a moral course. To simply label it as a form of starvation begs the question. The same is true when the text of the HCA next contrasts the alleged threat with “*this standard of humane care.*” If administration of AN&H is indeed “humane care” in all circumstances, one is ethically obligated to provide it. But whether in fact it is always humane, is exactly what is at stake.

#### *Part 1: The Main Provision*

The main part of the HCA is contained in the first sentence. This lengthy sentence itself consists of four parts:

[1.1] “The fundamental human right to food and water should not be denied to any person...

[1.2] No [caregiver] ... may refuse, deny, or fail to provide food and water sustenance and nourishment,

[1.3] however delivered, ...

[1.4] if death or grave physical harm could reasonably result from such withholding and the person at risk can metabolize.” [numbers added]

Part [1.1] casts the provision of food and water in rights language and assigns each Nebraskan a right to these goods. This raises the question whether Nebraskans currently do not have such a right. In fact, they already do. The existence of such a right is evidenced by various other laws, such as the “Rights of the Terminally Ill Act”. This Act, which regulates living wills, in Section 20-408 stipulates that these regulations “...shall not affect the responsibility of the attending physician or other health care provider to provide treatment, including nutrition and hydration, for a patient's comfort care or alleviation of pain.” Even more explicitly, Section 30-3426 of the Nebraska Revised Statutes insists that “[a power of attorney document will not impact a patient’s]... right to ...the usual and typical provision of nutrition and hydration.”

The authors of the HCA could counter that the amendment wishes to underscore that this right to food and water is a “fundamental” right. But that language raises more questions than it answers. Most importantly, the wording would imply that every human person has this right and not just terminally ill patients. Given that many millions of US citizens suffer from chronic hunger, one could argue that this amendment tasks the state to make available much needed nutrition and hydration for them, even though this was most surely not intended by the drafters of the HCA.

More troublesome is the amendment's limiting itself to food and water as stipulated twice in both [1.1] and [1.2]. Why this limitation? Why, for example, are patients not given a right to oxygen? Chemically, oxygen is as much needed as carbohydrates. One cannot metabolize carbohydrates without oxygen. And it would be unconvincing to argue that suffocation from lack of oxygen is more "humane" than starvation. Along similar lines, one has to wonder why dialysis is not included. From a biological perspective, equally important as the uptake of nutrients is the removal of toxic waste from the body.

More troublesome yet are the methods of delivery mentioned in part [1.3]. In effect, the HCA does not specify appropriate methods of delivering nutrition and hydration, but mandates that care givers use any method available ("...", however delivered, ..."). This would suggest that not only common china and silverware are to be used to assist patients who cannot eat themselves, but also intravenous lines and tubes, in short, medical means of administration. Moreover, the HCA does not rule out the use of a funnel either, nor the use of force or restraints when patients object to the caregivers' feeding efforts. Yet, if patients with Alzheimer's dementia are confused by the feeding tube and continue to pull it out it, it would seem less humane to strap them down for the remainder of their days than to allow nutritional deficiencies to occur.

Part [1.4] spells out the conditions under which AN&H must be administered. This part of the sentence contains three Boolean connectors (IF, AND, OR), leading to the following break-down (see Figure 1).

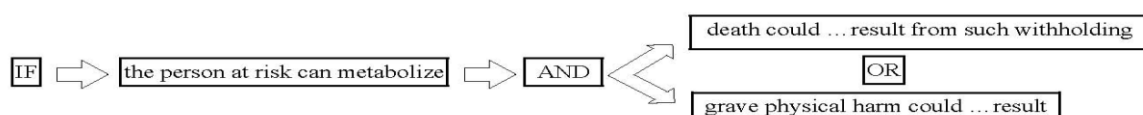


Figure 1

This break-down makes clear that a necessary condition of legally mandated nutrition is the person's ability to metabolize. But what does "metabolize" mean? When used in the context of biology, as it is here, to metabolize means to "process chemically".

Metabolization is an ongoing process in every cell of the human body. Parts of the human body, such as the skin, continue to metabolize even after the person's death. This would lead to the conclusion that even if the person is dying, when all organ systems are shutting down and the body is itself resisting more food and water intake, but is still metabolizing, the patient must be force-fed. One can only wonder whether the drafters of the HCA intended that conclusion. Ultimately the problem is linguistic. Trying to capture the complexity of human dying in a single term inevitably will lead to dangerous simplifications.

In addition to the patient still metabolizing, the HCA demands that one of two other conditions be met. The first of these is that "death could reasonably result from such withholding ...". This stipulation is odd because artificial nutrition and hydration is *only* indicated when patients cannot eat or be fed orally; not feeding these patients will inevitably result in their death. Remarkably, the HCA does not say: "...if death could reasonably result *sooner* from such withholding..." So a patient who has three weeks left to live with or without AN&H must still be force-fed. At least, the federal Baby Doe Amendment from 1985, which was intended to protect severely disabled newborns from medical abandonment, only requires the administration of "appropriate" nutrition and hydration, which "in the treating physician's (or physicians') reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such [life-threatening] conditions" (45 C.F.R. § 1340.15 Services and treatment for disabled infants; Moss, 1987). No such provision is included in Nebraska's HCA.

Alternatively, food and water must be administered "if ... grave physical harm could ...result from such withholding." The amendment, thus, is *only* concerned with harm that

may happen if food and water is *not* given. It is *not* concerned with what harm may happen if food and water *is* given. The HCA reflects – and appeals to – commonly held fears of dying from dehydration and starvation. It is these fears that make hunger strikes powerful political instruments. But the HCA fails to acknowledge that many patients who are dying no longer desire food or water, and choose to severely limit or altogether forego their food intake, reporting no lasting sense of hunger (Winter, 2000). This makes sense because the dying body biologically no longer has much use of new nutrients. It is even uncertain that terminally ill patients will live longer if they are fed artificially; no improvement in survival has been found so far in either patients with advanced cancer or those with advanced dementia (Gillick, 2000; Garrow et al 2007; Hallenbach, 2002; Mitchell, 2007).

The HCA furthermore fails to take into account the harms that can result from forcefully administering food and water. These range from discomfort from the feeding tubes and lines, to abdominal pain, nausea, and vomiting, particularly in the case of intestinal obstructions. By now, it has also become clear that artificial nutrition, particularly in patients with advanced Alzheimer's dementia, places the patient at a significant risk of pneumonia (food pumped into the intestinal system makes its way from the stomach back up the esophagus and the down the trachea into the lungs); thus, the artificial nutrition may actually shorten patients' lives. Forced administration of fluids, likewise, can be harmful. A fluid overload can result in swelling of legs, abdomen and other body parts; in extreme situations the body may try to get rid of the unneeded fluids by weeping through the skin. The extra fluid can also induce congestive heart failure and difficulty breathing from water retained in the lungs. In effect, the patient may end up drowning (Casarett, Kapo & Caplan 2005; Cervo, Bryan & Farber, 2006; Geppert, Andrews,& Druyan, 2010; Mitchell, 2007). It is difficult to see how such a death can be considered humane.

### *Part 3: The Patient's Will*

The third part is intended to grant a legal way out to those who wish not to be treated as described above. It allows health care providers to honor:

the will of any person who

[3.1] by means of a valid advance directive record,

[3.2] has fully, expressly, and personally

[3.3a] either authorized the withholding of food or water from himself or herself under specific conditions,

[3.3b] or delegated that decision, under specific conditions, to one or more relatives or to another person unrelated to the entity with a legal duty of care [numbers added].

This section appears to provide those unwilling to be force-fed ample opportunities for making their wishes known. But on closer inspection, patients' choices are actually quite limited. The HCA could have simply stated what is contained in [3.3a] and nothing more. This would still have been a digression from standard medical ethics and law. For a patient does not have to authorize the *forgoing* of treatment before it may be stopped; rather, the patient must *consent to treatment* before it can be initiated or continued. But at least it would not have limited the means by which patients can withhold their consent. Instead, the HCA in [3.1] specifies exactly how a patient can do so, namely by means of an advance directive record (AD). There are two kinds of ADs: living wills (in which the patient provides consent to medical treatment – or withholds such consent – in advance of becoming incompetent), and power of attorney documents (in which the patient authorizes another person to provide a substitute consent – or withhold it – in advance of becoming incompetent). The manner in which Part 3 is phrased makes clear that [3.3a] and [3.3b] are the two advance directives already listed in [3.1].

When a law specifically states which methods can be used to refuse artificial nutrition and hydration, other methods are thereby disallowed. For if the legislators had intended to allow other methods of refusal as well, they would have included those in the list of approved means. This is the same as a mother telling her son that he may color the side-walk using chalk or water paint. If she had not listed any methods, all methods would have been potentially admissible. But by listing only two methods of coloring, spray paint and all other methods were thereby excluded. Likewise, the HCA, by specifically listing ADs as the means of expressing one's refusal of treatment, thereby excluded all other methods.

The consequences of this exclusion are troubling. For it means that only people who have issued an AD – a mere one-third of Nebraska's population according to the latest statistics (Nebraska Coalition for Compassionate Care, 2004; Nebraska Hospice and Palliative Care Partnership, 2007) – may be spared the kinds of suffering described above if they end up suffering from Alzheimer's dementia and are force-fed. And they would only be spared such fate if they happen to have addressed artificial nutrition and hydration specifically in their AD, as required by the applicable Nebraska statutes. Furthermore, people who never were able to issue an AD are always going to be force-fed. This includes patients who are minors or who have been incompetent from birth because of mental disability. For the HCA does not allow parents, guardians, or other proxies to make decisions regarding artificial nutrition and hydration on behalf of these vulnerable patient populations. Finally, one has to wonder what the rights of competent adults are under the HCA. An AD only takes effect once the patient becomes incompetent. It would appear that the authors of the HCA even wanted to curtail the right of competent adults to withhold consent for these medical interventions.

It is quite remarkable that this kind of curtailment of individual rights had any chance of passing in the State of Nebraska (Furlong, 2007). Many of the 137,000 signers of the

petition may not have realized what the HCA's implications actually were and might have been shocked to learn what they just signed in favor of. Indeed, the question arises who was behind the petition drive. As mentioned, the petition was formally initiated by a group called "Nebraskans for Humane Care Committee." But who were the members of this new group that appeared to have been created solely for the purposes of this amendment?

### **The Origins and Fate of the Amendment**

Nebraska is home to two medical centers (one of which is Catholic), each with medical, dental, nursing, pharmacy and health sciences schools, as well as units specifically dedicated to the study of health care ethics and policy. But as it turned out, as far as this author could determine, none of their departments or faculty members were involved in this initiative or even consulted. Neither were professors in the state's two law schools. Nor were any of the state's professional organizations, including the Nebraska Hospice and Palliative Care Partnership, which has significantly improved humane end-of-life care in the state. If no academic and no health care institution or association was behind or even consulted in the drafting of the HCA, was it maybe initiated by a faith-based organization? Given Pope John Paul II's 2004 address and subsequent statements from Roman Catholic authorities such as the Congregation for the Doctrine of the Faith (2007), confirming the Pope's statement that nutrition and hydration in principle must always be administered using advanced medical technologies if necessary (Bradley 2009), maybe the HCA originated at the Nebraska Catholic Conference's Pro Life Office? But the HCA did it not originate there either; the Office wasn't even consulted but simply presented with a *fait accompli*: The amendment was ready to go, and the bishops were merely given the choice to be either in favor or against the initiative (Aksamit, 2006).

If apparently no known entity inside of the State of Nebraska was the driving force behind this initiative, where did it originate? Attorney Thomas Mann, the sole identified in-

state representative of the Nebraskans for Humane Care Committee, consistently refused to answer questions. Inquiries left on the NHCC electronic contact form, likewise, were met with deafening silence. This experience was shared by any and all Nebraskans who were concerned about the HCA and trying to find out who was behind the initiative and why.

The only published accounts on the origins of the HCA appear to be the research undertaken by Hart Williams (2006), who published his findings on his website, and by journalists Nichole Aksamit and Paul Goodsell (2006) of the Omaha World Herald (OWH) newspaper. Based on these two sources, it appears that the amendment was drafted by several out-of-state lawyers, including Steven Safranek (who at the time was a professor of law at the Catholic Ave Maria University in Michigan), and Wesley Smith (a lawyer from California who has written extensively about end-of-life care from a Catholic perspective). Smith has confirmed his involvement in the drafting process in a 2006 blog (Smith, 2006). When interviewed by the OWH journalists, both of these legal scholars insisted that the amendment was not conceived by them, and neither appeared to know exactly where it originated and why this initiative was targeted at the State of Nebraska. As argued above, state law already acknowledges the right of Nebraskans to receive nutrition and hydration when medically indicated.

Using publicly available campaign statements, made available by the Nebraska Accountability and Disclosure Committee (2006), both Williams and the OWH journalists followed the money trail, seeking to uncover who had financed the document preparation and the collection of the more than 137,000 signatures. The fact that large sums of money are donated to advance a particular moral view on end-of-life care through political means in and of itself is not unusual. Eisenberg (2005) has traced the funds that enabled the family of Terri Schiavo to protract their legal fight for many years. Conversely, the recent 58%-42% vote in favor of legalizing physician assisted suicide in the State of Washington (Washington

Secretary of State, 2009) may have been the result of advocates' access to \$4.3 million whereas opponents had to make do with only \$1.6 million in funds raised (Public Disclosure Commission, 2009). What renders the Nebraska situation rather unusual are the geographical locations of the financiers and their apparent lack of interest in the HCA itself.

Williams and the OWH journalists discovered that all of the funds were funneled to Nebraska via an organization called "America at Its Best," which is located in the State of Montana. Mr. Laird Maxwell of Boise, Idaho, who heads this organization, explained to the OWH journalists that the amendment was not his idea, but pitched to him. Nor did he know why Nebraska. In fact, he appeared not to even know attorney Thomas Mann, the single identified Nebraskan involved whose name was on the petition as the official contact person.

Since "America at Its Best" only funneled the funds, the source had to be elsewhere. The OWH traced the money back to various donors in two more states, Virginia and New York. But the bulk of the funds (\$835,000) turned out to be donated by "Americans for Limited Government" (ALG), located in Chicago, Illinois. Paradoxically, this organization's principle purpose is to *reduce* the size of federal, state and local governments across the nation. Its president, John Tillman, insisted that ALG did not have a specific position on the issue of artificial nutrition and hydration; indeed, he had not even read the amendment (Aksamit & Goodsell, 2006). Likewise, Mr. Eric O'Keefe, chairman of ALG's Executive Committee, explained that the ALG had donated funds to support two amendments, the HCA and the proposal to cap state spending ("Stop Over Spending Nebraska"); how to allocate the donated funds between these two proposals was left to their Nebraskan allies. Then again, Mr. O'Keefe must have known more than he was ready to admit. For it was his own wife, Ms. Leslie Graves, who started "Renewal Voter Outreach," the Wisconsin based company that was paid \$1.4 million to gather signatures for the two Nebraska petitions (Aksamit & Goodsell, 2006).

As mentioned, some 137,000 signatures were collected in the summer of 2006. However, the collection was subsequently contested by the State of Nebraska, which had reason to believe that a significant number of the signatures were not valid such that the HCA did not meet the level of support required by Nebraska law (Gale, 2006). A constitutional amendment requires signatures of 10% of the total number of voters who have registered for the upcoming general election at which the proposed measure will appear on the ballot. In addition, the signatures must represent at least 40% of Nebraska's 93 counties, and in each of those counties, signatures must equal at least 5% of the registered voters. The measure was, therefore, not placed on the ballot for the November 2006 elections. Court proceedings ensued and dragged out over more than a year. Finally in March of 2008, the NHCC decided to withdraw its opposition to the State's refusal to accept all 137,000 signatures. The NHCC officially dissolved on February 4, 2008 (Nebraska Accountability and Disclosure Committee, 2008). Why the NHCC did so after spending so much money and fighting such a protracted battle remains unclear, though lack of further out-of-state funding appears to have been a consideration (Deputy for Elections, Office of the Nebraska Secretary of State, personal communication, March 7, 2008).

### **Lessons to be Learned**

Throughout the history of medicine, those concerned about medical-ethical issues have attempted to regulate the behavior of physicians through the power of law. With the rather sudden and dramatic increase in medicine's effectiveness over the course of the 20th century, raising even more ethical questions and quandaries, such attempts at legal regulation have increased significantly. Some of these laws have successfully protected public interests. Notable examples are laws on the licensure of health care providers, laws requiring prompt reporting of highly infectious illnesses, and those regulating the testing of new drugs. But

many laws attempting to regulate medical practice, and likewise jurisprudential interventions, have failed to yield truly satisfactory results.

Among the root causes of this failure is the evident fact that the vast majority of lawyers have neither studied nor practiced medicine or another health care field. Consequently, they have limited familiarity with the complexities of medical care and health care systems, the process of medical decision making, the challenge of diagnosing and treating under conditions of fundamental and inevitable uncertainties, and the nature of the therapeutic relationship. The reverse is true as well. Health professionals' knowledge about the law and legal thinking tends to be very limited. Many either base their decisions on faulty legal knowledge and exaggerated malpractice fears, or they mistakenly believe that the law can yield quick solutions for medicine's thorny normative dilemmas. The aforementioned problems are further compounded when lay people who attended neither medical nor law school, such as most legislators or (in the case of a public referendum) the public at large, attempt to regulate medical practice with legal instruments.

The former problems are real but not insurmountable for they are practical in nature. More interdisciplinary courses for medical and law students, and similar continuing education offerings for practitioners in both professions would be a first step in the right direction. There is, however, a more foundational problem that concerns the very nature of these respective practices.

The practice of medicine, though informed by scientific data which enjoy a certain degree of objectivity and universal applicability, ultimately is an art. Health care is about caring for individual patients who are unique. They need treatments and care plans that are tailored to their particular physical and mental constitutions, their peculiar medical histories, their subjective experiences and expectations. Thus, medical care is largely a matter of trial and error, of experimenting and waiting, of adjusting and revising.

Law, on the other hand, is about universal principles and rules that apply to all people. It is about non-discrimination, fairness, and equal rights. Nobody can be charged unless there already exists a codified rule. And although jurisprudential interventions tend to focus on individual cases, there are strict rules for interpreting and applying the rules of law to individual cases.

This admittedly overstated comparison between medicine and law underscores how difficult it is to craft legal answers to medical problems, whether legislative or jurisprudential. Consider, for example, the issue of precedent. Whenever a particular case is decided, the court must always bear in mind that its decision in this case will and must have an impact on similar such cases that may arise in the future, including those that will be decided by different courts. In contrast, a physician trying to figure out how best to treat Mr. X does not have to worry how this decision may impact the treatment of future patients. And while physicians should learn from the successes and failures of past treatments, whether their own or those performed by other physicians, fairness does not demand that future patients are treated with the same drug or surgical intervention as past patients were.

These differences between medicine and law explain, at least in part, why the bulk of codified health law on, for example, end-of-life care only concerns patient decision making rights (e.g., informed consent, record access, confidentiality, and advance directives). There are laws on *how* to make decisions, *who* shall make decisions, and other such *procedural* aspects, but little to nothing on *what* is a good decision. The really hard, *substantive* questions, such as when to forgo further life-sustaining treatment, the admissibility of high and potentially life-threatening doses of pain killers, the use of terminal sedation, and the practice of euthanasia are rarely regulated by the law – or if so, in a very dissatisfactory manner (Ten Have & Welie, 2005).

When attempts are made to resolve complex medical-ethical quandaries by legal means, there is a risk of one of two dangers. If an attempt is made to require certain medical interventions, as happened in the Nebraska Humane Care Amendment, there is the risk of forcing physicians and other health professionals to provide these treatments even if they do more harm than good in individual cases. The records from the case of Sheila Pouliot reveal that many physicians continued to intervene medically in ways that they decried as being severely harmful to the patient, solely because of legal mandates (Ouellette 2004). The same is true, though in the reverse, for laws that prohibit medical interventions. The regulations by the Drug Enforcement Agency (DEA) that place stiff penalties on physicians who prescribe, pharmacists who provide narcotics, and nurses who administer in the absence of sound medical evidence justifying those drugs has also contributed to the undertreatment of dying patients who are suffering needlessly, even though the real risk of DEA action may be quite small (Brower 2009; Garrison & Mitty, 2010; Hellman, 2008; Quill & Meier, 2006; Jung & Reidenberg, 2006).

But it is also precarious if legal regulations completely abstain from any substantive guidelines, remaining limited to procedures only. The Dutch legalization of euthanasia is a case in point. In order for euthanizing physicians to be immune from prosecution, they have to report their cases to one of five review committees. Although these committees are required by law to assess each case using a set of substantive criteria, the only legally required source of information the committees have on which to base their assessments is what the euthanizing physicians themselves decide to report. If a physician reports the suffering was unbearable and the patient's wish was free and persistent, the committee has few grounds for questioning that judgment, which in turn explains why it takes these committees, on average, only five minutes per case to complete the kind of assessment that prior to the 2001 decriminalization used to take a full-blown prosecutorial investigation and

one or more court hearings, typically followed by at least one appeal to a higher court (Ten Have & Welie, 2005).

It is a folly to consider law and lawyers mere roadblocks to medical progress, or worse, the enemy of clinicians. It is equally misguided to expect legal solutions for normative quandaries that are intrinsic to the practice of medicine itself. In the fourth century BC, Aristotle in his *Nicomachean Ethics* already warned that one should not expect from a particular discipline more clarity, precision, or certainty than the subject admits (Aristotle, 1925). This is true of medicine. But so it is of law. Whether, when, and how long medical treatment, be it resuscitation, narcotics, or artificial nutrition, is indicated for any particular terminally ill patient is ultimately a medical question, not a legal one. Medical scientists who develop and apply ever more advanced life-sustaining and life-altering interventions, together with the patients who will undergo them, must also tackle the normative questions about their proper use, instead of simply delegating that responsibility to legislatures and courts.

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