

Behind the Jargon

The Remarkable Staying Power of “Death Panels”

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Abstract Sarah Palin’s phrase “death panels” derailed proposed provisions of the Affordable Care Act (ACA) to pay physicians for end-of-life discussions with patients, a policy designed to make dying more humane, something all Americans desire. Even now, “death panels” has truth-value for approximately half of Americans and is used to paint ACA components as threatening to “pull the plug on Grandma.” How can this be? To some, the death panels claim is simply a lie, an improvised explosive device hurled against any ACA provision. To others, the phrase’s power stems from the public’s lack of a common vocabulary to discuss end-of-life care. “Death panels,” however, taps into many Americans’ fear of government involvement, that government’s purchasing end-of-life discussions as commodities necessitates accountability and cost control. Standardization and reduction of humanity follows, something Americans already experience routinely in their health care system. Expert jargon, compelling among experts themselves, doesn’t evoke people’s images of chats with Marcus Welby. The jargon is unintelligible, off-putting. When that jargon enters the nonjargonized world, it mixes with common fears, extant experience of dehumanization and reduction, and awareness that someone’s plug is getting pulled all the time. “Death panels” cannot be dismissed as delusional, but neither can it help fulfill Americans’ aspirations for a humane last voyage.

Keywords end-of-life discussions, advance care planning, Affordable Care Act provisions, “death panels”

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The Democrats promise that a government health care system will reduce the cost of health care, but . . . government health care will not reduce the cost; it will simply refuse to pay the cost. And who will suffer the most when they ration care? The sick, the elderly, and the disabled, of course. The America I know and love is not one in which my parents or my baby with Down Syndrome will have to stand in front of Obama's "death panel" so his bureaucrats can decide, based on a subjective judgment of their "level of productivity in society," whether they are worthy of health care. Such a system is downright evil.

—Sarah Palin, 2009

With her post on Facebook in 2009 Sarah Palin coined the phrase “death panels” and made famous the charge that the Affordable Care Act (ACA) represents government-imposed euthanasia. Her claim had already been put into circulation by notables like Betsey McCaughey (e.g., Holan 2009; Nyhan 2010; Rutenberg and Calmes 2009) as an attack on proposed provisions in the House version of the ACA that provided Medicare payment for physicians’ voluntary discussions with patients about end-of-life planning, as reflected in the name of the proposed subsection, “Advance Care Planning Consultation” (H.R. 3200, 111th Cong., 1st Sess., § 1233 (2009)). Like the initial bombing of what have become multiple wars in Iraq, the words seem to have the power to “shock and awe,” and the phrase has taken on truth-value among a large part of the populace. As late as December 2014, 41 percent of Americans still believed that the ACA created death panels, and 19 percent remained unsure (DiJulio, Firth, and Brodie 2014). Perhaps more remarkably, a survey of 9,972 otolaryngologists, conducted in 2013, found that 40 percent of the surgeons who are Republicans believed that the ACA created death panels, a percentage that stands in great contrast to the finding that only 8 percent of Democrats shared that belief (Rocke et al. 2014: 232).

How can this be? How could Palin’s slogan have acquired such truth-value for so many people? The most important impact of the charge was to derail inclusion of advance care planning in the ACA, despite the fact that study after study has shown that a great majority of Americans long for a more humane death and want to plan their end-of-life journey. Given these desires, how could so many people still ardently believe the death panel charge, beliefs that took down proposed legislation designed to enable fulfillment of their wishes?

The simplest answer to these questions is that the death panel charge is just a lie, a trope to be hurled like an improvised explosive device (IED) in opposition to *any* provision of the ACA that opponents wish to kill. And it is a powerful one at that, well deserving of Politico’s “Lie of the Year”

award (Holan 2009). As James A. Morone (2010: 1098) has summarized, the language is “pungent, memorable, simple, and effective.”

The lie-as-IED explanation is supported by two types of evidence. First, once Palin put the phrase “death panels” into the public domain, it was picked up and elaborated by Republican politicians and their supporters in the pundit world and beyond. House minority leader John Boehner (R-OH) and Representative Thaddeus McCotter (R-MI) (2009) issued a press release stating that the ACA provision for advance care planning “may start us down a treacherous path toward government-encouraged euthanasia.” Senator Charles Grassley (R-IA) (2009) entered into the *Congressional Record* that “the purpose for [the proposed legislation] is to save money rather than ensure appropriate care at the end of life,” and he told a town hall meeting that attendees “had every right to fear” a government program “to pull the plug on Grandma” (quoted in Simon 2009). Richard Land, an influential religious leader, added that what President Barack Obama and supporters “are attempting to do in healthcare, particularly in treating the elderly, is not something like what the Nazis did. It is precisely what the Nazis did” (quoted in Mantyla 2009). Almost annually, bills introduced to enact the original or similar language go nowhere (e.g., H.R. 1173, 113th Cong., 1st Sess. (2013); H.R. 1589, 112th Cong., 1st Sess. (2011); see Pickert 2013), and efforts by the Centers for Medicare and Medicaid Services to add procedure codes to pay for end-of-life discussions continue, as of this writing, to be stymied (CMS 2010: 73,406; 2011; 2014: 67,670–71).

The second type of evidence supporting the lie-as-IED theory is that the lie has nimbly been used to mobilize opposition, not just against the ACA’s provision for advance care planning but also against other parts of the act. At roughly the same time as Palin’s initial post, the charge was also used, by McCaughey and others, to cast in a negative light provisions in the ACA creating the Patient-Centered Outcomes Research Institute (e.g., McCaughey 2009; see Iglehart 2010; Neumann and Weinstein 2010), whose mission is, stated generally, to provide a vehicle for the use of comparative-effectiveness research in private health insurance to reduce waste. More recently, the curse word has been thrown at the Independent Payment Advisory Board, created by the ACA as a mechanism to control Medicare expenditures. To support this effort Palin (2012) has been at her computer again, posting that despite accusations that she lied the first time, the ACA does contain death panels, morphed into the payment board. Representative Phil Gingrey (R-GA), who has introduced numerous bills to kill the board, stated at a press conference: “But under this [board] we described that the Democrats put in Obamacare, where a bunch of

bureaucrats decide whether you get care, such as continuing on dialysis or cancer chemotherapy, I guarantee you, when you withdraw that, the patient is going to die. It's rationing" (quoted in Mariano 2011). Representative Phil Roe (R-TN), who likewise has introduced legislation to kill the board, stated: "The board will decide, maybe you're 80 and that's a little too old to have your knee redone" (quoted in Khimm 2011). Perhaps most recently, Ben Shapiro (2014) has told us that "death panels are coming" because the US Preventive Services Task Force has issued recommendations against certain treatments. The lie seems to have nine, politically motivated, lives.

This explanation that the death panels claim is just a politically powerful lie has been further elaborated. The lie was disseminated widely and repeated time and time again by the twenty-four-hour news cycle with relatively little traditional journalistic control, fueled by and fueling extreme partisanship (Nyhan 2010). Further, the blogosphere has the ability to set political agendas (Veenstra, Hong, and Liu 2010). Finally, mainstream journalism has failed to provide the necessary clarification to kill it off (Schafer and Lawrence 2011).

Yet many lies are spread this way, and many pungent, memorable metaphors fail to gain traction in policy debates. We must still ask, why has this particular one stuck for so long? Why has the death panels charge remained so powerful over time?

As many have noted (e.g., Corn 2009; Piemonte and Hermer 2013), the issue of payment became entangled with the ACA proponents' own rhetoric of "bending the cost curve." As part of an overall plan to insure many more people, supposedly without increasing expenditures, advance care planning, cost-effectiveness research, the payment assessment board, and the preventive services task force could easily tap into Americans' unease about "rationing"—which is, after all, a determination of who gets care and who doesn't—by some "faceless bureaucrat" in Washington, DC. As one op-ed writer put it, "If the government says it has to control health-care costs and then offers to pay doctors to give advice about hospice care, citizens are not delusional to conclude that the goal is to reduce end-of-life spending" (Robinson 2009).

Citizens' discomfort is clearly exacerbated because the vehicle through which rationing allegedly would occur—discussions about death—remains "taboo" in our society despite some recent movement toward greater acceptance (IOM 2015: 352). As the Institute of Medicine summarizes: "The discussion of these two goals—individual care and collective savings—in the same public conversation may help explain why the proposed provision 'became the lightning rod it did'" (IOM 2015: 369) (citation omitted). Yet private insurers increasingly reimburse physicians'

time for advance care planning, and even though they have quite a conflict of interest, they have not been charged with creating death panels (e.g., Pollack 2014). The death panels assertion is so strong because so many Americans are suspicious of government (e.g., Lepore 2009).

To proponents of advance care planning, this is puzzling at best. The proposal to pay doctors to provide such planning is designed to facilitate autonomy, the value that has dominated law and bioethics around end-of-life care. The fact that the bill was designed to enable autonomous choice rendered the proposal the quintessential feature of the liberal state, the sole function of which is to provide value-neutral mechanisms to facilitate the exercise of freedom. Given this context, proponents are almost driven to ask, “How could anyone with a straight face characterize this proposal as the state’s valuation of some lives as not worth living, right up there—or, perhaps more accurately, right down there—with National Socialism?” *Damned lie!*

To sophisticated proponents of advance care planning, like the Institute of Medicine, this (mis)understanding of advance care planning, even when paid for by the state, stems from a lack of “public education” (IOM 2015; see chap. 6), even “civic literacy” (Meslin et al. 2014), the correction of which will create the “common vocabulary” (IOM 2015: 348) needed to discuss the real facts and painful issues surrounding end-of-life care. For example, most people don’t even understand terms like *palliative care*, much less options available to make dying more comfortable and not prolonged by aggressive use of our growing technological prowess. Most people don’t know that the majority of the populace wants less aggressive curative treatment and more comfort care. Moreover, they don’t know that advance care planning is “associated with increased survival, better quality of life, and decreased stress and psychological impacts on family members,” nor do they know that “no association has been found between having an advance directive discussion or document and earlier death” (IOM 2015: 368) (citations omitted). Facts must be taught and language reformed. This common vocabulary, once created and deployed, will “normalize” discussions of death (e.g., IOM 2015: 352, 353, 360).

But there must be more to it than that. “Death panels” *did* become the common language for many, and, regardless, for everyone it became the terms of debate. The absence of a common language in support of advance care planning cannot explain why this alternative language has a stranglehold on discourse. Our questions remain unanswered.

Let’s start with this, that thoughtful proponents of advance care planning fail to realize how much their characterization of what is needed shares common ground with the discourse of death panels. Over and over again,

proponents say that the crux is to “incentivize” physicians to engage in advance care planning. The debate, then, is played out on the rhetorical field that doctors do only what they get paid for (e.g., Stone 1997): if they are not paid for discussions of end-of-life care with patients, they won’t have them; if they do get paid, they will. Proponents bemoan the lack of payment and ask for it; opponents applaud the lack of payment and ask that it be withheld. Both sides reduce the provision of end-of-life discussions to a commodity to be bought and sold—or not—and they imagine no alternative. This is the monetization of both life and care.

In part for that reason, even modifications to the bill actually passed by the House did not have the power to ward off the death panel charge.¹ The initial legislative proposal was simple. The bill provided payment for a voluntary consultation between a doctor and a patient so long as certain required information was furnished: explanations of advance care planning; advance directives; health proxies; end-of-life services and supports available, including palliative care and hospice; orders regarding life-sustaining treatment; and the provision of a list of resources to assist patients and families (H.R. 3200 (2009)). Then, in the modified version designed to eliminate any hint of governmental compulsion, the word *voluntary* was put into the subsection’s subtitle; the word *shall* for the content of the conversations was replaced with provisions that regulations “may include the following, as specified by the Secretary”; the specified explanations were shortened (although the content remained largely the same); and newly added rules of construction specified that nothing in the revised subsection required completion of an advance directive, consent to restriction of services, or promotions of “suicide or assisted suicide” (H.R. 3962, 111th Cong., 1st Sess., § 1233 (2009)).

To thoughtful proponents of advance care planning, the modified House bill simply did not go far enough. According to them, even the modified legislation to pay for advance care planning lent itself to charges of creating death panels because it still contained a checklist of items that could be covered in the patient-physician encounter and left it to the secretary to specify the content of the discussion. They suggest that reimbursement should be based on units of time spent on the consultation, not its content, and that legislation should emphasize that what is paid for is “an open, genuine dialogue about end of life care” (Piemonte and Hermer 2013: 24). Accordingly, they suggest that “these consultations would not

1. In a remarkable legislative maneuver, the ACA derived from the bill passed by the Senate, and the bill passed by the House simply dropped away (e.g., Goldstein 2010), taking advance care planning with it.

be ‘regulated’ and physicians would not have to show evidence of having addressed any specific content” (Piemonte and Hermer 2013: 26).

With due respect, this suggestion is oblivious not only to how Medicare payment actually works but also to how much of that is actually understood by the public. People understand that government doesn’t just give money away—the gigantic war on fraud is intelligible only in light of that fact—but that it “gets” something in return and that it must control its expenditures. They also understand that the power of the purse necessitates accountability and that accountability can be attained only if discussions of death are reported back as having occurred. To accomplish that kind of accountability, discussions have to be quantified, standardized, and counted whether by content or by units of time (as in an “accounting”). In the modern era, this is high school Civics 101. Standardization and accounting, after all, are the sine qua non of rational-legalistic bureaucracy. Once money is on the table, discussion of death becomes yet one more commodity, yet one more physician service, to be purchased by government. Because the state must watch over its money, standardization becomes an accomplice of cost control. It is these features of reimbursed advance care planning, comparative-effectiveness research, the payment board, and the preventive services task force that cause opponents to recoil in fear.

Americans have many times experienced such commodification and standardization in the world of home maintenance organizations and managed care, likewise vilified in public discourse (e.g., the movies *As Good as It Gets*, *Sicko*, and *John Q*). Moreover, the manner in which America tries to control its health care system through increased standardization reinforces this consciousness. We have practice guidelines, performance measures, report cards, bonuses and penalties, evidence-based everything, and electronic health records (EHRs) and penalties for failure to use them.

The impact of EHRs is particularly potent. Recently, two astute observers suggested that in clinical education, EHRs threaten to create objectified “virtual patients,” which are now often the first encounter that medical students, residents, and attendings have with “the patient.” These electronic avatars are a “neat construct of a patient that can be a meta-fiction. This construct is often at odds with the real patient, accurate only in the laboratory results and other values but not always accurate in the sense of the patient’s story or the manifestations of illness on the patient’s body” (Chi and Verghese 2014: 2331). In the ACA, advance care planning was likewise to be reduced to EHRs. With this standardization we may end up with virtualized “patient preferences” to guide end-of-life care. People are

already unhappy with such standardization coming at them from multiple angles, but their being standardized by government ups the ante. They aren't so delusional to believe the death panel rhetoric.

Yet the answer to our puzzle of why "death panels" carried such force requires a final point, which pertains to the jargon of experts and what happens to that jargon in the street. The experts in end-of-life planning tell each other that there is a huge gap between what Americans want and what they actually receive. They tell each other a very nuanced, rich story, best illustrated by the Institute of Medicine's expansive report *Dying in America* (2014), which canvasses an enormous literature concerning what patients and their families want and what actually happens. The disjuncture between desire and reality is, painfully, extremely large. Here is what the experts say, taken from a part of the institute's report.

The evidence clearly shows that most people want to die at home, but most do not. "One in four adults aged 65 and older died in an acute care hospital, 28 percent died in a nursing home, and one in three died at home. Among all decedents, 30 percent were in an intensive care unit (ICU) in the month preceding death" (IOM 2015: 119) (citations omitted). Further, with important racial, ethnic, and religious exceptions, most people want to engage in advance care planning, but the vast majority do not do so. Most expect and want their physicians to initiate these discussions, but that rarely occurs. Most people want their families involved in the process of decision making; families echo that desire, but often their involvement is fairly minimal, lacks meaning, and leaves many emotional scars. With important exceptions, most people do not want aggressive life-sustaining treatment that merely prolongs the dying process, and most prefer comfort care instead. Nonetheless, most often aggressive treatment occurs and comfort care does not. In our "death-denying culture" (e.g., Jones et al. 2014), the medical profession most often sees death as "defeat"—a message imparted in education, still centered in acute care hospitals, and reinforced in many practice settings.

In planning advance directives, patients are usually most interested in outcomes, while conversations, if they occur at all, often focus on a list of interventions discussed in the abstract and result in a shallow advance directive that consists of check-box answers regarding different interventions. Even when advance directives exist, physicians most often are unaware of them, and even if they are, the documents rarely affect treatment decisions. Most patients clearly want their anxiety to be reduced and their expressions of emotions to be validated. However, physicians most often do not respond to expressions of emotions, and although they are

confident that they do show empathy, most often they do not. Patients simply give up expressing emotion, and physicians often suffer great stress and burnout. Moreover, dying is most often a somewhat prolonged process, with numerous ups and downs. Individuals' circumstances, preferences, needs, values, and beliefs change over time, and, perhaps most importantly, not when they are healthy but until they are actually experiencing the process of dying can individuals know what they want.

What is therefore required are long discussions over time rather than some quick, onetime filling out of a check-the-boxes form that is shallow in content. Yet even when such quick discussions occur, physicians often talk most of the time, spending little of that time eliciting patients' goals, values, and beliefs. Physicians simply lack the necessary education and skills—even basic communication skills—to competently engage in advance care planning.

To the experts, this story is absolutely compelling, and the merits of policy to “incentivize” and “standardize” advance care planning is a no-brainer. However, this narrative is not so compelling to the nonexpert public. The public simply hears something *other* than what the experts hear. They hear a string of jargon, which to them is unintelligible because it is the language of experts and which is actually quite off-putting. Visions of long, heartfelt discussions about dying with a caring doctor like Marcus Welby are simply not conveyed by the clinical and policy jargon: “advance care planning,” “end-of-life care,” “advance directives,” “health care proxy,” “palliative care.”

Moreover, once experts let loose their flow of jargon, they have no control over what then happens to it. *Their* jargon is the bearer of the no-brainer policy, but once policy jargon flows into the public domain, it gets all twisted together with beliefs and values, including especially fear of government, that pervade the “nonexpert-jargonized” everyday world of ordinary people. The resulting public jargon then comes back to slap the jargonizers in the face, defeating their magnificent policy in a very Hegelian process. “Death panels” is the “other” of expert jargon, created when the expert jargon is reformulated in the ordinary world in which people live their lives.

Proponents of advance care planning are therefore wrong that the widespread acceptance of the death panel charge squelched public discussion of issues surrounding end-of-life care, a “missed opportunity” (Perry 2010). Au contraire, public discussion *did* occur. The jargon used, however, was not the jargon that experts take for granted and prefer, their jargon of expertise. Instead, the jargon deployed in the public discussion

stemmed from a substantial number of people's transformation of experts' jargon into their own. Facilely dismissing them as liars is simply another form of reductionism, given that the modus operandi in the American health care system is to incentivize everything and, in the process, to reduce people to a few standardized questions and check boxes encapsulated in some form submitted to obtain payment (and to show adherence to some quality metrics). Seen through that prism, those who are worried about death panels have a point—once money gets involved in medical care, reduction begins, and the consequence of such reduction may well be that “the plug gets pulled on Grandma.” Indeed, in a system in which expenditures are out of control and in which, because of fragmented financing, the only possible means of reducing expenditures is to impose higher out-of-pocket costs, limit patients to narrow physician networks, and deny treatment at the bedside, *someone's plug is getting pulled all the time*.

Plug pulling is the modus operandi in such a system. That's why death panels have such staying power in the American popular imagination. They capture people's gut understanding of how the medical system works, and it's not a pretty picture. It's a dystopic nightmare. For many people, perhaps it was a darned good thing that the death panels charge stopped the advance care planning provision, and a few others besides. But if death panels succeeded in stopping a dystopic transformation, the death panel image did nothing—and cannot possibly do anything—to help create the kind of humane end-of-life journey that still lives in the popular imagination as an unfulfilled aspiration.

Epilogue

Three potentially significant events occurred in the late stages of this article's publication. First, Senators Johnny Isakson (R-GA) and Mark Warner (D-VA), with bipartisan cosponsors, introduced the Care Planning Act of 2015 (S. 1549, 114th Cong., 2nd Sess.), which supports advanced-care planning in a number of ways and also authorizes Medicare payment to physicians for end-of-life discussions. At this writing, the bill is in committee. Second, the Centers for Medicare and Medicaid Services (CMS 2015: 41773) included, in proposed Medicare rules, two procedure codes for payment of end-of-life discussions. Third, in reaction to the proposed rule, Representative Steve King (R-IA) introduced a bill to exclude advance care planning services from Medicare coverage (H.R. 3251, 114th Cong., 2nd Sess.).

Some mainstream organizations like Not Dead Yet and the National Right to Life Committee have expressed concern about the proposed rule, in the context of what they call the “culture of death,” but so far they have nonetheless distanced themselves from the term *death panels* (see, e.g., Leonard 2015). Representative King’s (2015) press release announcing the introduction of his bill walked right up to the term without using the words: “Americans are well-aware of the fact that Medicare is cash-strapped. . . . The worldview behind the policy has not changed since 2009, and government control over this highly personal decision is still intolerable to those who respect the dignity of human life. We need to block this harmful regulation before the Administration imposes yet another life-devaluing policy on the American people.” As usual, Betsy McCaughey (2015; see also Cunningham 2015), former lieutenant governor of New York, who is now a favorite conservative pundit and was in part responsible for the whole issue going viral in 2009, was not so circumspect: “Look out, Grandma: Medicare said on Wednesday it wants to start paying for end-of-life counseling. It’s being sold as ‘death with dignity,’ but it’s more like dying for dollars.” Press reports are speculating that the whole thing could devolve into another death-panel debate, particularly if the Republicans press for the repeal of the ACA as part of the imminent budget reconciliation process (see, e.g., Ehrenfreund 2015; Kilgore 2015; Leonard 2015).

It is not clear if “death panels” will maintain the traction with portions of the populace that it has up to very recently, as reflected in, for example, the KFF (2014) tracking poll. Whether or not the proposed rule is implemented, the fact remains that the debate continues to be framed within the context of economic incentives, and the reflections in this essay still hold. The proposed rule (and many provisions of the Care Planning Act) condition payment on only enumerated types of conversations—conversations that occur with certain kinds of patients and that are of certain length and content. Further, CMS did not issue a national coverage determination, which adumbrates conditions of coverage nationally but left the local Medicare carriers to develop their own local requirements. Therefore, more stipulations are likely to follow, with local variations (CMS 2015: 41773; American Academy of Family Physicians 2015). Given this regulatory treatment, standardization is contemplated and reduction follows, as is true of all payment in health care. Marcus Welby remains a figment of the popular imagination, but he plays no role in the payment system. As a result, he likely won’t be the star of many conversations.

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