

# Ethics Dispatch

*“The object of philosophy is the logical clarification of thoughts. Philosophy is not a theory but an activity.”*

- Ludwig Wittgenstein

## Hot Topic: Is Advance Care Planning Bogus?

Advance care planning (hereafter, ACP) involves a process where individuals identify, communicate, and document their healthcare preferences to ensure they receive the care they want. This process also involves appointing someone to communicate those preferences in the event they cannot speak for themselves. By many lights, the goal of ACP is goal-concordant care, that is, care that reflects a patient's goals/preferences. Let's suppose, for instance, that Dale's preference is to die a natural death in the event he's in a horrific car accident with irreversible loss of higher brain function and decisional capacity. If Dale communicates these preferences to his loved ones, documents them, and appoints someone to speak on his behalf (like his partner), we might say he has done his ACP. Ideally, these preferences will be communicated to Dale's medical team if/when he needs them, who will then offer treatment options that reflect Dale's own goals of care. Caregivers thereby will be able to ensure that goals of care are in line with and respect Dale's preferences.

ACP is considered normative and widely advocated by bioethicists. However, in a recent article titled “The Limits of Advance Care Planning,” Michael Pottash [calls ACP into question](#). He argues that ACP is self-defeating. Citing articles from [Health Affairs](#) and the [Journal of American Geriatrics Society](#), he notes that most Americans fail to complete advance directives (or living wills), and even if they do complete them, in many cases, they actually do not wish for their preferences to be followed. In other words, if the chief aim of ACP is goal-concordant care, then there is evidence to suggest that the process is ineffective at accomplishing this goal. These considerations have led some, like [Sean Morrison](#), to argue that ACP “is unlikely to ever achieve reliable occurrence of goal concordant care.”

While many would not go so far as to claim that ACP is self-defeating or unreliable, there are nevertheless legitimate concerns regarding the process. For instance, how can someone state a preference for a situation that has not occurred yet? What's more, how can you be sure that the person you appoint as a healthcare proxy will honor your decisions? Pottash's criticisms compound these issues. If Pottash is right, ACP is self-defeating and we have indeed “become enamored by the idea that clearly documented preferences” will save us “from some future purgatory between life and death.”

It bears mentioning that Pottash's evidence that most Americans do "not complete advance directives" is not itself a strike against advance directives or ACP. Rather, it implies that a small subset of the population completes an advance directive, a number that could change with more health education and advocacy. Also, Pottash's evidence for the claim that most "don't actually want their documented preferences to be followed" is lacking. This is because Pottash is citing a study with a very small sample size, which raises doubts about its generalizability. Also, the fact that patients in that study prefer that "their family and physician make resuscitation decisions for them" does imply that at least some individuals don't want that part of their documented preferences to be followed—or perhaps only if verified by their family and physician. Of course, delegating decisions about resuscitation to a healthcare proxy is itself a preference that can be accommodated in the ACP process.

Despite the obvious flaws in Pottash's argument, there are deeper, ethical questions belying ACP. The goal of ACP is to ensure that difficult medical decisions and interpretations of quality-of-life decisions remain up to the patient. But when a patient is not able to express those medical preferences, how can we be sure that ACP will achieve this goal, especially in complicated situations. The Case Study below highlights such a scenario.

## Bioethics in the News

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[Bioethics Institute Urges UK to review parental rights of very ill kids](#)  
[Reducing the Global Impact of Global Health Aid is Essential](#)

## Case Study: Trying to Honor Johnny's Wishes

Carson is a nurse at a long-term care facility.

He is caring for Johnny, an 88-year old, male-identifying patient, with a history of chronic respiratory issues and mild dementia. While retaining sufficient decisional capacity, Johnny appointed his youngest daughter, Kristin, as DPOA for healthcare decisions. Additionally, Johnny has granted Carson—and the medical team—access to his advance care planning documents, which specify his wishes in the event he loses decisional capacity.

Over time, Carson has grown close to this patient. When there is time to do so, he watches television, listens to music, and even plays board games with Johnny. During these moments, they share stories, discuss current events, and tell jokes from their favorite comedians.

Carson knows that Johnny's deepest wish is to reconnect with his estranged daughter before he passes away. He tells Carson, "I know I'm not doing well and that my time here is limited. So, I want you to promise me that you'll keep me alive long enough to touch my oldest daughter's hand and say goodbye." Carson shakes his hand, with every intention to keep this promise.

Weeks pass and Johnny's condition worsens. He is suffering complications from pneumonia, resulting in organ failure and fluid build-up in the lungs. Per Johnny's documented wishes, he remains at the LTC facility with no 911 calls for escalation to the hospital. Hospice workers come to coordinate his care, and it is anticipated that the patient may have only a few days before he passes. Kristin, the DPOA daughter, and her siblings, know that their father wants to die a natural death. Everyone is on board with this plan.

Carson is conflicted, however. He understands that Johnny's advance directive is consistent with comfort measures and no prolongation of dying. Carson knows also that, more than anything, Johnny had wanted to reconcile with and say goodbye to his oldest daughter, Maria, who lives across the country. She had hesitated to come, and now says she is making arrangements to do so. But the earliest arrival would be a week or more. Honoring Johnny's final wish for family unification implies life interventions as needed to keep him alive a bit longer.

Carson wholeheartedly believes the information he has from conversations with Johnny will or should make a difference to the care plan. So, he approaches Kristin, who promptly dismisses his concerns. She says, "No offense, but I think I know what my dad wants. He's written it down and communicated it to me and my family. He wants to be comfortable. If my older sister gets here in time to say goodbye, that's fine. If not, so be it. They were never that close anyway."

Johnny is no longer able to confirm or communicate his final wish to the rest of his family. And it had been verbal not written. His nurse also had neglected to chart this conversation in the patient's electronic medical record. There is no documentation that the conversation ever happened, despite a confirming handshake that Carson vividly recalls.

As Johnny is dying on hospice care, Carson desperately wants to keep his promise to help prolong life until there is opportunity to allow an estranged older daughter to hold her father's hand. The nurse acknowledges, however, that Kristin is the DPOA and that she is doing what her father had written in his advance directive. Carson is left with regrets.

## **Ethical Musings: The Importance of Appropriate Artifacts for Advance Care Planning**

Advance care planning (ACP) is ethically significant. This is because the ACP process carries potential for upholding ethics principles, like the principle of respect for autonomy. Roughly, this principle holds that we are morally obligated to respect a person's capacity to make their own decisions. Since ACP provides a means for capturing these decisions, medical providers can uphold the principle of respect for autonomy by offering treatment options that comport with a patient's desires. This process is significant, as it enables medical providers to promote and uphold a person's wishes in situations where they cannot speak for themselves.

How, then, should we understand the case study above? Did the ACP process fail to promote Johnny's wishes? Does the case scenario illustrate a failure in ACP? After all, Johnny's healthcare preferences for end-of-life care are well documented

and he had appointed his daughter Kristin as surrogate decision-maker. What's more, Kristin loves her father and wants what's best for him, so she wants to honor his wishes *as written*. Carson, however, had received additional, *verbally* transmitted directives from his patient. Left undocumented and not discussed with his DPOA and family, that part of Johnny's end of life wishes held little chance of being fulfilled by those legally charged with carrying out his advance directives. His nurse had been charged with doing so only informally, via a handshake. It proved insufficient at the time when decisions were made using surrogacy, and Carson was left morally distressed.

## Advance Care Planning as a Process with Artifacts

ACP is a process that involves artifacts. Procedurally, the aim of advance care planning is to ensure that the healthcare preferences of individual persons are reflected in the care they receive. Appointing someone to speak on your behalf when you cannot speak for yourself is part of that process. But it requires documentation, an artifact. ACP artifacts include the forms utilized by healthcare providers and found as a free download on the Center for Practical Bioethics website ([www.practicalbioethics.org](http://www.practicalbioethics.org)). We refer to them as a Healthcare Treatment Directive and a Durable Power of Attorney for Healthcare Decisions. Another important artifact for ACP (or, more specifically, serious illness care planning) is also found on our website: Kansas-Missouri Transportable Physician Orders for Patient Preferences ([TPOPP/POLST](#)). In other jurisdictions, this might be referred to as Physicians Orders for Life-Sustaining Treatments (POLST) or some variation of that, including the traditional Out of Hospital Do Not Resuscitate Order. Inpatient documentation of a DNR (or DNAR) order is an artifact directing in advance what should be done, or not done, for a patient at the end of life. Some patients have made video or audio recordings of their advance directives, have posted them in an online portal, and/or communicated wishes in a letter to those entrusted for surrogacy. ACP artifacts may differ from person to person depending on individual circumstances and preferences.

In a few highly publicized cases, a "Do Not Resuscitate" tattoo has been discovered on the chest of a person found down, not breathing or in cardiac arrest. That too is an artifact, although one that may leave more questions than clarity. ACP artifacts are an essential part of the process, but not all will be equally effective. Also, if there is a discrepancy between something stated in one artifact relative to another, or something merely said, not documented, there is the likelihood for controversy rather than clarity at the end of life. This is what happened in Johnny's case.

At the Center for Practical Bioethics, we have long emphasized the importance of "[caring conversations](#)." Write down your wishes, we say, but discuss them also with those you trust for surrogacy decisions, especially family and primary care providers. In Johnny's case, we note the ineffectiveness of conversation without an artifact, not even documentation in the patient's electronic medical record. There was a "caring conversation," yes, with someone trusted, a caring nurse. Unaccompanied by an appropriate artifact, the ACP process nonetheless failed in a way that mattered.

What might be done about Carson's moral distress while Johnny is dying? Errors of omission prior to loss of the patient's capacity cannot be undone. Going forward,

something might be learned about the necessity of artifacts for ACP process. For Johnny's sake, it is possible also that his caring nurse could approach the DPOA daughter once again with valid concerns. Prior to doing so, verification might be made with hospice staff that prolongation of the dying process is actually possible--it might not be--without unduly prolonging the patient's suffering, something Johnny also did not want. A family meeting convened by Carson might elicit a discovery that Johnny had conveyed to someone else also his dying wish to reconcile with daughter Maria.

While some things cannot be undone or accomplished after the fact, there remains a reasonable hope that something might yet be done, so as to honor Johnny's wishes to the fullest degree possible.

- By Polo Camacho, PhD and Terry Rosell, PhD, DMin