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Flipping the Default: A Novel Approach to Cardiopulmonary Resuscitation in End-Stage Dementia

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INTRODUCTION

Much of the recent attention on Alzheimer's disease has focused on potential cures from stem cell research, but has left largely neglected an issue that has been floating in medical circles for years: What constitutes appropriate care for patients with end-stage dementia (ESD)?¹ Over the coming years, patients with ESD from Alzheimer's disease will overwhelm the healthcare system. In 2000, according to the U.S. Census, 4.5 million patients had Alzheimer's dementia; that number is expected to surge to 13 million by 2050.² Since Alzheimer's accounts for approximately 60 percent of all patients with dementia,³ we estimate about 7.5 million patients have some form of dementia today, and approximately 20 to 30 percent, or 2 million patients, have advanced forms of the disease.⁴

We will first explore the present mechanisms by which care for the elderly with ESD is decided and the problems associated with these practices. Following the well-validated clinical definition, by "ESD" we mean a chronic state that is characterized by severe neurological incapacity as demonstrated by an almost complete loss of intelligible vocabulary, loss of ambulatory function, and complete dependence on others for one's basic needs, including feeding.⁵ We will review the empirical evidence, which suggests that the large majority of patients would prefer not to receive cardiopulmonary resuscitation (CPR) in ESD as well as the evidence that such care is common. We suggest and explain the practical application of a default approach in which CPR in ESD is routinely withheld. Lastly, we will discuss how such a default can be justly applied.

ADVANCE DIRECTIVES AND SURROGACY

In a pluralistic society that values choice and tolerates difference, the individual is the ultimate decision maker in the care of her or his body.⁶ When a patient is decisionally incapacitated, such as a patient with ESD, the accepted practice is to utilize either an advance directive or a surrogate, practices that attempt to preserve the patient's autonomy.⁷ Although shared decision making is commonly advocated,⁸ the patient — or, when the patient is incapacitated, the patient's surrogate — retains practical veto power.⁹ The courts have consistently upheld this principle of self-determination,¹⁰ and legislation such as the Patient Self-Determination Act embodies this principle.¹¹

However, serious questions have been raised regarding the use of advance directives and surrogate decision makers. Advance directives, as traditionally drafted, have not proven to be very effective and have been seriously questioned.¹² The vast majority of patients do not have an advance directive, and even when a directive is present, it often has a small effect on terminal care.¹³ A traditional advance directive specifically refers to terminal illness and persistent vegetative states. Applying an advance directive to a patient with ESD is fraught with uncertainty. Patients with ESD qualify as being terminally ill but are not recognized as being so.¹⁴ It is certainly possible that families interpret advance directives broadly, for example, by not pursuing hospitalization of a loved one.¹⁵ But physicians have been reluctant to make such judgments. In addition, physicians have difficulty adhering to an advance directive unless it is supported by a surrogate.¹⁶

The alternative to an advance directive is a surrogate decision maker, who either attempts to make decisions for the incapacitated patient according to a substituted judgment or a best interest standard.¹⁷ Surrogate decision making has been considered a vital component in the care of the decisionally incapacitated. To preserve the value of individual self-determination and autonomy, a surrogate, often a family member, is assumed to know best what an individual would have wanted.¹⁸

But surrogate decision making is also imperfect.¹⁹ Proxies often do not know the patient's preferences, are selected for reasons unrelated to how well they know the views of the patient, and often make estimates of a patient's preferences that are little different from chance.²⁰ Surrogates sometimes also knowingly disregard a patient's preferences.²¹

The imperfect nature of surrogacy should not be surprising. Even competent patients often make decisions for themselves that are less than optimal due to difficulties in assessing risk, misinformation, denial, and distrust.²² Decisions that have been placed in the hands of a surrogate are further complicated by an overwhelming sense of emotion as the surrogate struggles with feelings of guilt and the psychological desire to avoid being responsible for the death of a loved one.²³ Although a patient may be willing to have life-sustaining therapy withdrawn, surrogates are generally less willing to withdraw it for a relative.²⁴ Physicians have also noted that surrogates have difficulty letting a loved one go.²⁵ These guilt-based reasons, although compelling, fall far short of preserving autonomy by the substituted judgment standard.

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT), which combined a prospective observational study of seriously ill patients with a multilayered, nurse-based communication intervention focused on documenting patients' preferences, demonstrated a disturbing disconnect between the kind of care that people want at the end of life and the care they actually receive.²⁶ Ironically, SUPPORT frequently relied on surrogates themselves to establish a patient's preferences, the very approach we question. The lack of an effect of the SUPPORT intervention on the use of aggressive interventions at the end of life may be partly explained by the fact that cognitively intact patients are certainly willing to accept some life-sustaining therapy regardless of their baseline quality of life.²⁷

However, the evidence does strongly suggest a disconnect between preferences and practice in the case of patients with ESD. When the subjects in the studies described above were asked specifically about the use of CPR in the face of ESD, their responses were dramatically different than those for cognitively intact patients. Thus, an unchallenged role for advance directives and surrogate decision making for patients with ESD is problematic because our standard methods of decision making may fail to secure patients' preferences.

PREFERENCES FOR CPR IN DEMENTIA

A review of the existing literature indicates that a large majority of the patients queried do not want CPR in dementia, including ESD. We searched Medline and conducted a search of paper bibliographies and identified studies that evaluated the use of CPR in patients with dementia. We excluded studies that evaluated preferences in states of coma or permanent unconsciousness. We included all studies that mentioned dementia, even if they did not specify the degree of dementia.

We found 15 studies that suggest that a large majority of patients do not want CPR in dementia,²⁸ and only three studies that supported a preference for CPR in dementia (see table 1).²⁹ We categorized the studies

by severity of dementia to illustrate the increasing numbers of people who preferred no life-sustaining treatments in ESD. We roughly categorized the severity of dementia as follows:

- A person with early dementia has deficits in performing complex tasks of daily life such as balancing a checkbook;
- A person with moderate dementia requires assistance with activities of daily living such as bathing;
- A person with severe or ESD has speech limited to a few words and is unable to ambulate.³⁰

The studies varied in the manner in which the subjects' preferences were obtained; some questioned subjects directly regarding the use of CPR, while others used phrases such as "life-prolonging care" (see table 1).

As mentioned above, we did find three studies that found less agreement on preferences for treatment in states of dementia. In a study by Seckler and colleagues, only 32 percent of the patients queried did not want CPR in the setting of moderate dementia, in a racially diverse sample.³¹ Caralis and colleagues found only 38 percent of 49 non-Hispanic Whites, 26 percent of 51 African-Americans, and 11 percent of 39 Hispanics did not want CPR in dementia (not otherwise described).³² Reilly and colleagues evaluated 218 elders about moderate dementia and found only 46 percent of patients did not want CPR.³³

Most of the studies were performed in elderly patients whose opinions are more likely to be shaped by experience and knowledge about dementia. One study did report that knowledge and experience with Alzheimer's disease was associated with a desire to avoid CPR in dementia.³⁴ It is also interesting that two studies reported individuals were more willing to provide CPR to others than they were willing to accept it for themselves.³⁵

Although most of the studies did not directly specify or describe a state of ESD,³⁶ we presumed that individuals who do not desire CPR in mild or moderate states of dementia would also choose not to have CPR in ESD. In fact, one study reported that patients were less willing to accept CPR as dementia advanced.³⁷ Thus, we suspect that preferences against CPR would have been even stronger if cases of ESD were clearly described.

The majority of the studies were conducted in English-speaking countries, specifically the United States, England, Canada, and Scotland. The studies were also limited in that they were done in predominantly White populations; thus, firm conclusions could not be drawn about preferences in dementia for minority populations. Studies published in the early 1990s suggested that members of minority groups, mostly African-Americans and Latinos/Latinas, may have different cultural frameworks from which to understand end-of-life decision making.³⁸ But simply because members of minority groups may work from within a different cultural framework does not necessarily mean that their preferences regarding advanced dementia will be different from the preferences of Whites. In the study by Caralis and colleagues, 90 of 140 subjects were either African-American or Latino/Latina. After discussing preferences for life-prolonging treatments, regardless of how ill they were, 61 percent of the subjects did not want life-prolonging treatment.³⁹ A more recent study that included a sizable number of minority subjects and clearly specified ESD also suggests that when the health state of ESD is accurately communicated and described, minority patients differed little from Whites regarding their preferences for medical care.⁴⁰

CPR IN END-STAGE DEMENTIA

Despite this strong consensus to forgo CPR in ESD, patients with ESD continue to receive CPR out of proportion to their preferences.⁴¹ Ahronheim and colleagues evaluated the frequency of aggressive interventions in patients who died in an acute care hospital and found that out of 80 patients with advanced Alzheimer's, 24 percent received CPR. The evidence of the use of life-sustaining procedures on patients with ESD in nursing homes is no less disturbing. Although the use of CPR is rare in nursing homes,⁴² in a study on the use of CPR in nursing homes in Milwaukee from 1986 to 1989, Duthie and colleagues found that 38 percent of the patients who received CPR had dementia.⁴³ When the charts were abstracted, the authors were struck by the degree of disability and the burden of illness from which these patients suffered, suggesting that the patients had advanced disease.

TABLE 1 Summary of Studies Evaluating Patients' Preferences of Life-Sustaining Therapy in Dementia

Study	Year	N	Characteristics	Age	Race	No CPR
ESD						
Michelson et al.	1991	44	NH, US	83 ± 6	NR	64%
Gjerdingen et al.	1999	84	NH, OP, US	80 ± 9	99% White	96%
Finucane et al.	1988	34	OP, US	73.4 mean	NR	74%
Ebell et al.	1990	339	OP, US	63.8 mean	NR	4.1/5.0 ¹
Pearlman et al.	2000	342	OP, ² NH, US	= 65 & > 65 ³	NR	± 70 to 80% ⁴
Moderate dementia						
Lo et al.	1986	94	OP, US	= 65 & > 65 ⁵	NR	71%
Everhart et al.	1990	30	VA ICU, US	64 ± 9	90% White	63%
Seckler et al.	1991	69	OP, US	78	39% White; 50% AA; 11% Latino/Latina	32%
Robertson	1993	322	OP, Scotland	< 60 & = 60	NR	75%
	1993	196	OP, Scotland	< 60	NR	73%
	1993	126	OP, Scotland	= 60	NR	78%
Harrison et al.	1995	163	OP, Canada	42 ± 17.5	NR	80%
Gjerdingen et al.	1999	84	NH, OP, US	80 ± 9	99% White	93%
Reilly et al.	1995	218	OP, US	69 median	96% White	46%
Berger et al.	1998	37	NH, US	81.9 mean	97% White	4.8/5.0 ⁶
Mild dementia						
Malloy et al.	1992	201	OP, US	76 mean	NR	69% to 86% ⁷
Gjerdingen et al.	1999	84	NH, OP, US	80 ± 9	99% White	76%
Dementia (unspecified)						
Gunasekera et al.	1986	134	OP, England	80.7	NR	76%
Emanuel et al.	1992	507	OP, US	= 65 & > 65 ⁸	majority White	72%
Morgan et al.	1994	100	OP, England	80.4	NR	76%
Griffith et al.	1995	661	OP, US	= 65 & > 65	93% White	78%
	1995	535	OP, US	= 65	93% White	76% ⁹
	1995	126	OP, US	> 65	93% White	85%
Caralis et al.	1993	139	OP, US	53 ± 15	35% White; 37% AA; 28% Latino/Latina	38% 26% 11%

NOTES

1. Likert scale: 1 = definitely want, 5 = definitely do not want.
2. Diverse patient populations including young adults, older well adults, persons with chronic illness, terminal cancer, acquired immunodeficiency syndrome, stroke survivors, and nursing home residents.
3. Mean not reported.
4. Range across multiple subpopulations reported graphically. Exact values not reported.
5. Mean not reported
6. Likert scale: 1 = definitely want, 5 = definitely do not want. Average of three results over six months reported.
7. CPR aggregated with range depending whether intervention posed in negative, neutral, or positive fashion.
8. Mean not reported.
9. Calculated.

KEY

AA	African-American	ICU	intensive care unit	OP	out-patient
CPR	cardiopulmonary resuscitation	NH	nursing home	US	United States
ESD	end-stage dementia	NR	not reported	VA	Veterans Administration

Mitchell and colleagues sampled 1,609 patients with advanced dementia who were living in nursing homes and found that 45 percent had a "full code" in the final months of life; 95 percent of these patients died within three months of their last formal assessment.⁴⁴ The fact that almost half of such patients were full code so close to death suggests that many received CPR in a state in which the majority of patients would not have wanted it. We recognize that there are no data directly linking the preferences of individual patients prior to the onset of their dementia and the receipt of unwanted procedures later in a state of ESD. Such data would be difficult to obtain, but long-term follow-up studies would be highly useful. Nevertheless, in light of the proven unreliability of advance directives and surrogate decision making to secure the wishes of patients, the relatively high rates of these procedures when most patients would not have wanted them suggests a failure of our current approach.

Traditionally, medicine's default for patients with ESD continues to be life-prolonging care.⁴⁵ To not receive life-sustaining therapy, a patient must opt-out either by directly using an advance directive or by relying on a surrogate, a tenuous proposition. And so, contrary to the preferences of a large majority of patients, many patients with ESD receive CPR at the end of life. Our current *modus operandi* is to disrespect the wishes of a large majority of patients with ESD. It is time for a new approach.

FLIPPING THE DEFAULT

We reaffirm that the preferences of patients ought to be maintained. We certainly do not recommend a return to a more paternalistic model of the doctor-patient relationship in which the patient's principal role was to follow "doctor's orders."⁴⁶ We acknowledge that surrogate decision making attempts to preserve individuals' preferences in decisionally incapacitated patients.⁴⁷ Despite its flaws, we recognize that surrogacy will remain the dominant method of decision making for decisionally incapacitated patients. In the vast majority of cases involving decisionally incapacitated patients, in which we have little evidence to believe that surrogacy is harming patients, surrogacy makes sense. But in the case of patients with ESD, many of whom are likely to receive CPR at the end of life, we need better approaches to assist surrogate decision making.

So what can clinicians do to minimize the inappropriate use of CPR? First and foremost, clinicians need to improve their communication skills or enlist the help of others trained in palliative care to help patients make these decisions.⁴⁸ We hope the evidence presented encourages clinicians to address these issues in the early stages of dementia and to document those preferences. Advance directives remain a viable mechanism to secure patients' preferences, but they must be improved and specifically tailored to address patients' preferences in ESD. We feel that all patients in the early stages of dementia should be required to complete an advance directive.⁴⁹ In addition, advance directives must be seen as more than just a document for patients to sign, but as documentation of a deliberative process between the patient and a knowledgeable health professional.⁵⁰ We certainly need more innovation and research in this area, as well as novel forms of communication.⁵¹ Nevertheless, given past experience with advance directives and their need for significant improvement, there are legitimate concerns about relying on advance directives, particularly in the near future, to promote fidelity to patients' preferences.

We are concerned that applying our traditional default toward the use of CPR in patients with ESD has untoward effects. Presently, unless a patient has completed an advance directive that specifically limits medical treatment such as CPR, or the patient's surrogate has made a similar request, medicine's "default" is to provide CPR. This default, to implement the use of CPR in the vast majority of illness, is appropriate precisely because it is what a large majority of people want.⁵² But applying this same default to providing CPR for patients with ESD is flawed when a large majority of patients would not have wanted it.

Choosing defaults for emergency procedures, like CPR, is a reality that every healthcare system must face; healthcare systems must set emergency defaults.⁵³ Despite functioning in a system that respects individuals' preferences, a healthcare system must choose default rules for emergency procedures such as CPR when there is little time for deliberation with patients or surrogates. When a healthcare system chooses a

particular default while allowing an individual's choice, it only makes sense to consider what the majority of patients would want. Default rules ought to be chosen to favor behaviors that maximize the welfare of patients.⁵⁴

In the case of patients with ESD, the overall welfare is improved by maximizing individuals' preferences and avoiding unwanted procedures at the end of life. Our present default is to provide CPR to all patients. We propose that this be changed to a default against the routine use of CPR in patients with ESD unless an advance directive or a surrogate specifically requests it. Since most people queried have stated preferences against the use of CPR in ESD, it makes sense that when choosing a default to apply in emergency situations, such as when a surrogate is unavailable or the preferences of a patient are unknown, that the default reflect what the large majority of patients appear to prefer. Setting the default *against* the use of CPR in ESD would be consistent with what most patients have stated they would prefer, while it would allow the minority of patients to express their preference. Flipping the default maximizes welfare by respecting the preferences of most patients to a much greater extent than a default that favors the use of CPR for patients with ESD. A healthcare system's choice of which default to choose ought to reflect the majority of individuals' preferences while it allows for minority's preference.

We limit our proposal to CPR, which often includes mechanical ventilation, since defaults are put in place for procedures that are considered emergent, when discussion is not possible. Most procedures other than CPR are not emergent, and consent may be obtained from the surrogate. To maximize patients' welfare by respecting the stated preferences of the majority, the assumption should be that CPR is not desired in ESD. Since the majority of studies were conducted in the United States, and a default ought to reflect the preference of the majority in a particular system, we limit our argument to healthcare systems in the United States.

Of course, there will be some patients who will desire CPR in ESD and their welfare will be curtailed by such a flipping of the default. However, a default to not offer invasive medical procedures such as CPR that allows a patient to request those procedures will avoid such an infringement on patients' welfare. Such a change in the default maximizes patients' welfare while it preserves individuals' liberty, insofar as persons are able to act according to their own conception of the good by opting out of the default.⁵⁵

Flipping the default at the health policy level should be reflected at the clinical level. Surrogates would continue to play an important role in end-of-life decision making, but the framing of such discussions would be conducted very differently. For example, traditionally, a surrogate is asked, "If your father's heart were to stop and he needed CPR, is this something that he would have wanted?" With a new default, the clinician would approach the surrogate and say, "Most patients state they would not want CPR for a life-threatening illness if they have advanced dementia such as your father. Based on that, we generally do not provide these interventions to patients with advanced dementia. If you believe your father would have wanted this procedure, we will honor that. But you must specifically tell us that, for us to provide it."

This reframing of the question relieves surrogates from feeling guilty about not providing all interventions to their loved one and, we suspect, would significantly influence their decisions in a nonpaternalistic fashion that maximizes welfare. We feel strongly that the current default to provide all life-sustaining care shapes decision making in favor of such care. Withholding or withdrawing care is a highly emotional and guilt-laden process for surrogates. A default that relieves some of the emotional responsibility for the majority of surrogates will improve their adherence to the patients' preferences.

We do recognize that medical urgency in life-threatening situations, however, requires some type of advance notice to surrogates so that instructions requesting all life-prolonging care can fairly be provided. But emergent cases at the time of admission, in which a history of ESD is confirmed and in which no surrogate is available, should be treated according to our proposed default. When a patient with ESD arrives in an emergency room from a nursing home at 3:00 a.m. in cardiac arrest, we should not innocently agree to perform CPR now and sort out the ethical issues "in the morning," since this disrespects the wishes of the majority of patients. We reject the argument that it is better to resuscitate a patient with ESD and assess whether the patient did not want treatment than to avoid an unwanted death. On this approach, one risks a

day or two of unwanted treatment to avoid an unwanted death. As physicians, we feel that the additional suffering for the patient is abusive and an injustice, when it is well documented *ex ante* that most patients would not want such treatment. Even when a surrogate is later identified, the difficult and unreliable task of representing another's interests has been further clouded by the need to make an active decision to withdraw care.

We recognize that this approach may appear to lead to a premature death for some patients. Regardless, we are more troubled by the potentially abusive care that many patients with ESD today receive in these situations despite the fact that most competent people, when asked hypothetically, say that they would reject such care for themselves.

Using our proposed default, surrogates would remain active decision makers, but their evidentiary task would no longer be whether their loved one desired the curtailment of life-supporting care, but rather, whether their loved one asked for life-supporting care. The burden of evidence would no longer be on the surrogate to provide evidence that a patient did not want CPR; instead, the evidentiary burden would be to prove that the patient wished to have CPR in ESD. In *Cruzan*, Justice Brennan argued a similar point in regard to the state's evidentiary requirements for the default in care of patients in a persistent vegetative state: "[The state's] rule of decision imposes a markedly asymmetrical evidentiary standard. . . . No proof is required to support a finding that the decisionally incapacitated person would wish to continue treatment."⁵⁶ If most patients do not desire life-sustaining procedures in ESD, then it should be incumbent upon the surrogate to argue for life-sustaining treatment when it is desired.

In most cases, activation of the default in the absence of any discussions with a surrogate would, in fact, be rare. Patients living in the community and presenting to the emergency room are usually accompanied by family members who are available to help make decisions. For patients in nursing homes, advance notice of the default policy could easily be provided to surrogates. In those rare cases in which we have no advice from a surrogate, it makes sense to rely on what the majority of others say that they would want.

A flipping of the default can already be found in some nursing homes in which the default position is a do-not-resuscitate (DNR) policy.⁵⁷ In a study by Kane and Burns of 342 of 404 nursing homes in Wisconsin, 4 percent did not offer CPR, 23 percent would not initiate CPR themselves but would call emergency services if it was requested in advance, another 15 percent would initiate CPR only if it was requested in advance, and 57 percent would provide CPR unless it was specifically rejected.⁵⁸ Of the 95 facilities that did not provide CPR, the most common reason cited was poor outcome. The second most common reason cited was concern about suffering.

Although it is similar to the approach taken by nursing homes that require an opt-in strategy, our proposal is novel in two fundamental ways. First and most importantly, our proposal is based on maximizing patients' welfare by focusing on the stated preferences of the majority of patients, not on efficacy and potential futility. "Futility" refers to offering care that is highly unlikely to lead to a desired result.⁵⁹ In the case of futile medical procedures, the physical pain that may be inflicted is felt to be unwarranted, given the probable negligible benefit. We agree with other commentators that there is little consensus on what constitutes futility, and that the concept appears to have more use for physicians than for patients or their families.⁶⁰ At worst futile care is nonbeneficial — but it is not harmful. Previous arguments against the use of invasive life-sustaining interventions in ESD were arguments based on futility. For example, a consensus against the use of feeding tubes in patients with ESD has developed,⁶¹ but these arguments have been based on the belief that tube feedings in patients with ESD do not provide any benefit since they do not prolong survival.⁶² Gillick has proposed a similar flipping of the default in regard to tube feedings based on efficacy and potential futility.⁶³ Others have also suggested that an opt-in strategy in regard to CPR in nursing home patients may best serve patients because of concerns of futility.⁶⁴ Our argument suggests a change in the default based on maximizing patients' welfare by avoiding potential maltreatment of the elderly, a more pressing claim.

Finucane has also eloquently articulated the complex problems presented at the end of life in patients with ESD, with which we similarly struggle.⁶⁵ He has also suggested that a policy against CPR in nursing homes would be reasonable and compassionate, based on the complex and unfortunate realities of end-of-

life care in the debilitated elderly, but he leaves the policy question unresolved because such compassion seems to conflict with our long-standing values to prolong life.⁶⁶ The policy solution, grounded in maximizing welfare by honoring patients' preferences, is clear. We need to change our default approach for patients with ESD.

Second, we limit our alternative default to patients with ESD. Basing defaults generally in end-of-life care has been previously proposed.⁶⁷ These defaults and nursing home opt-in policies are not sufficiently selective. We limit our recommendations to patients with ESD, for whom the case for potential abuse is the strongest. Mild and moderate dementia are excluded, based on the findings previously discussed. Acute loss of cognition from stroke is excluded, since some recovery is certainly possible. Patients in other end-of-life situations, such as those involving cancer, cardiac, and respiratory disease, have expressed the desire to receive life-sustaining measures.⁶⁸ In addition, these patients are generally competent far into the advanced stages of their disease, and so have sufficient opportunity to articulate their end-of-life wishes, or for physicians and surrogates to learn them.

The natural trajectory of ESD — toward further deterioration — also distinguishes these patients from other chronically decisionally incapacitated patients, such as those with persistent vegetative states, for which current approaches may still be appropriate.⁶⁹ Similarly, pediatric populations, such as neonates and children with severe mental retardation, are different in that they are perceived to be at the beginning of their life trajectory and have not yet developed or never will develop the mental capacity to articulate their own preferences.

OBJECTIONS

We will identify and address several major arguments against changing the default. First, some may claim that changing the default in ESD returns us to unilateral paternalism, but such an accusation is unfounded. If patients do not want invasive procedures in ESD and we perform such procedures on them, we will violate a foundational pillar on which medical ethics and healthcare law rest, namely, patient self-determination. To do so is to actively bring harm upon nonconsenting individuals; to not change the default would be wrongly paternalistic, as it assumes that most patients desire all life-sustaining invasive procedures when our best evidence tells us otherwise. Those who strongly feel that life should be prolonged over other goals may seek that option from their physicians. When a patient or surrogate wants such care, even assuming it has the faintest possibility of benefit, the patient is entitled to such care in our current system. Physicians look to the patient or the surrogate to make decisions regarding treatment and its chance of success. Our proposal works from within that framework. Our approach, as opposed to an absolute ban on life-sustaining procedures in ESD, retains patients' right to formulate an advance directive, and thus is consistent with federal law.⁷⁰ We recognize, however, that our proposal may require statutory changes in some states that have wrongly paternalistic approaches.⁷¹

Second, a charge of a "tyranny of the majority" is also unwarranted.⁷² The present default position to perform invasive procedures that are not preferred by the majority of patients instead produces a "tyranny of the minority." There is a legitimate concern, however, regarding the effects of our default approach on members of racial or ethnic minority groups. First, there is a higher prevalence of dementia in minority communities.⁷³ Second, it has been documented in some studies that African-Americans may have different preferences for end-of-life treatments,⁷⁴ although one recent study suggests that members of minority groups, when appropriately informed about ESD, state preferences that differ little from those of Whites.⁷⁵ Nevertheless, our approach provides an opportunity to preserve and respect cultural variation by allowing patients to opt-out of the default, for example, by completing an advance directive. A similar line of reasoning can be used for patients who have religious beliefs that would be contrary to a changed default. Variations in preference are respected because patients retain the right to opt-in for CPR.

A potential objection to this opting-out strategy is that members of minority groups, particularly African-Americans, are commonly thought to be less likely to complete advance directives. Although numerous

studies in the past have found this to be the case,⁷⁶ the largest and best study to date looking at the rates of advance care planning reported no difference in the rates at which advance directives were completed.⁷⁷ This study was conducted at 34 randomly selected senior centers in New York City, with 700 community-dwelling adults 60 years or older: 239 were African-American, 237 were Latino/Latina, and 224 were White. Furthermore, a growing consensus within the medical and geriatrics community advocates for advance care planning in the earliest stages of dementia, and this helps to address that concern.⁷⁸

Another potential objection is that members of minority groups may eventually comprise the majority of the patient population. In that case, if members of minority groups indeed favor aggressive care for patients with ESD — a doubtful occurrence — would we again flip the default? We find this suggestion highly unlikely. The medical profession has refocused its understanding of ESD as a terminal condition akin to cancer.⁷⁹ As palliative care concepts continue to permeate the medical profession, it is less likely that patients, minorities or not, will insist on aggressive care in ESD.⁸⁰ But, if the majority of patients in a society favor a medical procedure, then society ought to set the default to favor delivery of that procedure to maximize the welfare of the public.

Some may also question whether a majority — but not unanimous opinion — is enough to justify changing the default in favor of withholding CPR in patients with ESD, particularly because withholding CPR is irreversible, and will likely lead to death. Although, as previously mentioned, we suspect that studies that better informed subjects about ESD would have demonstrated an even higher rate of refusal,⁸¹ we feel the default can justifiably be changed when a large majority of individuals do not favor such treatment. More importantly, the action of performing life-sustaining therapy in many patients who would not have wanted it must be viewed as causing harm, even when the therapy was later quickly withdrawn. Causing such harm at the end of life is also irreversible, and the value placed on avoiding that harm should not necessarily be less than the value placed on preserving life.

Another objection raises concerns regarding the validity and stability of patients' expressed preferences. There are important philosophical concerns regarding what a patient wants, and what the patient says she or he wants, and whether a patient's previous competent self may have any moral bearing on the patient's present decisionally incapacitated self. These questions are well beyond the limits of this discussion.⁸² Nevertheless, from a clinical perspective, an individual's previously expressed wishes are widely held as the ethical standard for all decision making, and this standard supports the legal rationale for advance directives and decision making in other nonmedical contexts.⁸³ Furthermore, we have used data that are primarily from patients who are elderly or who have experienced serious illness, which lends greater probative value to their expressed views, based on their thoughtfulness and maturity when their preferences were stated, a criterion also used by the courts.⁸⁴ Concerns regarding the stability of patients' preferences have also been evaluated in at least six studies in both healthy and sick patients. Most of the studies reported that patients' preferences remained largely stable (approximately 80 percent stable) over follow up of one month to two years.⁸⁵

Some may charge that a "slippery slope" will extend the alternative default beyond patients with ESD. We respectfully disagree. There are numerous instances in medicine in which criteria must be met to be included or excluded from diagnostic consideration or treatment. We envision similar strict criteria for patients with ESD, including evidence of the chronic nature of illness, loss of meaningful speech, complete dependence on others, and a battery of diagnostic tests to rule out other reversible causes.⁸⁶ These factors are easily identifiable and recognizable to experienced physicians; ESD is not a subtle diagnosis. Furthermore, these diagnostic criteria are not always documented in the medical record. With a change in the default, we anticipate that documentation of this criteria will improve dramatically. We believe that requiring adequate documentation to meet the criteria would prove an adequate safeguard to prevent misapplication of the default to other patients.

Some may accuse us of advocating for the default approach as a pretext to save healthcare resources, but that is not our concern here. It cannot be denied that resources are disproportionately consumed at the end of life.⁸⁷ However, healthcare costs are driven by many diseases that are not directly associated with dementia.⁸⁸ We do not suspect that any resource savings that may result would significantly stem the tide of healthcare

inflation.⁸⁹ More importantly, we are much more concerned about the use of resources by patients who did not want them, rather than the use of resources that produce marginal benefit. Surely, we can agree that using resources on patients who did not want them is simply wasteful.

Additionally, some may argue that policies should focus on educating and changing clinicians' practices while encouraging patients in early stage dementia to complete advance directives. We are not so optimistic. For the last two decades, millions of dollars have been directed toward changing clinicians' practices at the end of life and encouraging patients to complete advance directives. So far, the results are mixed. Although it would be valuable to direct more resources toward these ends, we feel that more extreme measures at the policy level are warranted. Flipping the default would not only change physicians' practices, but also encourage those patients who wish aggressive care to complete advance directives.

Lastly, some may argue that changing the default is tantamount to abandoning such patients, but the reality is that it does not lead to abandonment. These patients represent a unique class of vulnerable patients who are prone to abuse and deserve protection. Our policy aims to provide this general protection while allowing individual exception. Of course, we do not know how such a change might influence the care given to patients with ESD, particularly patients who lack a surrogate. However, even patients who do not have a surrogate are best served by a policy based on the majority's preferences. More importantly, all patients with dementia, regardless of end-of-life decisions, deserve aggressive care focused on comfort and their personal needs. This care can hardly be mistaken for abandonment.⁹⁰

CONCLUSION

We hope that a transparent deliberation among physicians, patients, and families will take place in which discussions, however difficult, of the care of patients with ESD will be addressed. Present defaults and policies that rely on advance directives and surrogate decision making are less than perfect and may lead to mistreatment of the elderly with ESD. This mistreatment can be minimized by a change in the default for the delivery of care to patients with ESD. To continue the status quo is to dishonor the preferences and dignity of some of our most vulnerable patients.

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