down and flip the turtle back over. Flustered and highly inconvenienced, the turtle scuttled away. Behind it, a small pair of hands and knees pressed against the ground.

“I saw the whole thing – that was *rad*!” A freckled face was brought before Todd’s, the buck-toothed child crouched low. “You *saved* that turtle! You’re a hero, mister!” The boy’s breath smelled like fruit punch. Todd tasted salt. “How do you feel?!” The kid demanded, bringing his face even closer. With great effort, Todd blinked.

“Shouldn’t…you…be…in…school?” he managed.

“You’re bleeding a lot, mister.” The boy’s blue eyes bore into Todd’s, alight with awe and the thrill of fear. “Are you okay?”

“—I-I’m so, *so* sorry, sir! The ambulance is on its way.” It was the first voice, accompanied by a hot hand on his shoulder blades. “Isaac, leave him alone!” the man added, and Todd watched as the boy retreated in shame.

“No, Isaac…don’t,” Todd mumbled weakly, “not yet.”

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The ambulance was bright light and pricks and tubes he couldn’t feel and agony that muted everything. Isaac’s father told the EMTs that he’d accidentally run Todd over, but didn’t mention the turtle. This bothered Todd. *I wasn’t trying to die*, Todd wanted to say. He wanted to rudely interrupt, like someone with authority. Instead, Todd alternated between opening his eyes and closing them, but both options were starting to look the same.

“We’re almost there, sir,” one of the EMTs assured Todd, and he wondered if they were touching him.

Todd wondered if he should tell them that he had been harboring a brain tumor for the last twenty-five years. He wondered if it would matter. He decided that, if he had just one story left, he would tell them about the turtle. *I was a hero*, he would say. *It was rad*. Besides, he couldn’t feel it just then. What an odd time for a tumor to take a nap, he thought.

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# Ethical Dilemmas to Ambiguous Definition of Autonomy:

## Adavanced Care Planning and End of Life Decisions for Cancer Patients

Elizabeth Magill

**Introduction**
With an aging population and higher mortality rates in hospitals than ever before,[1] the process of advanced care planning (ACP), or “communication between individuals and their health care agents to...discuss and plan for future health care decisions for a time when individuals are not able to make their own health care decisions,”[2] is becoming increasingly important in the United States. In November 2015, Medicare issued a statement outlining changes that will fund ACP appointments for Medicare patients beginning in January 2016.[3] While this marks a general acceptance for ACP, the process has not yet been successfully utilized for specific illnesses such as advanced cancer. There are a variety of reasons, including younger patient age and unwillingness to appear pessimistic,[4] that doctors are hesitant to discuss death with these patients, but evidence suggests that without ACP cancer patients’ end-of-life wishes are not met. Although most cancer patients want to die at home, unless patients have explicitly discussed or written down their preferences proxies are more likely to provide all care possible than limit life-prolonging treatment.[5] Some of these treatments, including ICU admission, are linked to substantially worse quality of life for patients’ last weeks.[6] Despite the clear necessity for more ACP with cancer patients, the potential for remission makes beginning these conversations extremely difficult.

While it is clear that ACP should be implemented to increase patient autonomy in end-of-life decisions, there is controversy surrounding the timeframe of such interventions; some ethicists believe that ACP should begin as soon as possible, but others argue that these discussions should only be started once cancer is at its terminal stage. Both groups, despite their different perspectives, state that their method best preserves patient choice—highlighting a broader tension about the definition of autonomy in end-of-life medical care.

**Timeline 1: Outpatient Visits after Cancer Diagnosis**
Many scholars argue that ACP for cancer patients should occur right after diagnosis of the disease during outpatient oncology visits. This perspective is backed by both the American College of Physicians and Canadian Medical Association[7] and echoes the push for ACP to be integrated into all general adult medical visits. Much of the stigma around ACP, it is argued, comes from the modern stigma around death. Surgeon and public health researcher Atul Gawande, in his book *Being Mortal: Illness, Medicine, and What Matters in the End*,[8] states that with current medical technology, death has become regarded as abnormal rather than part of a natural course, as it was characterized through most of history. He argues that

death now comes in stages, with patterns of illness and suffering gradually decreasing quality of life until final death—making it harder to qualify which occurrence will actually signal the end. Because of this, death is uncertain and ACP is ignored. Even with more knowledge about end of life care, the only type of ACP that increased significantly from 2000 until 2012 was durable power of attorney assignment. In 2012, 40% of cancer patients in a study by the *Journal of the American Medical Association* still had not talked about end of life preferences before death with physicians or family members.[9]

In order to reverse this silence, scholars argue that it is necessary to begin talking about end-of-life care as early as possible. Early outpatient oncology visits are seen as the most optimal time to begin ACP primarily because these initial outpatient appointments set standards for future agendas and discussions. Thus, only through initiating ACP directly following cancer diagnosis will ACP be fully integrated into all cancer treatment decisions. This perspective argues that integration is the most important part of ACP, as it normalizes discussions about death and end-of-life early to encourage numerous conversations between physicians, patients, and family members throughout different stages of cancer treatment.[10] While decisions do not need to be made within the first session of ACP, incorporating these considerations into standard cancer care ensures that ACP happens at all. In two studies of cancer patients published by the *Journal of Psycho-Oncology*,[11] 58% and 87% of patients respectively supported a policy in which ACP was offered in the hospital admissions process—45% of the patients in one of these studies did not have advanced directives because their doctors had not approached the subject until they felt emotionally unable to make decisions regarding end-of-life treatment. Interviews with terminal cancer patients also found that the longer doctors waited to begin ACP, the lower their satisfaction rating from family members who felt that they had given up hope for the patient.[12] Early ACP ensures that the end-of-life care process for cancer patients is standardized, ensuring conversations begin and decreasing stigma around discussion of death.

Even if ACP occurs later in cancer treatment, many ethicists substantiate early introduction because beginning end-of-life discussions upon diagnosis of cancer also increases the likelihood that patient decisions are rational. Discussions can continue for months or even years through this process, allowing the patient to obtain sufficient information to make clear decisions about treatment options and talk about different aspects of their care decisions with family members and physicians. After cancer treatment, the psychological and emotional impacts of pain and suffering leave patients more likely to make decisions in distress, not fully elucidating or even knowing the options for their true preferences.[13] At the same time, as cancer becomes more serious family members tend to become more involved, many of whom pressure patients to continue treatment or agree to life-saving procedures that the patients themselves may not choose. According to a study from the National Cancer Society,[14] as cancer treatment progresses, family-controlled decisions increase from only 1.5% to almost 20% of decisions and decisions labeled "equally sharing" encompassed almost 60% of advanced cancer treatment choices. Meanwhile, family members were significantly more likely than patients to speak positively to oncologists about continuing invasive cancer treatment,[15] exhibiting their motivation to change patients' decisions. Due to these factors, this perspective argues that early ACP at outpatient visits is essential to allow patients to make informed independent decisions.

Finally, scholars who argue for the initiation of ACP as early as possible explain that beginning ACP can initiate discussions about life goals, wishes, and desires that can improve life even before end-of-life care is necessary.[16] In La Crosse, Wisconsin, for example, ACP was standardized through a report entitled "Respecting Choices Advanced Care Planning,"[17] requiring all patients to fill out an advanced care directive upon entering any doctor's office or hospital. Because of this, 96% of adults in the city have an advanced care directive, and almost all of individuals with an advanced care directive have reported at least 3 conversations with a family member regarding their end of life choices.[18] Patients remarked in an analysis of the change that these discussions often quickly diverged from end-of-life preferences to desires and wishes that they wanted fulfilled before reaching that stage, such as travel, more time with family, and other personal goals.[19] Reflection upon current life, in addition to improving ACP discussions and rationality, provides evidence for the perspective that ACP should be implemented at outpatient visits directly after diagnosis of cancer.

### Timeline 2: Terminal Cancer

Although traditional ACP may be moving toward earlier implementation, some scholars argue that cancer ACP should be initiated at a later stage due to the distinct differences between cancer patients and the general population. Cancer ACP is recognized as significantly distinct from traditional end-of-life care, particularly due to the unpredictable nature of the disease and numerous treatment options available. Beginning ACP too early may signal that a doctor does not have hope for the current method of treatment, potentially isolating patients and family members, or emotionally overwhelm a patient attempting to cope with the implications of a cancer diagnosis.[20] Thus, these scholars argue that cancer ACP needs to be initiated more carefully than traditional end-of-life care discussions with Medicare or other generally healthy patients. To balance seriousness of illness with rational decision-making capability, scholars of this perspective argue that ACP should begin when cancer is labeled terminal, also known as end-stage or advanced cancer. Describing cancer as "terminal" expresses that the patient will have six months or less to live if the disease continues its current course.[21] This timing postpones ACP until it is required prior to potential end-of-life decisions.

The main reason that some scholars argue that physicians should wait to initiate ACP until terminal cancer diagnosis is the resistance of cancer patients at earlier stages to honestly discuss end-of-life care. Unlike Medicare patients with chronic illnesses, cancer patients are of all different ages and stages of life, making discussion about end-of-life planning considerably more difficult than with older patients naturally approaching death. Patients in their twenties and thirties diagnosed with breast cancer may not be able to cope with their initial diagnosis at such a young age, let alone also be forced into ACP during early outpatient sessions. Many of these patients might also have considerable treatment options and potential for remission, questioning the necessity of ACP for these cases in the first place. In a study of advanced cancer patients published by the *Journal of Palliative Medicine*,[22] participants focused most on the psychological and social implications of ACP, noting that they would not agree to discuss these options until it was necessary. Over 60% of patients rejected ACP the first time it was brought up by their doctor, citing the fact that it was too early to begin discussions about death.[23] Yet at the same time, patients recognized that cancer progression would force them to change their outlook on treatment: "If I progress...to another stage...I would...address a lot more of this."[24] By deferring ACP until terminal cancer diagnosis, doctors can still provide hope and not overwhelm their patients while still ensuring that end-of-life discussions occur in a reasonable timeframe when necessary.

In addition to patient resistance to ACP at early stages, cancer ACP is arguably more effective when occurring closer to end-of-life care due to the patient's familiarity with their foreseen circumstances. Many patients with terminal cancer have already gone through some type of cancer treatment and so can more clearly identify with the pain and suffering that certain end-of-life care might entail, allowing them to be more accurate about their wishes. Almost 70% of patients with advanced care directives prior to initial cancer diagnosis in a study by the *Journal of American Geriatric Society*[25] made changes to this directive after undergoing chemotherapy. Once terminal diagnosis is accepted, patients are also undergoing ACP in very close timeframe to the potential treatment, allowing for more accurate representation of patient choice at the time of the decision—accounting for changes in preferences and wishes based on how the patient's life changed over the course of the disease. Familial and personal reflection will also be more honest and give consideration to all factors influencing the current decision, rather than theorizing about it as a future potential situation. According to a study from the National Institute of Medicine,[26] advanced cancer patients admitted to not fully discussing or understanding ACP decisions because at the time they did not believe that the cancer would progress to its current stage. Temporal and physical closeness to end-of-life care after cancer is diagnosed as terminal allows for patients, families, and physicians to begin honest discussion about future treatment wishes and potential end-of-life options.

### Advanced Care Planning and Autonomy

Both stances surrounding cancer ACP employ conflicting evidence of patient preference about timing of end-of-life care decisions. Because of the limited nature of this data, with less than 2,500 patients surveyed in each study on both sides of the debate, these inconclusive personal accounts will not be addressed in this essay as analysis of each timeframe. Instead, each argument will be evaluated against the goal of ACP noted in the first paragraph of the essay: autonomy of the patient. While true autonomy can never be achieved in end-of-life cancer care since patients will be unable to communicate competent decisions, autonomy through ACP intends to allow the patient to preemptively make decisions that he or she would want made at that time through advanced directives or instructions to a healthcare proxy.

Initiating cancer ACP under both conditions promotes autonomy in different, sometimes conflicting ways. Cancer ACP at initial cancer diagnosis advances autonomy of the patient by providing ample time for discussions and research about end-of-life treatment options. This extended timeline can allow patients time to not only read and talk, but also reflect before forced to make future decisions—the lower stress of decisions further away allows patients make clear, coherent choices. While ACP at terminal cancer diagnosis may occur later and not allow as much time for patients to make decisions or ask questions, this late initiation will also promote autonomy by allowing patients to make decisions that are more informed by their current state of life and potential past cancer treatments. Discussions may also be more autonomous at this later stage because patients are more likely to understand the gravity of their ACP, encouraging deeper research and reflection. These competing claims underlie questions of autonomy and what is necessary for an autonomous decision.

Numerous medical articles outline key characteristics necessary for an autonomous medical decision: ample correct information, voluntary choices about interventions, assurance that the patient is competent to make the decision.[27] While neither significant time to make decisions nor proximity to the decision are defining factors on most major lists, ethicists have begun to debate the importance of "personhood" in autonomous health care decision-making. Dr. Rebecca Dresser, professor of Law and Ethics at Washington University School of Medicine, and other prominent ethicists, particularly those who study autonomy for values of Alzheimer's patients, argue that because people change over the course of their lifetimes, advanced directives may be objected due to "the greater likelihood that the creator of the advanced decision would be ill-informed about his or her decision compared to the contemporaneous decision-maker."[28] Medical advances and tolerance of past levels of pain and suffering are given as two examples that could alter personhood between ACP and their end-of-life treatment.[29] Although current medical ethics does not reject advanced directives made significantly prior to end-of-life, there has been general agreement that more contemporary advanced directives support autonomy.

With this ethical research in mind, the benefits of waiting until terminal cancer diagnosis for decisions about end-of-life care outweigh the benefits to extra time and lower stress of making end-of-life decisions early in the cancer treatment process. However, beginning ACP does not imply that decisions must be made right at the beginning of cancer treatment; instead, integration of ACP only requires "communication between individuals and their health care agents."[30] A combination of these two options, then, would be most effective in order to ensure autonomy of patients making health care decisions: an initial discussion during outpatient sessions introducing end-of-life care and providing end-of-life information with serious ACP and decision making deferred until necessary at terminal cancer diagnosis. Due to the preference of cancer ACP decisions during the terminal stage, however, if patients choose to ignore or deny initial ACP at outpatient sessions they should be allowed to wait until terminal diagnosis to begin these discussions so as not to repel the patient. This approach successfully balances promoting autonomy through both early information and contiguous personhood at the point of decisions.

While combining both approaches to cancer ACP may answer the question of best timeframe most successfully, it also implies necessary inquiry about ACP itself: particularly the nature of 'communication' between patients and physicians. What does this communication entail? Must decisions about end-of-life care be made to consider communication successful? Preliminary research into the definition of ACP finds that contradictory definitions muddle answers to these important questions.[31] Until ACP is more concisely defined, separating end-of-life discussions and decisions is necessary to ensure that patients remain autonomous and rational to make the most informed choices for their care and promote their dignity until death.

### Conclusion

Through analysis of the two main bodies of research surrounding the timeframe of ACP for cancer patients, it is clear that each perspective utilizes separate definitions of ACP: ACP as end-of-life discussions or end-of-life decisions. As the definition of ACP currently stands from the International Society of Advance Care Planning & End of Life Care, cancer ACP should begin as early as possible but ACP decisions must remain at terminal diagnosis to ensure correct moral personhood. As this combination conclusion indicates, however, ACP debates uncover ambiguous and changing definitions of ACP and autonomy. Recognition of these ambiguities, and clarification of outcomes, are necessary to better address quality of end-of-life care and ensure that patient choice is preserved as much as possible.

### ENDNOTES

1. Institute of Medicine, "Committee on Approaching Death: Addressing Key End-of-Life Issues," *Dying in America: improving quality and honoring individual preferences near the end of life* (Washington D.C.: The National Academies Press, 2015).

2. International Society of Advance Care Planning & End of Life Care, "The definition of care planning" (2011).
<http://acpelsociety.com/acpdefinition.php>

3. Centers for Medicare & Medicaid Services, "Proposed policy, payment, and quality provisions changes to the Medicare physician fee schedule for calendar year 2016" (Washington, D.C.: U.S. Government Printing Office, 2015).
<https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2015-Fact-sheets-items/2015-10-30-2.html>

4. L. Levit, E. Balogh, S. Nass, P. Ganz; Edited by Committee on Improving the Quality of Cancer Care: Addressing the Challenges of an Aging Population, Board on Health Care Services, Institute of Medicine, "Delivering high-quality cancer care: charting a new course for a system in crisis" (Washington D.C.: The National Academies Press, 2013).

5. A.K. Narang, A. Wright, L. Nicholas, "Trends in advance care planning in patients with cancer: results from a national longitudinal survey," *Journal of the American Medical Association Oncology* 1.5: 601-608 (2015).
doi: 10.1001/jamaoncol.2015.1976

6. Ibid, 603.

7. I. Harle, J. Johnston, J. Mackay, C. Mayer, S. Russell, C. Zwall, *Advance care planning with cancer patients: a quantity initiative of program in evidence-based care, cancer care Ontario* (Ontario, Canada: Program in Evidence-Based Care, 2008).

8. Atul Gawande, *Being Mortal: Illness, Medicine, and What Matters in the End* (New York: Metropolitan Books, Henry Holt and Company, 2014).

9. Narang, et al. 605.

10. S. Johnson, P. Butow, I. Kerridge, M. Tattersall, "Advanced care planning for cancer patients: a systematic review of perceptions and experiences of patients, families, and health care providers," *Journal of Psycho-Oncology* (2015).
doi: 10.1002/pon.3926

11. Ibid.

12. Ibid.

13. J. Peppercorn, T. Smith, P. Helft, J. DeBono, S. Berry, "American society of clinical oncology statement: toward individualized care for patients with advanced cancer," *Journal of Clinical Oncology* (2011).
doi: 10.1200/JCO.2010.29.2599

14. G. Hobbs, M. Landrum, N. Arora, "The role of families in decisions regarding cancer treatments," *Cancer by the American Cancer Society* 121.7: 1079-1087 (2015).
doi: 10.1002/cncr.29064

15. Ibid.

16. Harle, et al. (2008).

17. Gunderson Health System, "Respecting Choices Advance Care Planning," Gunderson Health (2002).
<www.gundersonhealth.org/respecting-choices>

18. Gawande (2014), 134-5.

19. C. Joffe-Walt, "The town where everyone talks about death," *National Public Radio* (2014).
<http://www.npr.org/sections/money/2014/03/05/286126451/living-wills-are-the-talk-of-the-town-in-la-crosse-wis>

20. B. Kiely, M. Tattersall, M. Stockler, "Certain death in uncertain time: informing hope by quantifying a best case scenario," *Journal of Clinical Oncology* 28.16: 2802-2804 (2010).

21. Harle, et al. (2008).

22. K. Barnes, L. Jones, A. Tookman, M. King, "Acceptability of an advance care planning interview schedule: focus group study," *Journal of Palliative Medicine* 21:23-28 (2007).

23. Ibid, 25.

24. Ibid, 26.

25. T. Fried, K. Bullock, L. Iannone, "Understanding advance care planning as a process of health behavior change," *Journal of American Geriatric Society* 57.9: 1547-1555 (2010).

26. Levit, et al. (2013).

27. J. Billings and E. Krakauer, "On patient autonomy and physician responsibility in end-of-life care," Archives of Internal Medicine 171.9: 849-853 (2011).

28. R. Huxtable and R. Meulen, *The voices and rooms of European bioethics* (London, UK: Routledge, 2015): 94-95.

29. Ibid, 95.

30. Institute of Medicine, "Committee on Approaching Death: Addressing Key End of Life Issues," *Institute of Medicine* (2015).

31. L. Emanual, C. von Gunten, F. Ferris, "Advance care planning," Archives of Family Medicine 9.10:1181-187 (2000).

### WORKS CONSULTED

V. Entwistle, S. Carter, A. Cribb, K. McCaffery, *Journal of Geriatric Internal Medicine* 25.7: 741-845 (2010).

M. Gillick, "Advance care planning," *New England Journal of Medicine* 350.1: 7-8 (2004).

R. Sudore and T. Fried, "Redefining the "planning" in advance care planning: preparing for end-of-life decision making," *Annals of Internal Medicine* 153.4: 256-261 (2010).