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Widespread Misinterpretation of Advance Directives and Portable Orders for Life-Sustaining Treatments Threatens Patient Safety and Causes Undertreatment and Overtreatment

Ferdinando Mirarchi, DO, FAAEM, FACEP†*
and Thaddeus Mason Pope, JD, PhD, HEC-C‡

Advance directives (ADs) and Portable Orders for Life-Sustaining Treatment (POLST) are powerful communication tools that help preserve an incapacitated patient's wishes regarding life-sustaining treatment.[1] They also help prevent conflicts,[2] reduce moral distress,[3,4] and control health care costs.[5–7] Portable Orders for Life-Sustaining Treatments can even predict the location[8] and possibly timing[9] of death. However, despite all these benefits, ADs and POLSTs too frequently result in medical errors.

These medical errors manifest as both undertreatment and overtreatment.[10] With undertreatment, a patient suffers harm or dies. For example, clinicians do not perform advance cardiac life support on a patient that should have been a full code patient. The patient fails to receive potentially beneficial life-sustaining treatment that they wanted.

In contrast, with overtreatment, a patient is harmed by receiving unwanted medical treatment. They are often forced to live against their predetermined wish to die naturally, often in the very circumstances that they wanted to avoid. For example, clinicians administer cardiopulmonary resuscitation on a patient with a do-not-resuscitate (DNR) order, or they aggressively treat a patient with orders for comfort measures only (CMO). Today, a growing number of malpractice lawsuits are settled or adjudicated in favor of families when patients receive treatment discordant with their AD or POLST.[11–13]

In this article, we first describe the issue of discordance. Because clinicians frequently misinterpret POLSTs and ADs, patients regularly get treatment discordant with the orders and instructions in those documents. This discordance often results in wrongful prolongation of life or death. After describing this problem, we turn to solutions. Fortunately, we may already have better tools to mitigate discordance and improve patient safety. We specifically highlight the promise of video testimonials.

PATIENTS REGULARLY GET TREATMENT DISCORDANT WITH THEIR POLST

Significant evidence shows that patients regularly get treatment discordant with their POLST in both prehospital and hospital settings. One of the original purposes of POLST was to be a useful tool with emergency medical services (EMS) as described in its original research and then implementation. However, growing research casts doubt on how well POLST serves this function.

A 2015 Pennsylvania statewide study showed that POLSTs were confusing and discordant, and presented a risk to patient safety in the prehospital setting.[14] For example, nearly half of EMS practitioners failed to correctly identify patients as DNR. The study showed 16% discordance with a POLST-formatted DNR/CMO, 29% discordance with DNR/limited treatment, and 50% discordance with DNR/full treatment. This means that patients would receive treatment (in the form of resuscitation) that they do not want. It also means that patients would not receive treatment that they would desire and would be beneficial to their medical care. Those results were confirmed in a 2022 California study showing an almost

From the *Department of Emergency Medicine, UPMC Hamot, and UPMC Northern Tier, Erie, Pennsylvania; †MIDEO Advance Care Planning Service Line, US Acute Care Solutions Research Group, Canton, Ohio; and ‡Mitchell Hamline School of Law, Saint Paul, Minnesota.
Correspondence: Ferdinando Mirarchi, DO, FAAEM, FACEP, UPMC Hamot, 201 State Street, Erie, PA 16550 (e-mails: mirarchifl@upmc.edu; mirarchif@usacs.com).

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exact level of discordance with respect to resuscitation.[15] Because the question has now been evaluated on both the East and West coasts of the United States, it is likely that POLSTs present the same patient safety risks in other parts of the country.

Furthermore, POLST discordance, with respect to resuscitation and the decisions impacting medical treatment outside of cardiac arrest, extends beyond the prehospital setting. A statewide evaluation of emergency physicians revealed similar levels of discordant understanding.[16] The study showed 11% discordance with a POLST-formatted DNR/CMO, 25% discordance with DNR/limited treatment, and 50% discordance with DNR/full treatment. This reflects that a patient who is at end of life with a POLST (DNR/CMO) would be overtreated and prevented from naturally dying. It reflects that patients who are seeking medical care and some limitations in medical care with a POLST (DNR/limited treatment) are at risk for both overtreatment and undertreatment. Lastly, this discordance means that patients who are seeking aggressive care or who needed critical care are at grave risk for undertreatment with a POLST formatted as DNR/full treatment.

Although this study was survey-based research, 4 more recent studies confirm its results. First, one review of a retrospective cohort of POLST patients found 14% discordance with DNR/CMO and 20% discordance with DNR/limited treatment.[17] Second, a prospective evaluation of existing DNR and POLST orders in hospitalized patients revealed that the POLST or DNR order was discordant 44% of the time.[18] Third, a similar POLST discordance rate was found in nursing facilities.[19] Fourth, a systematic review of 20 observational studies describes the level of POLST discordant care as "moderate."[20]

PATIENTS REGULARLY GET TREATMENT DISCORDANT WITH THEIR AD

Although studies of POLST discordance have only been published since 2015, studies of discordance of ADs began much earlier. The first TRIAD studies (The Realistic Interpretation of Advance Directives) describing misinterpretation of ADs and discordant care began in 2002. The level of discordance was initially found in a small pilot.[21] That was followed by an EMS pilot.[22] Then, the research expanded to a national scale, revealing that 78% of physicians in multiple specialties equated an AD with an automatic DNR (notwithstanding the affirmatory resuscitation instructions in the AD). The same study showed that 64% of respondents thought that the term "DNR" meant comfort care at the end of life rather than no chest compression when the patient was pulseless or apneic.[23]

The national level of confusion was reconfirmed when a later study compared the AD and POLST as stand-alone documents with the AD and POLST combined with a scripted patient to clinician video.[24] The second national study again confirmed that physicians equate an AD with an automatic DNR order 78% of the time (notwithstanding the content of the AD). Based on this evidence, a recent literature review recommends that clinicians inform patients of the risks from creating an AD.[10] In sum, although ADs generally help achieve value-concordant care, they also often increase the possibility of discordance.

DISCORDANCE RESULTS IN WRONGFUL PROLONGATION OF LIFE AND DEATH

Advance directives and POLSTs are designed to help assure that patients both get the treatment they want and avoid the treatment they do not want. However, when these documents are misinterpreted or ignored, patients either get unwanted treatment or fail to get desired treatment. This commentary focuses on misinterpretation, but both concerns represent a serious violation of patient autonomy and self-determination rights. Both ignoring and misinterpreting an AD or POLST can be physically harmful.

As an example of overtreatment, take the case of Gerald Greenberg.[25] Greenberg completed an AD directing that he was to be given "comfort measures only, no intravenous fluids and no antibiotics." However, after Greenberg was transferred from his New York nursing home to a hospital, clinicians administered intravenous antibiotics, a brain computed tomography, chest x-ray, electrocardiogram, blood tests, and other medications not necessary to alleviate pain. Had Greenberg not received this treatment, he likely would have died of sepsis within a few days. Instead, he endured pain and suffering over a period of approximately 30 days, a result that he specifically sought to avoid by completing his AD.

As an example of undertreatment, take the case of Arline Nelson.[26] She completed a POLST directing "full code" while she was living independently in the Seattle community. Later, still with the same POLST, Nelson was admitted to the hospital after a small stroke. However, when she suffered from a cardiac arrest, hospital clinicians made no efforts at resuscitation because they thought she was DNR.

QUALITY PROCESSES TO ACHIEVE CLARITY, COMFORT, AND CONFIDENCE

Advance directives and POLSTs offer significant benefits.[1] but they have also introduced a patient safety risk related to misinterpretation and discordance.[27] To mitigate this risk, we must develop quality processes to check and verify the appropriateness of DNR or POLST orders. In addition, we must approach these issues with the same level of action and scrutiny that we place upon other medical errors. Modern health care has developed and implemented many technologies and processes to prevent medical errors.[28] Most well known are the surgical pause (a process) or guardrails (a technology) for pain pumps. After those models, we must act on the patient's behalf and use newer technologies to enhance the safety of patient care.

We suggest a conceptual process we describe as the 3-C approach. To align with the 3-C's, the patient safety tools we need must (1) produce Clarity to the family and medical team as to the actual patient wishes, (2) provide Comfort to the current and next medical provider as well as the family, and (3) instill Confidence. It is crucial that everyone involved in the patient's course of care acts confidently. Patients should feel confident that they are creating something that will be followed. The family must feel confident that, although in a vulnerable situation, they are doing the right thing for their loved one. Finally, the medical team must be confident that they are following the patient's wishes without adding additional risk to themselves or the system they serve in. Determining the real-world process surrounding an AD that aligns with the 3-C's in clinical practice is the challenge we are facing today.

NEW TOOLS CAN BETTER ENSURE CONCORDANCE AND IMPROVE PATIENT SAFETY

Fortunately, better tools to ensure concordance and improve patient safety may already be available. Patients can supplement their written ADs and POLSTs with videos of themselves stating and explaining their treatment preferences and goals.[29–31] Although seemingly simple, like checklists, videos can prevent medical errors. Several clinical practices (eg, Dartmouth Dementia Directive and the Institute on HealthCare Directives) and those performing research are recommending that patients not only complete a directive on paper but also make a video recording of it.[32,33] Some (Dartmouth Dementia Directive) provide recommendations as to what to record. Others (Institute on HealthCare

Directives) have a more streamlined education, creation, and retrieval process. Larger nationwide multicenter research is still required to show the impact of video and the ideal format to create the video, but initial clinical practice is very promising.

Most research on using videos in health care focuses on using them to inform patients.[34,35] Significant evidence now shows that educational video tools like patient decision aids help patients better understand their treatment choices by enabling them both to envision future circumstances and to deliberate about their decisions. However, videos are not only for clinician to patient communication but also for patient to clinician communication.

One recent study examined the effectiveness of videos to communicate patient wishes to clinicians.[24] It found that a scripted video testimonial helps providers understand patient decisions. The study further found that the nonverbal information in a patient-recorded testimonial helps both the health care team and family better understand and accept the patient's wishes. For example, a video testimonial allows doctors to see facial muscles, hear the inflection of a person's voice, and better understand nuances. In contrast, written documents are subjected to degrees of interpretation with respect to current patient medical status and their desire for treatment.

In sum, both clinicians and family appreciate a more multimodal and personal expression of patient wishes, in addition to the written directive. In initial clinical practice and in legal case, law videos materially mitigate the risks of discordance. In addition, the study revealed that consensus understanding was not possible with a stand-alone living will or POLST. However, adding a scripted video testimonial achieved consensus understanding in 4 scenarios and achieved near consensus or produced statistically significant changes to support its use.[24]

Furthermore, the value of video testimonials has been demonstrated not only in clinical trials but also in court cases involving ADs and similar tools like wills.[36] Supplementing a written document with a video helps in 2 respects. First, it ensure the validity of the AD by confirming that the patient had capacity, voluntariness, and understanding when she signed it. Second, it clarifies the patient's meaning and intent. Conflicts over the interpretation of ADs occasionally escalate to court. The resolution of these cases shows that videos help ensure concordance with ADs.

CONCLUSIONS

Advance directives and POLSTs offer significant benefits, but they also have introduced a patient safety risk related to misinterpretation and discordance. We must not conceal or dismiss this risk. Instead, we must openly acknowledge it and develop tools to make ADs and POLSTs safer for patients. Additional research is required, and we are not suggesting that video replace the ADs or POLST. We are suggesting that video can and already is being used in practice today to act as a clarifying tool of both documents, better documenting the intent of the patient (or appointed agent) to ensure the appropriate delivery of care at the appropriate stage in time of the patients care continuum.

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