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Garnering Support for Advanced Care Planning

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The recent transfiguration in the popular press of a proposal to provide Medicare reimbursement to physicians for advance care planning (ACP) into the creation of "death panels," which would decide the fates of the elderly and disabled,[1] can be seen as more than a political maneuver to discredit health care reform efforts. It provides valuable insights into how the notion of ACP is perceived by the general public and a lesson for the medical community about how to promote ACP.

As originally presented in HR 3200 (the former House bill outlining health care reform) Section 1233, entitled "Advance Care Planning Consultation," described reimbursement for a clinician visit in which a practitioner explained advance care planning, living wills, the role of a healthcare proxy and orders regarding life sustaining treatments.[2] This section of the bill was distorted by numerous politicians and commentators into a mandate by which older and disabled persons would be forced to forgo life-sustaining treatments. ACP, widely viewed by the medical community as an underutilized means of improving end-of-life care by allowing patients to exert their fundamental right to self-determination over future events and to ensure that they receive care at the end-of-life consistent with their values, was thereby transformed into a means for the government to deny persons the care that they desire. How could this have happened?

We believe the answer lies both in the history of and prevailing attitudes toward ACP. Although ACP had been a part of medical care and local legislation for a decade before, it became a nationally sanctioned method by which individuals could forgo medical care with the Patient Self-Determination Act (PSDA) of 1990 and the Supreme Court decision *Cruzan v. Director, Missouri Department of Health* in the same year.[3] In the latter, the court affirmed the right for individuals to refuse unwanted therapies if they became incapable of making decisions. The PSDA required that all agencies receiving Medicare or Medicaid funds ask all patients about the existence of advance planning documents and offer to help them complete such documents if desired.[4] Thus, the focus of ACP became the documentation of directives regarding the care that individuals would *not* receive at the end of life.

The medical community caring for seriously ill patients generally assumes, based on the recognition that seriously ill patients are at risk for receiving highly burdensome care with limited benefit, that there is a pent-up demand among individuals to participate in ACP and to put a limit on the technologically invasive care that they will receive at the end of life. Undoubtedly, many people may want the opportunity to state their desire to forgo medical

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interventions in advanced illness. However, the recent media experience with the health care bill provided the opportunity for expressions of support for ACP. The fact that this support did not occur reflects what we suspect may be in part due to a pervasive concern in the general public not that they will receive too much care, but rather, that they will receive too little. Although there has been little direct empirical study of the phenomenon, there is indirect evidence to support this assertion. Even patients with advanced illness often desire technologically aggressive and potentially burdensome care for illness exacerbations. One commentator attributed this willingness to undergo continued interventions to the “widespread and deeply held desire not to be dead.”[5] Although individuals may want to limit their care under conditions when death is inevitable, medicine can rarely provide this level of prognostic certainty, and, accustomed to hearing about the miracles of modern medicine, they may worry that the doctor will give up too soon. Moreover, there is growing evidence that substantial proportions may not want to plan for their end-of-life care, out of the beliefs in the need to take things “one day at a time,” the impossibility of being able to plan for the future, or the difficulty in contemplating serious illness and death.[6, 7] Underlying these attitudes is the societal phenomenon in modern western cultures of the denial of death,[8] which is fueled by the ever increasing ability of modern medicine to postpone the inevitable.

ACP may best be considered a part of medical care similar to exercise, smoking cessation, dietary change, and cancer screening; i.e. activities that are good for individuals but which they may not want to do. Unlike these behaviors, however, ACP may not even be recognized as something that they *ought* to do. How, then, can public support for ACP be garnered? It may be that a demand for more and better ACP will not occur unless and until there is a broad societal change to accept death as a part of life and to “de-medicalize” the dying process. It may also be possible, however, to promote ACP with less sweeping change. Whereas opponents of the bill were able to convince the public that ACP restricted choice, proponents of ACP need to emphasize the fact that ACP facilitates choice. This requires acknowledging the concerns of those who believe ACP is a mechanism for limiting care.[9] Clinicians tend to engage patients and families in discussions about preferences for care only late in the course of illness[10] and to ask about preferences only in the most dire of hypothetical scenarios.[11] These practices suggest that clinicians frequently use ACP to encourage patients and families to make decisions to forgo care when the clinician believes the care would be inappropriate. In contrast, the promotion of ACP requires that clinicians be prepared to accept whatever option the person chooses by including a consideration of all *reasonable* treatment alternatives. Clinicians and policy makers must be clear that ACP is not the means for addressing issues of futility or the high costs of end-of-life care.[9]

Just as for other preventative health care behaviors, the promotion of ACP also requires the development of a public health message. Although the process of personal participation in ACP should take place on the clinical level with an individualized interaction between patient and clinician, the process of encouraging participation ACP must occur on the population level. Building on health behavior models, this effort requires raising the public's awareness of ACP by providing accurate information about the benefits of engaging in ACP, the potential negative consequences of failing to engage, and strategies to overcome barriers to engagement. Delivering these messages will require broad outreach, such as through the use of public service announcements. The prominent role of religious beliefs in shaping attitudes toward advance care planning also calls for outreach to religious institutions. The promotion of ACP may be most effective if it takes advantage of situations in which individuals overcome their reluctance to think about death and dying to engage in other forms of planning for the future. For example, information about ACP could be provided to individuals at the times in which they participate in estate or funeral planning. Only by convincing the public of the benefits of ACP as a process to promote choice can we hope to gain widespread support and demand for this practice to be a reimbursable part of medical care.

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