

**IS THERE A MORAL OBLIGATION FOR HEALTH CARE ORGANIZATIONS TO DEVELOP ROBUST ADVANCE CARE PLANNING PROGRAMS?**

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ABSTRACT

*Advance care planning (ACP) has become an integral part of patient care because of its ability to help guide treatment decision making for individuals in need of medical care but who have lost the ability to communicate—temporarily or permanently—due to illness or injury. Not all persons have the same treatment threshold; some persons value their lives above all else and will accept a high level of physical debility regardless of personal discomfort to stay alive. Others value their individual personal comfort over the length of their lives and will refuse otherwise life-sustaining treatment if they believe the treatment will cause them to sacrifice their comfort. The purpose of ACP is to help mentally capable adults express their individual goals, values, and treatment preferences prior to becoming unable to communicate so that medical providers and loved ones can make treatment decisions that best align with those adults' wishes. When persons in need of medical care have not done ACP, medical providers and loved ones are left to guess what treatment decisions to make and may experience guilt or moral distress if they believe they have made the “wrong” choice.*

*Not all ACP, however, is capable of bringing clarity to the treatment decision-making process. Simply asking persons to complete advance directives typically fails as a helpful treatment guide. ACP that occurs as part of a conversational process in which persons have the opportunity to reflect, understand, and make informed choices about their treatment preferences has a better chance of being useful in treatment decision making. This paper explores the ethical and legal foundations of ACP, demonstrates how robust ACP is superior to basic ACP, and argues that health care organizations have a moral obligation to develop robust ACP programs.*

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## I. INTRODUCTION

Not all persons have the same treatment threshold. Some persons are willing to accept any available medical intervention that can extend life by any amount of time, regardless of physical debility, potential discomfort of the treatment, or the predictable negative impact treatment will have on their daily activities. Others, though, are not willing to accept all available medical interventions as needed just to extend life. Some of these individuals will forgo needed medical interventions if the interventions are likely to negatively interfere at all with daily activities, even if the consequence is death. A recent patient of mine, for example, elected to forgo a life-saving operation to remove a dead part of her intestine because she did not want to live the rest of her life managing a colostomy bag (a bag surgically attached to the gut that holds diverted fecal matter and must be emptied regularly). Because her dead intestine prevented her from digesting food, she died a few days after refusing surgery.

Since treatment thresholds can vary widely, medical professionals are trained not to make assumptions about individuals' treatment preferences.<sup>1</sup> As a result, the default position of medical practice in the United States is to use all available interventions to treat unless the intervention is judged by the physician responsible for the individual's care to be medically unsound (e.g., continuing ventilator support for an individual with no neurological or cardiac activity) or the individual has made his or her treatment preference known to medical providers.<sup>2</sup> When a person's treatment preferences are unknown to his or her medical providers, that person is at risk of receiving treatment not aligned with that person's goals of care—that is, the person may receive too much, or even in some cases, too little treatment for what the individual would have been otherwise willing to accept. As a practical matter, when treatment does not align with an individual's treatment preference, the utilization of health care resources becomes inefficient, often leading to wasteful medical spending.<sup>3</sup>

Advance care planning (ACP) is one way that is now broadly referenced and utilized to understand persons' treatment preferences, which helps to better ensure that the individuals in need of medical care receive the treatments that they want and, equally important, that they avoid receiving treatments they do

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1. ALBERT R. JONSEN ET AL., *CLINICAL ETHICS: A PRACTICAL APPROACH TO ETHICAL DECISIONS IN CLINICAL MEDICINE* § 2.0.1 (8th ed. 2015).

2. See AM. MED. ASS'N, *COUNSEL ON ETHICAL & JUD. AFFS., CODE OF MEDICAL ETHICS* § 5.3–5.5 (2016).

3. See Thomas D. Harter, *Why Medicare Should Pay for Advance Care Planning*, 23 *PROGRESS PALLIATIVE CARE* 148, 148 (2015); Thomas Harter, *What Kind of Advance Care Planning Should CMS Pay For?*, *HEALTH AFFS. BLOG* (Mar. 19, 2015), <http://healthaffairs.org/blog/2015/03/19/what-kind-of-advance-care-planning-should-cmspay-for/#more-45549>.

not want. ACP is commonly defined as a process by which mentally capable adults identify health care treatment preferences or health care agents prior to becoming mentally incapable.<sup>4</sup> Typically, ACP is most utilized in situations when persons need medical treatment but cannot clearly communicate with medical providers in order to participate in the treatment decision-making process. Knowing individuals' treatment preferences in advance of medical complications that could prevent them from participating in future treatment discussions is now viewed as such an important component of patient care—in part because of concerns of mistreating patients and the misutilization of resources—that in October of 2014, the Centers for Medicare and Medicaid Services (CMS) issued two new practice billing codes in the revisions to its payment policies.<sup>5</sup> Once in effect, these billing codes, 99497 and 99498, will allow physicians to bill for the time they take having ACP conversations with their patients.<sup>6</sup>

This move by CMS to allow for the billing of ACP conversations between physicians and their patients is a strong indication that the work of providing ACP to individuals is falling to health care organizations. Even if this is not the case, there is still a strong argument to be made that health care organizations have a responsibility to help both their patient and provider populations by developing ACP programs. First, health care organizations are the institutions responsible for providing medical care in the communities they serve. Second, the medical providers employed by health care organizations are the individuals responsible for providing the clinic-based and hospital-based treatment to patients, including patients who can no longer make their own treatment decisions. Lastly, as organizations with discretion over relatively large spending budgets, they are in a position to provide the patient education, ACP training and staff, and physical space necessary to develop ACP programs.

One potential concern with billing for ACP is that not all ACP practices or programs are equally valuable to patients. It was once assumed that living wills or advance directives alone would suffice as proper indications of persons' treatment preferences near the end of life. Yet, as discussed below, evidence shows living wills and advance directives alone do little to ensure that the medical care incapacitated patients receive actually aligns with their preferences. Given the promise of ACP to help identify and align persons'

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4. Arianne Brinkman-Stoppelenburg et al., *The Effects of Advance Care Planning on End-of-Life Care: A Systematic Review*, 28 PALLIATIVE MED. 1000, 1001 (2014).

5. Medicare Program; Revisions to Payment Policies Under the Physician Fee Schedule, Clinical Laboratory Fee Schedule, Access to Identifiable Data for the Center for Medicare and Medicaid Innovation Models & Other Revisions to Part B for CY 2015, 79 Fed. Reg. 67547, 67670–71 (Nov. 13, 2014).

6. *Id.* at 67663.

treatment preferences with the medical care they receive during times of mental incapacity, this paper thusly addresses the question of whether health care organizations have a moral obligation to develop robust ACP programs.

Section II discusses the historical foundations of ACP. Beginning with the case of Karen Ann Quinlan—a quintessential case in treatment decision making at the end of life in absence of known treatment preferences—the ethical and legal justifications for basic ACP are detailed. Section III demonstrates the failure of basic ACP in practice, while defining and distinguishing robust ACP from basic ACP and describing how robust ACP is superior to basic ACP.

Section IV demonstrates how robust ACP aligns with and is supported by several moral frameworks including Principlism, Utilitarianism, Virtue, and Care. The discussion in this section is not meant to be fully exhaustive of the different moral justifications of robust ACP; instead, it shows how and why there is a reasonable argument to be made justifying a moral obligation of health care organizations to develop robust ACP programs. Lastly, the paper concludes that the current status quo of ACP in health care settings is morally unacceptable, that there is indeed a moral obligation of health care organizations to develop robust ACP programs, and that more research is needed to clearly identify the metrics that separate basic ACP from robust ACP and to allow for further moral and legal distinction between the two.

## II. FOUNDATIONS OF ACP

### A. *The Case of Karen Ann Quinlan*

While attending a party in 1975, Karen Ann Quinlan ingested a combination of aspirin, barbiturates, and valium, which caused her breathing to stop for a prolonged period of time.<sup>7</sup> After being resuscitated by paramedics, Quinlan was transferred to Newton Memorial Hospital in New Jersey, where she was placed on a ventilator.<sup>8</sup> Although her body was still functioning, Quinlan had suffered irreversible brain damage and was ultimately diagnosed as being in a persistent vegetative state.<sup>9</sup>

Since Quinlan had permanently lost the ability to make her own decisions, her parents made the decision to discontinue her ventilator support, expecting she would die soon afterward.<sup>10</sup> Knowing the stakes of the request, the hospital

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7. *In re Quinlan*, 348 A.2d 801, 806 (N.J. Ch. 1975), *modified and remanded*, 355 A.2d 647 (N.J. 1976).

8. *In re Quinlan*, 355 A.2d. 647, 654 (N.J. 1976).

9. *Id.*

10. Robert S. Olick & Paul W. Armstrong, *In Re Karen Ann Quinlan (1976): Establishing a Patient's Right to Die in Dignity*, in *COURTING JUSTICE: TEN NEW JERSEY CASES THAT SHOOK THE NATION* 77–78 (Paul L. Tractenberg ed., 2013).

would not honor this wish without a court order.<sup>11</sup> Eleven months after her hospitalization, the New Jersey Supreme Court appointed Quinlan's father as her guardian, granting him the right to make all her medical decisions, including the right to discontinue extraordinary means of treatment.<sup>12</sup> In its ruling, the court claimed that because of Quinlan's poor prognosis, her case was unique to others in which treatment was ordered and that the degree of her injury weakened the State's interest in keeping her alive while subsequently strengthening her individual right to privacy.<sup>13</sup> Quinlan died in 1985—nine years after her ventilator support was stopped—when her body succumbed to pneumonia.<sup>14</sup>

Quinlan's case is discussed here for three reasons. First, her case garnered national media attention,<sup>15</sup> and for many Americans who saw the earliest news reports about her case, it was the first time they had been presented with questions about the goals of medicine. Second, those who remember the earliest reports about this case are now at a target age for doing ACP. Ideally, all competent adults should undergo some ACP process. Those aged fifty-five and older, however, are more likely to need ACP because of their advancing age and, thus, the increased likelihood of having greater health care needs requiring medical intervention. Third, her case brought to the forefront at least two elements directly related to the philosophical importance of ACP.

First, Quinlan's case demonstrated how far medical technologies and innovations had advanced. The general public saw how it was now possible to keep a person alive even after suffering from neurocognitive devastation. Since neurocognitive functioning—broadly construed as the ability to meaningfully interact with oneself, others, and one's environment—is generally treated as an integral component of personhood,<sup>16</sup> Quinlan's situation caused people to question what is most important to them as individuals once consciousness is gone: the quantity or quality of one's life.

Second, her case highlighted the importance of and legal complexities surrounding the newly emerging role of surrogate health care agents. By virtue of her neurologic devastation, Quinlan could no longer make her own treatment decisions. The United States (U.S.) court system therefore had to decide what level of protections should be afforded to Quinlan in her debilitated state and what level of authority and legal protections could be, or should be, granted to those who were now responsible for making her

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11. *Id.* at 78.

12. *Id.* at 79.

13. *In re Quinlan*, 355 A.2d. at 664.

14. Olick & Armstrong, *supra* note 10, at 85.

15. *Id.* at 86, 94.

16. Martha J. Farah & Andrea S. Heberlein, *Personhood and Neuroscience: Naturalizing or Nihilating?*, AM. J. BIOETHICS, Jan. 2007, at 37, 40.

treatment decisions. In regard to the legal complexities surrounding surrogate decision making, Quinlan's case also demonstrated the U.S. court system's general unwillingness to intervene in medical decision making. Many U.S. court decisions regarding surrogate decision making define the court's role as ensuring the rights of patients are not unduly infringed upon throughout the decision-making process, but courts commonly refrain from exerting authority in making particular treatment decisions.<sup>17</sup> In Quinlan's case, once the court ruled that forgoing ventilator support would not unfairly infringe on her constitutionally-protected rights, it further ruled that the actual decision to remove ventilator support was a private matter between her physicians and her guardian.<sup>18</sup>

### B. Moral and Legal Foundations of ACP

As exemplified in the Quinlan case, the practice of medicine has undergone incredible changes over the past 100 years. We have gone from a time when there were few treatments that cured or effectively managed a disease to a time when there are not only many effective ways of treating or managing an array of illnesses or injuries, but also to a time when these treatments are relatively open and available to large populations. These changes have resulted in a transition from a time when people often died after a relatively brief period of illness to a time when life can be extended for persons suffering from a variety of diseases and loss of functional capacity.

During this period of rapid progress of medical science, we have also seen a clear shift in medical decision making. Whereas physicians historically controlled treatment decisions, patients are now expected to decide the treatments they will and will not accept. This change occurred in conjunction with many social changes where individual and civil rights have taken front stage, often labeled as a patients' rights movement.<sup>19</sup> Today, medically-paternalistic decision making has been usurped and replaced by shared

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17. See Noreen R. Henig et al., *Biomedical Ethics and the Withdrawal of Advanced Life Support*, 52 ANN. REV. MED. 79, 81 (2001) ("In the United States, both the common-law right of self-determination and the constitutionally derived right of privacy support legally competent adults' rights to be in charge of their own health care, even if it means refusing treatment."); Christopher M. Burkle & Jeffrey J. Benson, *End-of-Life Care Decisions: Importance of Reviewing Systems and Limitations After 2 Recent North American Cases*, 87 MAYO CLINIC PROCS. 1098, 1098 (2012); Claire M. McGowan, *Legal Aspects of End-of-Life Care*, CRITICAL CARE NURSE, Oct. 2011, at 64, 68.

18. See McGowan, *supra* note 17, at 65.

19. See Glyn Elwyn et al., *Shared Decision Making: A Model for Clinical Practice*, 27 J. GEN. INTERNAL MED. 1361, 1361 (2012) (noting that "sharing decisions, as opposed to clinicians making decisions on behalf of patients, is gaining increasing prominence in health care policy").

decision-making models where patients and physicians make treatment decisions together based on patients' values and preferences.<sup>20</sup>

With patients now playing a central role in medical decision making, questions about how to make vital medical decisions arise whenever patients are mentally incapable of making their own treatment decisions. Given the association of patient-centered medical decision making and the possibility that some individuals—at the time they need to make medical decisions—lack decisional capacity, it seems obvious and reasonable to say that individuals should have the right to expressly clarify their treatment preferences for future medical care in advance of their potential incapacity. This way, patients' values and preferences can be clear to families and health professionals so that if patients cannot participate in medical decision making because of incapacity, medical decisions still can be made in ways that reflect the patients' values and preferences.

Although it is now widely accepted that competent adults can plan for future medical decisions should they become incapable,<sup>21</sup> the extension of a patients right to decide in future situations was not completely clear to all at first. Some argued that when a person loses decisional capacity, certain rights can no longer be exercised—such as the right to vote or get married—and that this reasoning extended to medical decision making.<sup>22</sup> It makes sense that when individuals' cognitive functioning has been impaired, their abilities to make well-reasoned, informed decisions in the moment are thusly compromised. However, this argument does not adequately speak to what occurs with ACP.

When individuals make decisions about future medical care, the decisions are not really about specific treatments *per se* but about how different states of health accord with individuals' values and preferences. To plan for future medical decisions is to identify the thresholds at which the goals of medical care would change based on the circumstances of persons' current or future medical conditions.<sup>23</sup> If a mentally-capable person who struggles with understanding medical details is asked to choose whether to have cardiopulmonary resuscitation (CPR) at some future point, and this option is presented with no other contextual information, then—yes—her choice might be uninformed and might raise questions about whether medical providers should honor her choice if her heart or breathing stops. However, if this person

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20. *See id.*

21. *See* NAT'L BIOETHICS ADVISORY COMM'N, RESEARCH INVOLVING PERSONS WITH MENTAL DISORDERS THAT MAY AFFECT DECISIONMAKING CAPACITY 29 (1998).

22. *See* Thaddeus M. Pope, *Legal Briefing: The New Patient Self-Determination Act*, 24 J. CLINICAL ETHICS 156, 156 (2013).

23. EMANUEL L.L. ET AL., ADVANCE CARE PLANNING M1-1 to -2 (EPEC Project eds., 1999).

is asked to make a choice about CPR after a recent diagnosis of severe congestive heart failure, and she communicates that she values her independence and does not wish to ever live long term in a nursing home, she could make an informed decision about CPR: reasonably refuse it if a successful CPR attempt would likely result in her needing long-term or permanent nursing care.

In the United States, the social policy and legal systems eventually and universally supported the notion that competent adults are free to make advance medical decisions for future events. Legislative efforts in all fifty states first recognized living wills and, later, affirmed the rights of individuals to appoint surrogate health care agents—who could refuse treatment on the behalf of patients—via powers of attorney for health care and advance directives.<sup>24</sup>

Basic principles of biomedical ethics added support to these efforts. For many, the principles of respect for patient autonomy and nonmaleficence provide sound rationale not only for individuals to make their own informed treatment decisions but also to plan for potential future medical decisions, to communicate those decisions in advance directives, and to have those plans followed by surrogate decision makers—especially when individuals opt for less medical treatment than medical providers recommend. Tom Beauchamp and James Childress, for example, root the establishment of advance directives in the principle of respect for autonomy, but they describe the ethical importance and implications of advance directives under the principle of nonmaleficence.<sup>25</sup> On their view, whereas respect for patient autonomy supports the idea that persons should be reasonably free to direct their medical care via advance directives, nonmaleficence supports the importance of the legal protections granted via advance directives to elected health care agents when making decisions that keep incapacitated individuals from receiving medical care they would otherwise perceive as harmful if they retained capacity.<sup>26</sup>

Further legal and ethical support of ACP also has come via the concept of informed consent. Expressed in international documents like the Nuremberg Code as well as supreme court decisions in multiple countries, informed consent has become a separate legal doctrine and professional ethic that—except in emergency cases—requires patients to make informed, voluntary

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24. See TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMED. ETHICS* 103, 133–58 (5th ed. 2001).

25. *Id.*

26. *Id.* at 139–40, 186–87.

acceptances before medical treatment can be provided to them.<sup>27</sup> In short, the doctrine of informed consent mandates that treatments should be provided to competent adults only after they are fully informed of the different treatment options available to them as well as the risks and benefits of those treatments.<sup>28</sup> This doctrine affirmed the asymmetrical rights of patients to refuse treatment recommendations as long as they were competent, informed, and free to act, but it did not affirm the right to demand or require physicians to provide treatments or tests when physicians judge those treatments and tests to be ineffective or capable of causing serious harm.<sup>29</sup>

Given the U.S. court system's involvement in the issues of informed consent and end-of-life medical decisions as well as the subsequent laws passed to legitimize the use of advance directives, it is not surprising that ACP is easily tied to and treated as a matter of patient rights and patient autonomy. Conceptually, advance directives appear to be the ultimate expression of individual choices and the embodiment of patients' rights to make decisions about their future medical care. However, one result of tying ACP to patient rights and patient autonomy is that other conceptual and ethical constructions of ACP and advance directives are undervalued or depreciated. For example, Edmund Pellegrino long argued that the purpose of health care is to help individuals continue their lives as they have conceived them and that this aim constitutes an intrinsic good that ought to be valued more than the expression of patient rights.<sup>30</sup> On this view, ACP is more than an expression of rights; it is a tool of health care that helps persons identify and communicate to medical providers and loved ones both how best to use medicine to achieve what they conceive to be the best life possible and the thresholds at which medicine can no longer help restore them to their individual conceptions of health.

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27. 2 TRIALS OF WAR CRIMINALS BEFORE THE NUERNBERG TRIBUNALS UNDER CONTROL COUNCIL LAW NO. 10 181–82 (1949) [hereinafter TRIALS OF WAR CRIMINALS]. See also, e.g., *Rogers v Whitaker* (1992) 175 CLR 479, ¶¶ 14, 16 (Austl.).

28. See TRIALS OF WAR CRIMINALS, *supra* note 27; *Rogers*, 175 CLR 479, ¶¶ 14, 16.

29. Steven H. Miles, *Informed Demand for Non-Beneficial Medical Treatment*, 325 NEW ENG. J. MED. 512, 514 (1991).

30. See EDMUND D. PELLEGRINO & DAVID C. THOMASMA, FOR THE PATIENT'S GOOD: THE RESTORATION OF BENEFICENCE IN HEALTH CARE 76–77 (1988); Edmund D. Pellegrino, *The Commodification of Medical and Health Care: The Moral Consequences of a Paradigm Shift from a Professional to a Market Ethic*, 24 J. MED. & PHIL. 243, 259 (1999) (discussing the intrinsic goodness of health care).

### III. BASIC AND ROBUST ACP

#### A. *Basic ACP*

Legislative support for ACP arrived in 1990 with the Patient Self-Determination Act.<sup>31</sup> Enacted as part of the Omnibus Budget Reconciliation Act, the Patient Self-Determination Act requires health care organizations to provide information and education about advance directives to individuals admitted to their facilities.<sup>32</sup> Advance directives—including power of attorney for health care documents, living wills, and Physician Orders for Life-Sustaining Treatment<sup>33</sup>—are instruments used to document ACP preferences, including treatment goals and decision makers. This requirement of asking for and providing information about advance directives to hospitalized individuals is the *minimal* ethical and legal standard for ACP among the general public and health care organizations.<sup>34</sup> “Basic ACP” therefore refers to this minimal requirement of asking persons, namely those who are hospitalized, whether they have an advance directive and, if not, whether they would like information about completing one. Anything above and beyond this minimum regarding ACP is perhaps considered praiseworthy, but not yet expected or morally obligatory.

In essence, basic ACP focuses on document completion. The assumption with basic ACP is that individuals already know, or have at least a general idea of, what their treatment preferences are or who they believe might be a good health care agent in the event they become mentally incapacitated.<sup>35</sup> It is further assumed that should a person’s advance directive be utilized, the person’s health care agent will know what health care decisions to make that best align with the incapacitated person’s treatment preferences—either through prior conversations with the incapacitated person or simply by reading and interpreting the advance directive document.<sup>36</sup>

Unfortunately, research over the past twenty-five to thirty years has demonstrated that these assumptions are false. Not only is it the case that the completion of advance directives among the general adult population remains relatively low (around twenty-five to thirty percent), but the documents themselves often fail to provide useful clinical guidance because of their focus on specific treatment decisions that exist outside of a clinical context and

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31. *See* Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101-508, 104 Stat. 1388-15 to -16, -204 to -06.

32. *Id.*

33. *Id.*

34. *Id.*

35. *See* Angela Fagerlin & Carl E. Schneider, *Enough: The Failure of the Living Will*, HASTINGS CENT. REP., Mar.–Apr. 2004, at 30, 34.

36. *Id.*

because the decisions documented in advance directives often are made without exploration into persons' individual value systems.<sup>37</sup> This research also demonstrates that health care agents typically are ill-prepared to act in their roles as surrogate treatment decision-makers. In one review of studies involving surrogate decision-makers, at least one third of patient-designated and next-of-kin decision makers incorrectly predicted patients' end-of-life treatment preferences.<sup>38</sup> Furthermore, recent research demonstrates that when persons engage in basic ACP, the choices they elect on an advance directive can be influenced simply by how the treatment options are listed on the document. This suggests that persons who complete advance directives without engaging in conversation about their individual life goals and values may make treatment decisions on their advance directives that are not reflective of their actual treatment preferences.<sup>39</sup>

### B. Robust ACP and the Failure of Basic ACP

Why has basic ACP failed in practice? Apart from overall low rates of document completion among the general public—which is its own multifactorial problem, including issues such as unsuccessful community engagement and a general reluctance of persons to discuss with loved ones treatment preferences that have end-of-life implications—basic ACP does not account for the complex medical possibilities that create nuance in the treatment decision-making process. Furthermore, basic ACP does not have any way to guide persons through reflection of their individual goals and values that may translate into treatment decisions, nor does basic ACP have a way to ensure that those responsible for making treatment decisions for incapacitated persons accurately understand and interpret incapacitated persons' treatment preferences. Basic ACP—again, ACP that focuses only on advance directive

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37. See Stacey M. Fischer et al., *Advance Directive Discussions: Lost in Translation or Lost Opportunities*, 15 J. PALLIATIVE MED. 86 (2012); Fagerlin & Schneider, *supra* note 35, at 32, 34; Joan Teno et al., *Advance Directive for Seriously Ill Hospitalized Patients: Effectiveness with the Patient Self-Determination Act and the SUPPORT Intervention*, 45 J. AM. GERIATRICS SOC. 500, 506 (1997) (finding that only forty percent of surrogates found the patient's advanced directive helpful in making end-of-life decisions); Edward J. Larson & Thomas A. Eaton, *The Limits of Advance Directives: A History and Assessment of the Patient Self-Determination Act*, 32 WAKE FOREST L. REV. 249, 276–78 (1997).

38. David I. Shalowitz et al., *The Accuracy of Surrogate Decision Makers: A Systematic Review*, 166 ARCHIVES INTERNAL MED. 493, 496 (2006).

39. See generally Scott D. Halpern et al., *Default Options In Advance Directives Influence How Patients Set Goals for End-Of-Life Care*, 32 HEALTH AFFS. 408 (2013); Catherine L. Auriemma et al., *Stability of End-of-Life Preferences: A Systematic Review of the Evidence*, 174 JAMA INTERNAL MED. 1085 (2014) (looking at patients' choices in treatment options in advance directives over time).

document completion—lacks any sort of description or recognition of a systematic approach to the planning process.

As noted in the 2014 Institute of Medicine report, *Dying in America*, successful ACP requires far more than just document completion.<sup>40</sup> Per the report, successful ACP programs require meaningful conversations between the persons doing the planning and their loved ones (especially those chosen as health care agents) and involvement with treating physicians to help address medical questions that arise during the planning process.<sup>41</sup> They also require institutional support and resources directed toward training in ACP conversations, the documentation and retrieval of advance directives, and establishing and maintaining a culture of accountability in which medical providers are willing to trust and honor a patient's or health care agent's treatment decisions as truly reflective of the patient's wishes.<sup>42</sup> In short, successful ACP involves a complete approach, in which the goals include not only document completion but also helping persons reflect on their individual goals and values, supporting discussions between the persons doing the planning and their health care agents and medical providers, and establishing a system that allows health care organizations to easily store and retrieve advance directives as needed. When ACP involves these elements of a systematic approach, this is what is meant by "robust" ACP.

Another important aspect of robust ACP, as noted in the Institute of Medicine report, is that it should have demonstrable and reproducible outcomes.<sup>43</sup> This is an important piece of my overall argument that health care organizations have a moral obligation to develop robust ACP programs. We know that the status quo of basic ACP fails in practice. Yet the reason we can say that basic ACP fails in practice is because there is evidence that robust ACP is a superior form of ACP. Without such evidence the force of my argument diminishes, since I could not then successfully argue why, even with the failure of basic ACP in practice, there is a moral obligation for health care organizations to supplant basic ACP with robust ACP. The need for evidence of the success of robust ACP is further validated when we consider that fulfilling this obligation has financial and resource costs to health care organizations.

There is at least one ACP program described by the Institute of Medicine with demonstrable and reproducible outcomes that also meets the "robust" ACP criteria.<sup>44</sup> Gundersen Health System's Respecting Choices model is

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40. COMM. ON APPROACHING DEATH & INST. OF MED., *DYING IN AMERICA: IMPROVING QUALITY AND HONORING INDIVIDUAL PREFERENCES NEAR THE END OF LIFE* 117–18 (2014).

41. *Id.*

42. *Id.* at 6–20.

43. *Id.* at 12.

44. *Id.* at 179–81.

widely recognized as a highly successful ACP program.<sup>45</sup> Gundersen Health System is located in La Crosse, Wisconsin.<sup>46</sup> Outcomes data shows that as of 2008, ninety-six percent of decedents in La Crosse County had some sort of advance care plan that was documented in their medical records and that treatment decisions were consistent with patients' treatment preferences and ACP instructions 99.5% of the time.<sup>47</sup> The program produces educational materials for persons wanting to create advance care plans, it trains ACP facilitators to converse with persons during the ACP process about their individual values, goals, and treatment preferences, and it works to ensure advance care plans are available to patients, medical providers, and patients' loved ones wherever they receive care in the community.<sup>48</sup>

The Respecting Choices program also has been adapted and implemented with equal success in many other health care settings both nationally and internationally. In a randomized controlled trial, Maureen Lyon, et al., utilized this program in doing ACP with teens with cancer, showing the program decreased anxiety and depression among study participants from baseline to three months post-intervention.<sup>49</sup> Kristen Pecanac, et al., further showed that this program was able to increase the prevalence of advance directives in several racially and ethnically diverse communities in the United States (overall from 25.8% to 38.4%).<sup>50</sup> Jürgen in der Schmitten, et al., implemented this program in German nursing homes, showing a significant increase in advance directive completion (36% among the study group compared to 4.1% in the control group) with noted relevance in medical decision making.<sup>51</sup> In another randomized controlled trial in Australia, Karen Detering, et al., showed that 84% of the study subjects who underwent ACP expressed their treatment preferences or appointed health care agents, or both, and that as a result of ACP, families of deceased patients experienced notably less stress, anxiety,

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45. COMM. ON APPROACHING DEATH & INST. OF MED., *supra* note 40, at 179–81.

46. *Id.* at 179.

47. Bernard J. Hammes et al., *A Comparative, Retrospective, Observational Study of the Prevalence, Availability, and Specificity of Advance Care Plans in a County that Implemented an Advance Care Planning Microsystem*, 58 J. AM. GERIATRICS SOC'Y 1249, 1252 (2010).

48. *Respecting Choices*, GUNDERSEN HEALTH SYSTEM, [www.gundersenhealth.org/respecting-choices](http://www.gundersenhealth.org/respecting-choices) (last visited Oct. 17, 2016).

49. Maureen E. Lyon et al., *A Longitudinal, Randomized, Controlled Trial of Advance Care Planning for Teens With Cancer: Anxiety, Depression, Quality of Life, Advance Directives, Spirituality*, 54 J. ADOLESCENT HEALTH 710, 715 (2014).

50. Kristen E. Pecanac et al., *Respecting Choices® and Advance Directives in a Diverse Community*, 17 J. PALLIATIVE MED. 282, 285 (2014).

51. Jürgen in der Schmitten et al., *Implementing an Advance Care Planning Program in German Nursing Homes*, 111 DEUTSCHES ÄRZTEBLATT INT'L 50, 53 (2014).

and depression after the death than those of family members of a deceased patients who died without having done any ACP.<sup>52</sup>

This section highlights sound, practical reasons why robust ACP should be the new ACP standard for health care organizations in the United States. However, it is not yet clear how or why these reasons translate into a moral obligation for health care organizations to develop robust ACP programs. I now turn to add support to this obligation by showing how robust ACP aligns with several moral frameworks commonly utilized within the realm of medical ethics.

#### IV. MORAL FRAMEWORKS SUPPORTING ROBUST ACP

The purpose of this section is not to give a fully detailed account of how different moral frameworks support ACP in general or robust ACP in particular. Instead, the purpose of this section is to give reasonable accounts of how each of the following moral frameworks—Principlism, Utilitarianism, Virtue, and Care—can be used to justify health care organizations having a moral obligation to develop robust ACP programs. Absent in this section, then, is any sort of exploration or justification about how or why each of the frameworks discussed should themselves be valued as barometers of moral action. It is merely assumed in this section that each of the moral frameworks discussed is a valid construction of how persons think about morality in medical practice.

##### A. *Principlism*

Perhaps one of the most well-known frameworks for addressing ethical issues in medical practice is the principle-based approach of Beauchamp and Childress.<sup>53</sup> Each of the four major principles discussed by Beauchamp and Childress, as well as the principle of informed consent (which they subsume under respect for autonomy), is demonstrated in robust ACP.

As Beauchamp and Childress describe it, respect for autonomy is a principle in which there is an acknowledgement that individuals have the “right to hold views, make choices, and to take actions based on personal values and beliefs.”<sup>54</sup> In addition to being a moral right of autonomous individuals—broadly construed as individuals who are capable of making their own decisions<sup>55</sup>—the ability of autonomous individuals to hold views, make decisions, and act on their personal values and beliefs is a constitutionally-

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52. Karen M. Detering et al., *The Impact of Advance Care Planning on End-of-Life Care in Elderly Patients: Randomised Controlled Trial*, 340 *BMJ* 847 (2010), <http://www.bmj.com/content/340/bmj.c1345>.

53. BEAUCHAMP & CHILDRESS, *supra* note 24, at 12.

54. *Id.* at 63.

55. *Id.* at 58.

protected right.<sup>56</sup> ACP aims to help individuals express their goals and values that will guide treatment decision making during times when those individuals are not decisional.<sup>57</sup> ACP, in essence, aims to give individuals a voice in their medical care even after they have become voiceless. In this regard, a core element of ACP is respect for autonomy.

One of the key components to making autonomous decisions is knowledge and understanding about one's available choices.<sup>58</sup> Obtaining informed consent is also a legal requirement prior to initiating any treatment with a patient.<sup>59</sup> Herein is a significant moral distinction between basic and robust ACP. As previously noted, basic ACP operates under the assumption that individuals have *a priori* treatment preferences that are well-formed based on their individual goals and values.<sup>60</sup> Yet there is no way under basic ACP to verify whether individuals have or have not received important medical information about their states of health that would reasonably shape or influence their treatment preferences. Imagine, for example, someone with a new diagnosis of congestive heart failure is completing an advance directive under the rubric of basic ACP and is attempting to decide whether he or she wants CPR in the event of a cardiopulmonary arrest. How is this individual to know whether CPR would or would not be medically advisable prior to completing the form, and how would a physician know whether to question the individual's CPR choice once the advance directive is complete? In this case it is clear that the individual is not making an informed choice, but unless the physician is prompted to review the advance directive with the patient, it is likely the individual's choice will go unquestioned.

Robust ACP—as an intensive or comprehensive form of ACP—makes it a point to have individuals reflect on their decisions and to uncover gaps in understanding that could have significant impacts on their choices.<sup>61</sup> *A priori* preference formation is not assumed under robust ACP; instead, robust ACP recognizes that treatment preferences depend on contextual information.<sup>62</sup> As such robust ACP aligns with ethical and professional obligations of informed

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56. *Id.* at 63.

57. Lois Snyder et al., *American College of Physicians Ethics Manual*, 156 ANNALS INTERNAL MED. 73, 82 (2012).

58. Richard H. Workman, Jr. et al., *Clinical and Ethical Implications of Impaired Executive Control Functions for Patient Autonomy*, 51 PSYCHIATRIC SERVS. 359, 360 (2000).

59. 42 C.F.R. § 482.13(b)(2).

60. Patricia A. Bomba, *Advance Care Planning*, PUB. HEALTH & EMERGENCY, Sept. 2016, at 1, 4, <http://phe.amegroups.com/article/view/3587/4324>.

61. Daisy J.A. Janssen et al., *Advance Care Planning for Patients with COPD: Past, Present and Future*, 86 PATIENT EDUC. & COUNS. 19, 20, 22 (2012).

62. Heidi Scharf Donovan, *An Update on the Representational Approach to Patient Education*, 39 J. NURSING SCHOLARSHIP 259, 265 (2007).

consent to ensure individuals are making well-informed decisions when creating advance care plans.

Robust ACP can also be seen in terms of the principles of beneficence and nonmaleficence. In general, beneficence is about intentionally acting for the sake of patient benefit,<sup>63</sup> while nonmaleficence is acting to avoid patient harm.<sup>64</sup> We know from the studies conducted with robust ACP programs that they are proven to improve patient outcomes in several significant ways, such as helping to create treatment plans that are better followed by health care agents and medical providers, by allowing patients to receive the levels of care they want, and by helping improve patients' overall experiences of illness and death.<sup>65</sup> In this regard, robust ACP can be valued in terms of acting to benefit patients and avoiding harm to them. By helping to ensure that treatment decisions for incapacitated patients align with their individual treatment preferences, robust ACP better ensures that incapacitated patients receive the treatments they want while also helping them to avoid getting treatments they do not want. An additional benefit here with robust ACP is that by further helping improve the accuracy of the treatment decision-making process for patients (who are receiving the treatments), their loved ones (who may otherwise question whether a treatment decision was the "right" one), and medical providers (who are responsible for the actual care of patients), robust ACP can further help diminish the possibility that medical providers, health care agents, and patients' loved ones will experience moral distress over a treatment decision.

Robust ACP also exemplifies the principle of justice in at least two ways. If we think about justice as all people in the same situation being treated equally and fairly regarding decisional processes without being subjected to third-party coercion or bias, then the first way in which robust ACP aligns with justice is that it insulates incapacitated persons from being subjected to third-party decisions based on interests that are not their own. Again, for persons with unknown treatment preferences who need medical treatment, the default position of medical providers is to treat to the fullest extent possible.<sup>66</sup> The reason for this default is twofold: (1) so that medical providers are not put in the position of trying to assume a patient's treatment preferences by offering too little treatment; and because (2) in acute situations, the failure to treat can—and often does—result in the death of the patient. As a former attending physician of mine would say of clinical ethics cases when it was unclear whether an incapacitated patient with unknown treatment preferences would want to continue or forgo life-sustaining treatment, providers only get one

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63. Harter, *supra* note 3, at 150.

64. *Id.* at 151.

65. *Id.* at 150.

66. COMM. ON APPROACHING DEATH & INST. OF MED., *supra* note 40, at 12.

chance to make the wrong choice—meaning if there is a decision to forgo effective life-sustaining treatment, and the incapacitated patient truly wanted to continue with treatment, the decision to forgo treatment not only would be wrong but also likely uncorrectable since the removal of life-sustaining treatment usually has a fatal result.

The problem with this reasoning is that it is, itself, a value judgment about providing medical treatment to patients in need. Whether and why this default position is ethically or morally justifiable in all cases is not in question here. The point here is that persons with unknown treatment preferences will be subjected to treatments they otherwise might not want, especially in the case of an acute medical event, which could leave them in permanently incapacitated states and continuing to receive the otherwise unwanted treatments indefinitely. Further, the decisions about whether or not to initially treat or continue ongoing treatment are not decisions they (the incapacitated patients) get to participate in.

Robust ACP can help correct patients being exposed to this default position within medical practice by providing them the opportunity to identify their treatment preferences and to have those preferences recognized and honored by medical providers. Likewise, when persons' treatment preferences are unknown, loved ones might be asked to assist in the decision-making processes and might use their own values and beliefs to guide decision making instead of trying to make decisions for those incapacitated individuals as they would if they were decisional. Here, again, robust ACP helps to ensure that incapacitated persons are treated equally and fairly in the treatment decision-making process by allowing them to articulate and incorporate their own treatment preferences, goals, and values in the decision-making process.

Tied to this first way in which robust ACP exemplifies justice, robust ACP also exemplifies justice regarding fair use of resources and the individual economic considerations of incapacitated persons receiving medical treatment. As I have argued elsewhere, the failure to implement ACP programs leads to wasteful medical spending at the end of life.<sup>67</sup> This is based on Medicare data that shows having more medical treatment within the last two years of life does not actually help improve the quality or length of one's lifespan.<sup>68</sup> Maintaining the status quo of ACP is thereby economically unjust as the cost of spending on end-of-life care is an economic burden paid by all U.S. citizens that is not only unsustainable, but it does not actually improve end-of-life care. Secondly, data shows that most persons prefer limited medical interventions when they are nearing death.<sup>69</sup> Unfortunately, some individuals who prefer limited

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67. Harter, *supra* note 3, at 150.

68. *Id.* at 149.

69. See Bernard J. Hammes & Brenda L. Rooney, *Death and End-of-Life Planning in One Midwestern Community*, 158 ARCHIVES INTERNAL MED. 383, 389 (1998); Alexi A. Wright et al.,

interventions are likely to experience an acute medical event in which they become mentally incapacitated prior to exploring and articulating their treatment preferences. These individuals will be subjected to the default position of medical practice to treat to the fullest extent possible. As a result, these individuals will also therefore be subjected to whatever economic costs are associated with receiving otherwise unwanted treatment, including costs associated with the treatments themselves, as well as legal fees associated with any estate issues that might need to be addressed once they become incapacitated.

### B. *Utilitarianism*

Utilitarianism is a framework in which the moral worth of an action is determined not just by the consequences of the action but also by whether the action itself complies with desired outcomes or socially accepted principles or rules.<sup>70</sup> For incapacitated individuals in need of medical care, decisions are made according to what third parties—namely, medical providers and surrogate decision makers—believe are in those persons' best interests.<sup>71</sup> What constitutes "best interest" is a balance between a patient's current medical state, the available treatment options, and the patient's known treatment preferences.<sup>72</sup> When persons' treatment preferences are unknown, medical providers and surrogates are left to determine whether available treatment options align with those persons' goals and values.<sup>73</sup> The less that is known about a person's goals and values, the harder it is to determine what the desired outcome of treatment should be. Presuming a person's treatment preferences, goals, or values are completely unknown, the desired outcome, as noted in the previous section, is a default position of maximal treatment to sustain life.<sup>74</sup>

Robust ACP allows individuals to articulate for their health care agents and medical providers what are their preferences, goals, and values—in short, their

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*Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment*, 300 JAMA 1665, 1668 (2008); Maria J. Silveira et al., *Advance Directives and Outcomes of Surrogate Decision Making Before Death*, 362 NEW ENG. J. MED. 1211, 1216 tbl. 2 (2010).

70. COMM. ON APPROACHING DEATH & INST. OF MED., *supra* note 40, at 12, 140–41.

71. BEAUCHAMP & CHILDRESS, *supra* note 24, at 99; *see also* COMM. ON APPROACHING DEATH & INST. OF MED., *supra* note 40, at 131.

72. R.M. Hare, *A Utilitarian Approach*, in A COMPANION TO BIOETHICS 80, 80–82 (Helga Kuhse & Peter Singer eds., 2nd ed. 2001).

73. *See* Carl Elliott, *Patients Doubtfully Capable or Incapable of Consent*, in A COMPANION TO BIOETHICS, *supra* note 72, at 452, 454 (suggesting that "when incompetent persons have not expressed any such wishes, surrogates should rely on the 'substituted judgment' standard, according to which decisions are reached according to what patients would have decided if they were able, based on the patients' values, goals, and desires").

74. *See* COMM. ON APPROACHING DEATH & INST. OF MED., *supra* note 40, at 12.

desired treatment outcomes. As a matter of medical providers and health care agents acting to make treatment decisions for incapacitated patients, knowing those patients' preferences, goals, and values allows providers and health care agents to make decisions that best align with what those patients' would select for themselves if they were decisional. In terms of Utilitarianism, robust ACP is morally justified as a way to establish the outcomes for which treatment decisions should aim.

As discussed in the previous subsection, robust ACP also aligns with accepted ethical principles of medical practice. As such, what constitutes morality in medical practice in terms of Utilitarianism is whether or not decisions comply with these accepted norms of medical practice. Robust ACP thusly aligns with Utilitarianism in that it allows for medical providers and health care agents to make decisions for incapacitated persons in ways that are supported by common principles of medical practice.

### C. *Virtue Approach*

Morality based on virtue focuses on character development. This framework centers on the question: How does a virtuous person act?<sup>75</sup> In this very broad sense, robust ACP does not necessarily inspire one to adopt traits or act in ways that might be considered virtuous. It actually may be the case that through the process of ACP, one might articulate treatment preferences that others find to lack virtuous content. For example, if someone in an extremely poor state of health (i.e., a state in which aggressive forms of treatment predictably will not work to restore health or promote life) prefers to receive full treatment measures without concern for the overall ineffectiveness of treatment or the potential financial burden selecting full treatment could place on the person's loved ones, then one could reasonably argue that the individual is being selfish or callous to the concerns of medical providers or loved ones.

However, a basic tenet of a virtue-based approach to morality is personal reflection.<sup>76</sup> One cannot hope to attain a virtuous character without reflecting on how one's current character traits or choices may or may not align with being virtuous.<sup>77</sup> So in terms of virtue, it is preferable, as a means of cultivating a virtuous character, for an individual to reflect on his or her treatment preferences, goals, and values despite whether or not that individual will actually ever face a situation in which he or she becomes incapacitated and treatment decisions fall to third parties. A basic element of robust ACP is to encourage reflection and understanding on the part of persons doing the

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75. Justin Oakley, *A Virtue Ethics Approach*, in *A COMPANION TO BIOETHICS*, *supra* note 72, at 88.

76. *Id.*

77. See BEAUCHAMP & CHILDRESS, *supra* note 24, at 38 (discussing the conscience as a "form of self-reflection").

planning,<sup>78</sup> and so, at least in terms of virtue, it is a practice that is supported under this moral framework. This is especially true in contrast to basic ACP, which asks persons to articulate their treatment preferences without actually urging reflection of those choices and understanding of how those choices align with persons' actual states of health and realistic medical possibilities.

#### D. Care Approach

Robust ACP is also supported under a care-based moral framework. I discuss this framework last for two reasons. First, it is one of the least popular ways of considering ethics and morality in medical practice.<sup>79</sup> This is because questions of patient care are not orientated around the patient *per se* but are instead orientated around the relationships patients have with others.<sup>80</sup> Second, the care approach is reasonably the framework that best matches the purpose and force behind ACP.

A care approach to ethical or moral thinking is the idea that people sometimes do not make decisions by appealing to abstract principles, but instead they make decisions by appealing to the social context in which those decisions are made.<sup>81</sup> Its central tenants are that people see themselves—and interact with others—via their relationship roles (e.g., parent, child, friend, relative, significant other), and that the relationships individuals have to one another are the basis of each person's identity formation.<sup>82</sup> Under this approach, not only do individuals have moral standing but so do their relationships.<sup>83</sup>

Considering the purpose of ACP as well as some of the consequences of not having an advance care plan in times of need, how it fits within this framework becomes obvious. Medical providers have a professional responsibility to act in patients' best interests as the individuals responsible for administering treatments.<sup>84</sup> When treatment decisions align with patients' known preferences, medical providers can feel confident they are correctly fulfilling their responsibility. However, providers may question whether they are correctly fulfilling their responsibility to act in a patient's best interests when it is unclear whether treatment decisions align with what an incapacitated patient would truly want. Likewise, loved ones of incapacitated patients

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78. See P. Gardiner, *A Virtue Ethics Approach to Moral Dilemmas in Medicine*, 29 J. MED. ETHICS 297, 301 (2003).

79. See Michelle Howard et al., *Advance Care Planning, Let's Start Sooner*, 61 CANADIAN FAM. PHYSICIAN 663, 663 (2015) (discussing elements that a good ACP should have).

80. See Rita C. Manning, *A Care Approach*, in A COMPANION TO BIOETHICS, *supra* note 72, at 98–105.

81. *Id.* at 101.

82. *Id.* at 102.

83. *Id.* at 101.

84. See generally AM. MED. ASS'N, CODE OF MEDICAL ETHICS (2001).

typically believe it is their responsibility, by virtue of their relationships to those patients, to make treatment decisions that align with the patients' values, goals, and preferences, and may believe they have failed to fulfill this responsibility if they are unsure whether treatment decisions truly reflect what those patients would have wanted. When decisions have to be made for incapacitated persons with unknown preferences, the relationships between providers and patients' loved ones can also become strained as both parties may argue—while individually experiencing guilt or distress—over whether the “right” decisions were made. Loved ones may further experience anger and frustration toward patients for not previously articulating their treatment preferences.

One of the primary values of ACP—perhaps *the* primary value—is that medical providers and health care agents know, or at least have a good sense of, what decisions to make for incapacitated patients. We know that even when treatment decisions result in a patient's death, the patient's loved ones experience less anxiety and depression when there is an ACP that helped guide the decision-making process.<sup>85</sup> The reason is that the patients' loved ones feel confident that they made decisions that best aligns with the patients' known values, goals, and preferences.<sup>86</sup> Providers, too, are likely apt to experience less distress if they know patients' treatment preferences have been honored in practice.

Robust ACP also reflects the care approach in the motives persons have for doing ACP. It is common during the ACP process for persons to orient their values, preferences, and choices for health care agents to their personal relationships. While some persons might appeal to their autonomous rights to make their preferences known to medical providers as their motivation for doing ACP, it has been the experience of this author that the reasons people most often give for why they do ACP center around wanting their loved ones to be aware of what matters the most to them and not wanting to burden loved ones with having to guess about what sorts of treatment decisions to make on their behalf.

For Dr. Bernard Hammes, founder and director of the Respecting Choices program, the core of ACP is the reciprocal care that results from the planning process between the persons doing the planning and the surrogates—typically family members—who will be responsible for enacting the plan if needed.<sup>87</sup> In a 2014 interview with CBS about the Respecting Choices program, Dr. Hammes noted that, “I think the ultimate topic that's being discussed is how people care for each other. And so what comes out at the end of the

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85. Detering et al., *supra* note 52, at 1.

86. *Id.* at 7.

87. BERNARD J. HAMMES, HAVING YOUR OWN SAY: GETTING THE RIGHT CARE WHEN IT MATTERS MOST 16 (2012).

conversation is, 'I love you, and I now know how to take good care of you.'"<sup>88</sup> In Dr. Hammes' view, the purpose of ACP has less to do with ensuring basic principles of patient care and more to do with the relationships people have with their loved ones.<sup>89</sup>

## V. CONCLUSION

Work in the field of ACP provides empirical evidence that the standard of care is—or at least should be—shifting from basic to robust ACP. By not working to transition the standard of care from basic to robust ACP, health care organizations are providing what can reasonably be viewed as suboptimal care to patients. It is thusly argued in this paper that there is a moral obligation of health care organizations to develop robust ACP programs, primarily by showing the practical evidence of the success of robust ACP, while then showing how and why robust ACP fits within standard moral frameworks that guide ethical medical practice.

There is, admittedly, a significant limitation of this argument, as I did not attempt to give an in-depth argument for why health care organizations should bear the responsibility of fulfilling this obligation as opposed to some other organization or entity. I only highlighted in the introduction why it is reasonable to assume that health care organizations should take on the work of developing ACP programs, but I did not carefully tie these reasons to the moral obligation to develop robust ACP programs for which I subsequently argued. Future work in this area should first attempt to develop stronger arguments for why health care organizations should be obliged to develop robust ACP programs. These arguments will likely need to come from either the realms of business ethics or organizational ethics, as opposed to medical ethics alone.

The next step beyond establishing this moral obligation is to clearly identify the legal rights and risks of both following and failing to follow this obligation. For example, if we know that robust ACP improves outcomes related to patient and family experiences and is necessary toward ensuring the obligation of informed consent, would a failure of health care organizations to develop robust ACP programs be akin to medical negligence? And if so, how? What will help further support moral and legal arguments in favor of robust ACP is additional research that not only shows the impact of robust ACP on different aspects of patient care but also the impacts on providers and loved ones honoring advance care plans, with a particular focus on their long-term health outcomes as well.

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88. *Being Prepared for the Final Days*, CBS NEWS (Apr. 27, 2014), <http://www.cbsnews.com/news/being-prepared-for-the-final-days/>.

89. HAMMES, *supra* note 87, at 13–14.