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Health Care Reform's Proposed End-of-Life Provisions

Brandy C. Hill, JD, Nick Lebrede, CPA, MBA, Christopher R. Shafer, MBA

ABSTRACT

End-of-life planning promotes patient autonomy by allowing individual patients to inform and direct care givers and healthcare proxies on their desired level of end-of-life care, where the patient prefers to pass away (whether at home or in a hospital setting), and the methods and levels of pain management that the patient deems desirable. Given that, it is counter-intuitive that a significant majority of American's fail to execute, or fail to properly execute, advance directives. The author's efforts focus on what can be done to improve, generally, end-of-life care. To that end, the authors conclude that improvements in end-of-life care must be achieved at three levels: the individual level, the healthcare provider level, and at the government level. On the individual level, patients must assume greater accountability for their own end-of-life care. That entails making one's wishes for end-of-life care known to family members and healthcare providers. On the healthcare provider level, improved patient communication and improved delivery of palliative-oriented care are first order initiatives. Finally, the government can play a significant role in improving end-of-life care by collecting better healthcare utilization and cost data on end-of-life experiences, expanding benefits for palliative care services, and promoting the use of advance directives through legislative efforts that include patient education measures.

Florida Public Health Review, 2010; 7, 50-63.

Background

Perhaps at no point in this country's recent history has a debate fueled emotions within the halls of Congress, and within the citizenry, more than healthcare reform. Much of the debate during the 2009 healthcare reform effort, arguably President Barack Obama's biggest domestic policy initiative during his first year in office, has been rife with hyperbole; politicians have charged that reform of the American healthcare system will result in the creation of "death panels" that will "pull the plug on grandma" or otherwise coerce people to "die quickly" (Palin, 2009; Grayson, 2009). Consequently, end-of-life considerations, mired with the complexities of patient autonomy, costs, and ethics, have been highly visible in the current healthcare reform debate.

As a result of advancements in medicine and medical technology, individuals in the United States are living longer lives. Although these advances continue to increase life expectancy, attention to the quality of life and to the inevitable experience of dying, has not kept pace (Grady, 1999). With increasing life expectancies come increasing healthcare costs. To that end, there are three central concerns regarding end-of-life healthcare policy reform. Those are: (1) the use of advance directives and other measures that serve to increase patient autonomy; (2) the benefits of hospice care to improve the quality of care received at end-of life and avoid unnecessary costs associated with futile medical treatments at end-of-life; and, (3) the use of pain

management at end-of-life and the delicate balance between patient autonomy and ethical medical treatment that must be achieved in connection therewith (Werth & Blevens, 2002).

At the outset, it is important to establish the parameters of what constitutes end-of-life. For purposes hereof, the National Institutes of Health definition is adopted. The term end-of-life can take on various meanings, and none are definitive. According to The National Institutes of Health, there are two constituent parts to end-of-life. The first is the presence of one or more chronic diseases, symptoms, or functional impairments that may persist or fluctuate. The second is the presence of symptoms or impairments resulting from an underlying, irreversible disease, requiring formal (paid, professional) or informal (unpaid, unskilled) care, and can lead to death (Heitkemper, Bruner, et al., 2004). End-of-life can also be defined by advanced age. However, with advanced age there are generally indicia of "debility, dementia, and protracted chronic and terminal illnesses" (Hardwig, 2009).

Individuals at end-of-life may face legal incapacity and rendering them incapable of expressing their wishes, with regard to end-of-life healthcare. This very point was evidenced in the Terri Schiavo case. Recall that Ms. Schiavo was in a persistent vegetative state and a fierce legal battle ensued between her parents and husband regarding who had the right, if anyone, to order her life support withdrawn. That legal battle played out in the

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national news media in early 2005. The case ultimately ended with her various life support treatments being removed, and Ms. Schiavo passing away shortly thereafter. The case offered a valuable lesson in advance directives, and their vital importance within society.

The majority of Americans fail to adequately plan for end-of-life. As a result, many are ill-prepared for end-of life and/or otherwise uneducated about available end-of-life planning tools. On the individual level, the risk of failing to plan for end-of-life is the possibility of being unable, because of legal or physical incapacity, to relay one's desired end-of-life healthcare wishes. On the societal level, the implications of failing to adequately plan for end-of-life can result in legal battles regarding healthcare decisions, and needless escalation of healthcare costs. "We do not have a [end-of-life] game plan as a society" (Gari, 2009). This proposition is a risky one.

Though a controversial issue that touches upon medicine, law, ethics, religion, politics, common sense, and extremism, giving a patient the right to determine the manner in which he or she handles end-of-life (including the right to die) is a powerful directive that individuals and their families feel should be within their control (Haras, 2008; Caplan, McCartney, & Sisti, 2007). Further to that commonly-held sentiment, it becomes apparent that understanding and using advance planning directives is essential. Advance directives, including living wills, healthcare proxies, do-not-resuscitate (DNR) orders, and healthcare powers of attorney, are legal documents governed by state law that express an individual's choice of surrogate healthcare decision-maker and/or an individual's treatment preferences in the event of incapacity (Kohn & Blumenthal, 2008; Darr, 1999). Even though the importance of advance directives is high, it is estimated that the use of advance directives is relatively low—between 16% and 27% (Cohen-Mansfield & Lipson, 2008; Ho, Thiel, Rubin, & Singer, 2000; Rosnick & Reynolds, 2003; Wallace, Weiner, Pekmezaris, Almandral, Cosiquien, Auerbach, & Wolf-Klein, 2007). Most significantly, for purposes of the instant discussion, advance directives generally provide instruction as to whether the maker wishes to receive or decline artificial life-sustaining treatments at end-of-life.

Advance directives may serve a financial purpose, aiding in healthcare cost containment. This is a commonsense conclusion. If an individual is willing to forgo costly measures to artificially sustain life and/or other heroic end-of-life treatment options, we assume that there will be a resulting net reduction in the cost of end-of-life treatment provided to that individual (Nishimura, 2007). There is research that substantiates this assumption, while other research

has been inconclusive (Mezey & Ramsey, 1994). Irrespective of the cost containment issue, it is important not to lose sight of the reason advance directive laws exist. That is, to carry out the intentions and wishes of the person making the advance directive in the event of his or her incapacity.

Patient Autonomy: Legislative Attempts at End-of-Life Planning Mandates

America's Affordable Health Choices Act

In any end-of-life discussion, a complex set of policy issues, economic issues, and legal issues is expected to emerge. Weighty ethical concerns are adjunctive thereto. Public debate of end-of-life issues abounded following the introduction, in mid-July 2009, of the America's Affordable Health Choice Act (H.R. 3200) H.R. 3200 was politicized for the reason that the proposed legislation contains a provision for advance care planning consultations in Section 1233 thereof (H.R. 3200 § 1233). Such advance care consultations—proposed to take place on a voluntary basis every five years between a patient, namely, a Medicare or Medicaid recipient, and his or her healthcare practitioner—include explanation, by the healthcare practitioner, of advance directives and the continuum of end-of-life services, including palliative care and hospice care. One of the more controversial provisions within H.R. 3200 § 1233 includes providing patients with "an explanation of orders regarding life sustaining treatment or similar orders ... [and] the reasons why the development of such an order is beneficial to the individual and the individual's family." Impliedly contained within H.R. 3200 § 1233 is the dictum that executing an advance directive is beneficial for the reason that it ensures that the individual's wishes regarding end-of-life care will be carried out, in the event that the individual becomes incapacitated and unable to make his or her own healthcare decisions.

H.R. 3200, the proposed legislation responsible for the timeliness of this discussion, comprises a significant piece of proposed legislation in the 2009 healthcare reform initiative, but it is by no means the only proposed legislation germane to that effort. H.R. 3200 is the product of three U.S. House Committees, namely, the House Energy and Commerce Committee; the House Ways and Means Committee; and the House Education and Labor Committee. Collectively, these committees, with regard to H.R. 3200, are sometimes called the "Tri-Committee." There are additionally two pieces of proposed legislation relating to the 2009 healthcare reform initiative introduced in the U.S. Senate. Those are America's Healthy Future Act of 2009 (S. 1796) introduced in the Senate Finance Committee

and the Affordable Health Choices Act (S. 1679). Significantly, neither Senate bill includes language similar to H.R. 3200 § 1233 or otherwise provides for advance care planning consultations.

H.R. 3200 § 1233, has been attacked on the basis that it is, according to its opponents, intended to dissuade certain persons from consuming certain end-of-life healthcare treatments—charging, essentially, that there is potential for abusive and/or disparate application. In particular, H.R. 3200 § 1233 is limited to Medicare and/or Medicaid recipients and, accordingly, it is those persons who would receive the voluntary (or, voluntary but for the “white coat” influence) advance care planning consultations provided for therein. It is proposed that those consultations occur at five-year intervals or “more frequently ... if there is a significant change in the health condition of the individual, including diagnosis of a chronic, progressive, life-limiting disease, a life-threatening or terminal diagnosis, or upon admission to a skilled nursing facility” (H.R. 3200 § 1233). There can be little argument that aforementioned group (Medicare and/or Medicaid recipients) is comprised largely of the elderly, the terminally-ill, or other groups which may be at or near the end-of-life stage. By reimbursing physicians for time spent counseling patients who experience “a significant change in ... health condition” a straight-faced argument can be made that § 1233 promotes the use of advance directives as a means of cost containment and/or healthcare rationing. Further, that cost containment or healthcare rationing would come at the cost of disproportionately providing less available healthcare services and measures, to Medicare and/or Medicaid recipients. This, though, may be an incurable inequity inasmuch as some research suggests that physicians treating patients whose care is covered by government-funded insurance (namely, Medicare and Medicaid) are more likely to issue a DNR order, or otherwise forgo heroic end-of-life treatment options, than they are for patients covered by private insurance (Nordquist, 2006).

Proponents of H.R. 3200 § 1233 advocate the position that advance care planning consultations necessarily involve only cognitive and legally competent persons. Furthermore, in connection with providing an advance care planning consultation under § 1233, a healthcare practitioner is required to advise the patient of the substantial legal safeguards available. This would further protect the individual against the risk of an appointed surrogate healthcare decision-maker terminating life-sustaining measures based on the surrogate's judgment, morals and/or values (H.R. 3200). Those favoring legislation which encourages advance care planning argue that such

“measure[s] would not only help people make the best decisions for themselves, but also ensure that their wishes are followed. To suggest otherwise is a gross, even cruel, distortion, especially for a family that has been forced to make the difficult decisions on care for loved ones approaching the end of their lives” (Blumenauer, 2009). The cost containment argument cannot be ignored here. Proponents of legislative efforts to encourage the use of advance directives also maintain that the outcome will be the alleviation of exorbitant federal spending on costs incurred, arguably, largely in connection with futile efforts to unnaturally extend the life of an individual (Schneider & Hall, 2009).

Further substantive discussion of by H.R. 3200 § 1233—which may be somewhat cumulative in light of the Patient Self-Determination Act, *infra*—is not ripe as it has not as of the time of this writing, and perhaps may not, mature into enacted federal legislation. However, the proposed legislation did, as previously mentioned, serve to bring the end-of-life planning issue to the forefront of the American conscious. It also served to bring to light the question of whether federal legislative efforts can increase the use of end-of-life planning instruments such as advance directives. Analysis of other enacted federal and state legislation is both germane and instructive in the end-of-life planning discussion at this juncture. In particular, the Patient Self-Determination Act is examined herein relative to encouraging end-of-life planning in furtherance of patient autonomy. Additionally, the Oregon Death with Dignity Act and the Washington Death with Dignity Act, which authorize physician-assisted suicide in limited circumstances in those states, are examined relative to their policy implications relative to patient autonomy at end-of-life. The concomitant economic effects of those legislative initiatives are also addressed.

Patient Self-Determination Act

The Patient Self-Determination Act (42 U.S.C. §§ 1381, *et seq.*) (hereinafter the “PSDA”), enacted in 1991, made it a federally legislated requirement that individuals treated in institutions receiving Medicare and/or Medicaid reimbursements be asked about the presence or the absence of an executed advance directive regarding that individual's express wishes for potential end-of-life care (42 U.S.C. § 1395). The legislative purpose behind the PSDA was to increase the use of advance directives regarding end-of-life treatment decisions (O'Rourke, 2000). In relation to H.R. 3200 § 1233, the language of the PSDA is notably less value-laden. The specific language of the PSDA provides that “each hospital nursing facility, provider of home healthcare or personal care services, hospice program, or health

maintenance organization...receiving funds under [Medicaid and/or Medicare] shall...provide written information...concerning an individual's right under State law (whether statutory or recognized by the court of the State) to make decisions concerning such medical care, including the right to accept or refuse medical or surgical treatment and the right to formulate advance directives...[and] to document in the individual's medical record whether or not the individual has executed an advance directive" (42 U.S.C. § 1395 cc (a)). The PSDA does not require the healthcare provider to determine the legal sufficiency of the advance directive or obtain a copy thereof (Mezey & Ramsey, 1994). By presenting an individual's right to execute an advance directive as an individual choice to accept or refuse certain life-sustaining treatments, the PSDA is significantly more value-neutral than H.R. 3200 § 1233. Also, under the PSDA, a covered institution may not make the provision of care conditional upon whether the individual has or has not executed an advance directive, to do so is considered discriminatory under the Act (Mezey & Ramsey, 1994; 42 U.S.C. § 1395cc (a)(2)(C)). H.R. 3200 provides reimbursements to physicians for time spent conducting advance care planning consultations held, in part, for the purpose of explaining to the individual "the reasons why the development of such an order is beneficial to the individual and the individual's family" (H.R. 3200 § 1233). There is no explanation in H.R. 3200 as to how the proposed legislation presumes advance directives to be beneficial. One view is that they are beneficial for the reason that they are designed to instruct family and/or healthcare provider, on how an individual may desire to carry out end-of-life treatment. A more cynical view is that forgoing certain end-of-life treatments result in less federal healthcare spending.

One major difference between H.R. 3200 § 1233 and the PSDA regarding advance directives is that H.R. 3200 § 1233 proposes to educate individuals on advance directives. There is not a similar education component in the PSDA. Accordingly, to the extent that later federal legislation may provide for patient education regarding advance directives, the same would not be wholly cumulative in light of the PSDA. It is significant to note that research suggests that advance care planning education (in the nature of that proposed by H.R. 3200 § 1233) may increase the rate at which advance directives are executed, but that the resulting executed advance directives may fall short of the legal requirements set forth by state law to make them sufficient, valid and/or enforceable (Ho, et al., 2000; Aroskar, Moldow, & Good, 2004). Therefore, a critical failure of any law enacted for the purpose of increasing the use of advance directives,

that does not require a determination as to whether or not an individual has a valid and legally enforceable advance directive, is that a significant number of individuals may believe that they have an advance directive, and may report that fact to their healthcare provider, when, in fact, they have executed a document which cannot later be given effect. Neither the PSDA nor the proposed H.R. 3200 requires that the legal sufficiency of an individual's advance directive be determined.

It is suggested that that legislative efforts can positively influence the rate at which individuals execute advance directives to express their wishes for end-of-life, which conforms to the legislative purpose of the PSDA. Accordingly, the ability of legislation to change patterns of end-of-life care consumption and the ability of legislation to promote the use of advance directives is a potent consideration. To that end, it is suggested that further research is needed to determine whether narrowly tailored legislation, which includes a patient education component and a means for determining the legal sufficiency of advance directives, is likely to positively impact patient autonomy at end of life.

The Right to Die

The right to die may be the ultimate measure of patient autonomy. When considering various end-of-life options for terminally ill patients, it must be considered whether physician-assisted suicide is a viable one. Oregon became the first state in the United States to permit physician-assisted suicide in 1997. Eleven years later, Washington state, became the second (Campbell, 2008; Jecker, 2009).

The Oregon Death with Dignity Act (Or. Rev. Stat. Ch. 127, hereinafter the "Oregon DWDA") and the Washington State's Death with Dignity Act (Rev. Code of Wash. §§ 70.245.010, *et seq.*, hereinafter the "Washington DWDA") are measures of patient autonomy inasmuch as they provide a legal right for physician-assisted suicide in certain limited circumstances. The Oregon DWDA sets forth detailed requirements and procedures by which a mentally competent but terminally ill adult resident of Oregon may voluntarily "make a written request for medication for the purpose of ending his or her life in a dignified manner" (Or. Rev. Stat. §127.805(1)). The patient must be suffering from "an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months" (Or. Rev. Stat. § 127.800(12)). The patient's written request must be signed and dated in the presence of at least two witnesses who attest that the patient is "competent and acting voluntarily" (Or. Rev. Stat. § 127.810(1)). The Washington DWDA, modeled after the Oregon statute, contains substantially similar

limitations on its application. The Oregon DWDA was enacted primarily to “expand patient control over end-of-life choices” (Campbell, 2008). Between 1998 and 2008, 401 individuals ended their lives under the Oregon DWDA (Oregon Department of Human Services). In 1998, 97% of those individuals died at home, whereas 98% had some form of hospice care. The primary reason, as stated by 95% of those terminally-ill individuals choosing to end their lives under the Oregon DWDA, was loss of autonomy. Accordingly, there appears to be a compelling policy argument in favor of laws such as the Oregon DWDA and the Washington DWDA in furtherance of patient autonomy.

Prior to enactment of the Oregon DWDA, the state of the law regarding physician-assisted suicide was shaped by two United States Supreme Court decisions rendered in 1997. In the first seminal case, *Washington v. Glucksberg*, 521 U.S. 702 (1997), the Supreme Court held that a Washington state law banning physician-assisted suicide was constitutional and, accordingly, an individual, even a terminally-ill individual, has no constitutionally protected right to die by means of intervention provided by a licensed medical physician (i.e., physician-assisted suicide). Specifically, the Supreme Court held that “[t]hroughout the Nation, Americans are engaged in an earnest and profound debate about the morality, legality, and practicality of physician-assisted suicide. Our holding permits this debate to continue, as it should in a democratic society” *Glucksberg*, 521 U.S. at 737. This holding suggests that states have the right to enact legislation permitting physician-assisted suicide in limited instances. The second contemporaneously issued Supreme Court ruling, rendered in *Vacco v. Quill*, 521 U.S. 793 (1997) held, similarly, that a New York state law that banned physician-assisted suicide in that state was constitutional. The *Vacco* Court decided that states could ban physician-assisted suicide but it was silent as to whether a state could affirmatively authorize the same.

Glucksberg and *Vacco* seemingly opened the door for state legislation permitting physician-assisted suicide in limited instances where the “proper balance between the interests of terminally ill, mentally competent individuals who seek to end their suffering and the State's interests in protecting those who might seek to end life mistakenly or under pressure” could be achieved (*Glucksberg*, 521 U.S. At 737). Nonetheless, the Oregon DWDA faced significant legal challenges following its enactment. Those challenges were based primarily on the federal Controlled Substances Act (21 U.S.C. §§ 801, *et seq.*, hereinafter the CSA). The CSA is a federal law that regulates the legal and illicit manufacture,

distribution, and possession of controlled substances. Oregon physicians who sought to assist terminally-ill patients in ending their lives in conformity with the Oregon DWDA, were threatened with federal prosecution for violation of the CSA, by reason of a 2001 interpretive rule issued by the U.S. Attorney General (John Ashcroft, at that time) which opined “assisting suicide is not a 'legitimate medical purpose' within the meaning of 21 C.F.R. § 1306.04 (2001), and that prescribing, dispensing, or administering federally controlled substances to assist suicide violates the CSA. Such conduct by a physician registered to dispense controlled substances may 'render his registration...inconsistent with the public interest' and therefore subject to possible suspension or revocation under 21 U.S.C. § 824(a)(4). This conclusion applies regardless of whether state law authorizes or permits such conduct by practitioners or others and regardless of the condition of the person whose suicide is assisted.” This interpretive rule came to be known as the Ashcroft Directive (Hilliard, 2005). Accordingly, under the Ashcroft Directive, any physician who prescribed a lethal dose of a controlled substance to a terminally-ill patient would be subject to federal criminal prosecution.

The United States Supreme Court ultimately resolved that the Attorney General was not authorized to issue an interpretive rule limiting the right of the State of Oregon to legislate medically appropriate uses of drugs not otherwise prohibited under the CSA—that matter is reserved to the states. *Gonzales v. Oregon*, 546 U.S. 243 (2006). To that end, physician-assisted suicide in the limited manner provided by the Oregon DWDA is specifically sanctioned and similar legislation may be enacted by the various states.

Whereas patient autonomy is a paramount concern at end-of-life, and in healthcare policy more generally, the matter of physician-assisted suicide is not appropriate for national policy. The “challenging task of crafting appropriate procedures for safeguarding...liberty interests is entrusted to the 'laboratory' of the States” (*Glucksberg*, 521 U.S. at 737).

Hospice Care

It should come as no surprise that medical costs tend to increase with age, with the peak spending rate coming at the final stages of life. The Kaiser Family Foundation, a leader in health policy communications, conducted a study in 2006, highlighting the enormous increase in healthcare spending at end-of-life. The Kaiser Family Foundation study examined six age groups: newborn to age 5; age 5 through 17; age 18 through 24; age 25 through 44; age 45 through 64; and 65 years of age

and older. The latter group, which is Medicare-eligible and which accounts for 70% of all deaths in the United States annually, consumed, on average, \$8,776 in federal healthcare dollars per person in 2006 (Grady, 2009; Adamy, 2009). This figure is almost \$4,000 more than the next highest spending age group: those between the ages of 25-44. The findings reported by the Kaiser Family Foundation support the argument that there is extraordinary spending in the final stages of life. The study also raises questions, with regard to whether Americans are being over-treated at end-of-life. The U.S. healthcare system offers multifarious treatment options during an individual's end-of-life period. However, many seeking care often go directly to the hospital, regardless of their signs or symptoms. This often drives up unnecessary costs and further increases pressure on curbing medical spending during end-of-life. Many are unaware of other end-of-life care options that can provide an appropriate level of care, at a more modest cost. A survey conducted with the input of 2,515 Medicare patients found that 86% of those surveyed would rather spend the last days of their lives at home, rather than in a hospital. However, 80% of Americans die in institutions, mainly hospitals or nursing homes (Jaffe, 2009).

With Baby Boomers entering retirement age, Medicare, Medicaid, and Social Security spending are on the rise in the United States. As of 2008 there were over 45.3 million Medicare beneficiaries (Overview Medicare Enrollment Reports, 2008) consuming \$468 billion in healthcare services annually. This number amounts to 3.2% of the nation's total Gross Domestic Product (GDP), and that figure is projected to balloon to 11.4% over the next 70 years (Medicare Trustees Report & Trust Funds, 2009). By that estimate, Medicare spending will reach \$931.9 billion by 2019—essentially doubling in the next 10 years (Jaffe, 2009). Medicare spending is not distributed evenly over all beneficiaries. From 1995-1999, 5% of Medicare beneficiaries accounted for some 47% of total Medicare spending (Lieberman, Lee, Anderson & Crippen, 2003). As a result, end-of-life (and, more particularly, end-of-life healthcare spending) has become a hot button topic in American politics and policy. Because Medicare commands such a presence in the overall federal budget, cost containment in high spending areas has become a focal point. So the following question arises: How do we as a society cut costs, while at the same time, provide high quality healthcare to those in end-of-life scenarios? “In some [potentially end-of-life] cases hospital care is essential, especially for those experiencing trauma, cardiovascular, cerebrovascular, among other

emergent events.” (Ortiz-Rios, 2009) In other cases, however, individuals could receive the appropriate level of end-of-life care in the home, or in a hospice environment. When individuals choose to spend their final days in hospitals, they are choosing a costly option. By way of example, an individual 65 years or older, suffering from pancreatic and/or liver cancer, seeking care in a Florida hospital, can expect to spend from \$18,017 to \$49,050 for a 6-day hospital stay (FloridaHealthFinder.gov, 2008). The average of that range is \$33,533. Many individuals turn to hospital care because that is the assumed choice. There is also a sense of comfort for patients knowing that they have a doctor or nurse in close proximity, no matter what time of the day it may be.

Hospice care, though, offers a variety of end-of-life treatment and care options for patients and their families, including in-home care, inpatient facilities (Hospice Houses), and around-the-clock nursing care. Hospice care is an ever-growing popular option for end-of-life care. In 2007, Hospice served 1.4 million patients, which is a 450,000-patient increase from 2003 (NHPCO Facts and Figures, 2008). Hospice was also involved in 38.8% of all deaths occurring in the United States in the year of 2007 (NHPCO Facts and Figures, 2008). It is a benefit that is covered by Medicare, and has been since 1982. Significantly, hospice care is often less costly than hospital care. In a typical hospice scenario, a family member serves as the primary care giver for the patient, with hospice healthcare providers being available 24 hours a day. An interdisciplinary team of healthcare providers works with family members to create an explicit care plan for the terminally ill individual. Hospice often reduces cost while, at the same time, improves the quality of end-of-life care over that which would be received in a hospital or institutional setting. A study conducted by Duke University researchers, concluded that hospice saves the Medicare program around \$2,300 per beneficiary when the beneficiary expires in hospice care. The maximum cumulative savings noted by the study were as high as \$7,000 when beneficiaries with terminal illnesses used hospice for 58–103 days prior to their death (Taylor, Ostermann, Van Houtven, Tulskey & Steinhauer, 2007).

Similar to hospice care, is the option for private in-home care, which enables a patient and their families more control in what type of care is provided. Many commercial insurance plans, as well as Medicare, offer an in-home care benefit, allowing various healthcare providers to engage patients in the comfort of their own homes at end-of-life (ACHC; Maxim Healthcare Services, 2009). In-home care can include around-the-clock nursing, nursing aide, or physical therapy care, resulting in considerable cost

savings when compared to hospital or institutional care. Skilled providers, such as registered nurses providing in-home care, are compensated at about \$10 less per hour, than facility nurses. Similarly, unskilled providers, such as nursing aides or home health aides, are compensated at a rate of about \$5 less per hour than facility unskilled providers. For end-of-life patients serving out their final days, “there is nothing that can’t be done at the home” (Gari, 2009).

Pain Management

Pain management is a dicey subject for some healthcare professionals. It is fraught with moral and ethical concerns. There is not a “one size fits all” handbook for pain management medication at end-of-life. Healthcare providers have to use sound judgment and education to determine the appropriate level of medication(s) to administer. A comprehensive pain assessment is required both to choose initial therapy and to measure its effectiveness (Abraham, 1998). Generally, the severity of the patient’s symptoms will determine the amount of the drug given by the healthcare provider to the patient. The ethical concern from a provider standpoint arises most commonly when the patient is unable to verbally indicate their pain level, and the provider is forced to make a determination about appropriate types and amounts of medications.

End-of-life can often be accompanied by severe pain and other unpleasant symptoms that cause undue suffering (ASPMN, 2003). Turning to pain management or palliative care techniques, can be a cost effective health option that may improve the quality of life (and the dying experience) for terminally ill individuals. Palliative care is defined by the World Health Organization as “improving the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support to, from diagnosis to the end of life and bereavement (WHO-Palliative Care, 2009).” Pain management procedures can be administered in an office setting, an outpatient ambulatory surgery facility, hospital, and/or in-home care. Regardless of the setting, however, healthcare providers often times have to walk a fine ethical line, between what is appropriate amount of medication for comfort, and what can be detrimental to the patient.

For a patient that has mild pain and suffering, the provider may choose to give a lower strength medication such as an over-the-counter analgesic. However, if the patient’s pain goes into the moderate category, a controlled substance such as oxycodone may be given. Severe pain levels for those suffering end-of-life illnesses are often treated by highly potent

drugs, such as morphine, to allay pain symptoms. Drugs like morphine, if given in an accidentally overdosed quantity, can weaken a patient's pulse, shallow breathing, cause fainting, halt breathing, and can cause death at certain dosage levels (Morphine Information, 2009). There can be a wide range from the initial dosage given to a patient, to the maximum recommended dose (Ortiz-Rios, 2009). Proportionate palliative sedation is the practice of administering the lowest dose of pain management therapy to achieve comfort for the patient. Proportionate palliative sedation is widely accepted as an ethical medical practice (Quill, 2009). Contrast proportionate palliative sedation with palliative sedation to unconsciousness, a pain management therapy whereby unconsciousness is the intended effect to achieve maximum pain relief for the patient. The patient is then left in an unconscious state generally without artificial nutrition or hydration until the patient dies (Quill, 2009). The practice has been condoned by the United States Supreme Court in *Glucksberg, supra*, wherein the Court held that “[a] patient who is suffering from a terminal illness and who is experiencing great pain has no legal barriers to obtaining medication from qualified physicians, even to the point of causing unconsciousness and hastening death” However, the practice is considered controversial within the medical community and should not be used as a back door means of carrying out physician-assisted suicide (Quill, 2009).

Whereas pain management may be controversial in nature, it is important to not overlook its important role in the end-of-life discussion. When taking into account all the end-of-life aspects conferred herein, pain management can offer a sense of autonomy and comfort to a patient, while being a cost efficient health choice. With the extensive choices, both in treatment options and environments in which services can be rendered, pain management should be a meaningful option for anyone seeking or planning end-of-life care.

Historical Policy Analysis – Lessons from the Past

Healthcare policy reform recommendations, as previously mentioned and discussed, have largely been focused in three key areas with regard to end-of-life: “(a) advance directives; (b) hospice benefit; and (c) pain management” (Werth & Blevens, 2002, p. 406).

Further to those recommendations, it is germane to examine outcomes of the PSDA to determine the extent to which legislative efforts can promote the use of advance directives. In a report completed nearly five years after the enactment of the PSDA, the General Accounting Office (GAO) indicated that

a significant majority of covered healthcare institutions were complying with most of the provisions of that legislation (GAO, 1995). The GAO report, however, expressed concern about the “effectiveness” of the legislation. Two of the major challenges to the efficacy of the PSDA identified in the aforementioned GOA report included: (1) the persistent low level of participation among people actually choosing to exercise the right to execute an advance directive and (2) the lack of thorough discussion between patient and healthcare provider regarding treatments that may be carried out pursuant to an advance directive for those individuals with completed advance directives (GAO, 1995). According to the GAO, a counseling session was deemed critical to ensure that the patient was fully aware of the implications of their decisions, as well as to ensure that the healthcare provider fully understood the patient’s wishes (GAO, 1995). According to several empirical studies, advance directive planning expectations have fallen short of the initial promise of the PSDA legislation (Prendergast, 2001).

With respect to hospice services, the Tax Equity and Fiscal Responsibility Act of 1982 (42 U.S.C. § 1395, *et seq.*), which expanded coverage for hospice care for qualified Medicare beneficiaries, was a significant legislative accomplishment (Blevins & Deason-Howell, 2002). However, making an accurate prognosis of the point in time that marks end-of-life (and, coincidentally, the start of Medicare benefits for hospice care) remains a substantial challenge (Werth & Blevens, 2002). Notwithstanding the significant advances in medicine, predicting death with a high degree of certainty remains extremely difficult (Scitovsky, 2005). As a result, there are wide variations in treatment periods, quality of care, and cost associated with hospice care on a patient-to-patient basis. Improving our understanding of the causes of these variations could be enormously beneficial to benchmarking performance and standardizing best practices (White, Cochran, & Patel, 2002).

Efforts to improve pain management at end-of-life center primarily around three key issues: (1) managing the cost for effective pain management, which can be expensive and sometimes not covered by Medicare; (2) improving physician education about pain management; and, (3) dealing with regulatory barriers that may restrict a physician from prescribing certain aggressive pain management regimens (Werth & Blevens, 2002). Recent federal legislation initiatives related to end-of-life pain management have not seen much, if any, real success. The most recent, the Conquering Pain Act of 2005 (S.B. 999), which proposed to establish “evidence-

based practice guidelines for pain treatment”, experienced a fate similar to its predecessors by failing to emerge from committee referral (S.B. 999). However, it has become more and more clear to the medical community that the importance of effective pain management during end-of-life cannot be understated. “To restore a balance between a physician's obligation to prolong life and obligation to relieve suffering, a peaceful death must be acknowledged as a legitimate goal of medicine and as an integral part of a physician's responsibilities” (Meier, Morrison, & Cassel, 1997, pg. 226).

Imminent Crisis or Opportunity for Incremental Reform

Whereas end-of-life concerns are certainly not confined to the elderly, it is important to note that approximately two-thirds of the people that die in the United States each year are the elderly, i.e., 65 or older (Scitovsky, 2005). This is significant because Medicare studies provide some of the best information on end-of-life costs (Scitovsky, 2005). Conceding the limitations of this data source, we can still glean valuable insights on end-of-life costs from its consideration.

Approximately one-fourth of Medicare spending is attributable to individuals in their final year of life (Buntin & Huskamp, 2002). At least one study has reported that Medicare beneficiaries in their final year of life spend nearly six times as much as other Medicare beneficiaries (Hogan, Lunney, Gabel, & Lynn, 2001). Whereas on the surface this seems to suggest an imminent crisis with end-of-life costs, further research on the issue suggests otherwise.

Of particular interest is the observation that the percentage of Medicare costs due to end-of-life care has remained relatively consistent over the last two decades (Hogan, et al., 2001). This same study concluded that end-of-life costs do not appear to be a leading cause of the growth in healthcare spending (Hogan, et al., 2001). In fact, the stability of this trend may suggest that higher end-of-life costs are largely inevitable and, consequently, there is little that can be effectively done to reduce the need for higher levels of end-of-life healthcare spending, particularly when related to acute care (Liu, Wiener, & Niefeld, 2006). Some researchers suggest that the higher cost of end-of-life care may be primarily associated with treating severe illness and functional impairment, rather than exceptional or extraordinary circumstances associated with being near the end-of-life (Hogan, et al., 2001). Further to this hypothesis, multiple studies have concluded that the healthcare costs of decedents and survivors suffering from similar illnesses are comparable (Liu, et al., 2006).

These studies suggest that seeking ways to reduce end-of-life healthcare costs, while highly worthy of consideration, may not be the panacea that some reform advocates suggest to controlling the high growth of national healthcare spending. With respect to end-of-life care, there are certainly many prospects for incremental reform. Some of these opportunities will be explored below. Maintaining reform expectations within the realm of actionable and realistic is imperative. As Scitovsky (2005) concludes, “the data from studies conducted to date do not provide a basis for a policy of singling out one group of patients for cost-containment strategies” (p. 837).

Perception vs. Reality

The ensuing controversy associated with the end-of-life counseling provision in H.R. 3200 § 1233 prompts us to consider additional questions. What do we really know about cost inefficiencies that exist with respect to end-of-life care or the quality of end-of-life care? Can we significantly reduce healthcare spending by reducing end-of-life healthcare costs without sacrificing quality of care? A common perception is that there are widespread cost inefficiencies and unnecessary provisions of healthcare during the end-of-life. While it is clear that inefficiencies do exist, the potential cost savings from end-of-life care reforms are not as certain. A recently completed study by the Urban Institute, a public policy research organization, indicated that while there were opportunities for cost savings, most of healthcare spending at the end-of-life was unavoidable (Urban Institute, 2009). This same report suggested that many analyses that target the “high cost of dying” inappropriately disregard similarly sick survivors that receive comparable care and benefited from the high cost treatments (Urban Institute, 2009).

In a 2009 report, “How Can We Pay for Healthcare Reform,” the Urban Institute identified over \$1.3 trillion in possible cost savings over a ten year period. Of this amount, the cost savings attributable to end-of-life healthcare reform was about \$91 billion over the ten-year period from 2010-2019 (Urban Institute, 2009). Clearly, this estimated level of potential healthcare savings is not trivial. Yet, it accounts for only approximately seven percent (7%) of the total estimated cost savings identified in the report. Most of the end-of-life cost savings estimate in the Urban Institute’s 2009 study was attributable to reducing Medicare beneficiary related costs by 1.25% per year (Urban Institute, 2009). Accordingly, while the potential for end-of-life related cost savings does exist, it is prudent to moderate expectations with respect to the attainable impact that may have on healthcare reform.

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What can we state about the potential for improving the quality of end-of-life care? The common perception and, in some respects, common fear, regarding this issue may be that greater consideration of palliative care will likely involve decisions leading to less quality of care. While the results of much of the earlier qualitative research were mixed, relatively recent quantitative research appears to indicate that palliative care particularly when it is possible to provide at home provided the highest quality of care satisfaction from the perspective of family members (Teno, Clarridge, Casey, et al., 2004; Higginson, Finlay, Goodwin, et al., 2003). Notwithstanding the recent research, the possible benefits of palliative care are not fully understood. Unfortunately, many still fear that palliative care means the end of care.

Actionable Initiatives

What can be done to improve the provision of end-of-life care? Is it realistic to expect quality improvements while pursuing cost efficiencies? Discussed below are key initiatives that individuals, healthcare providers, and the government may consider to potentially improve end-of-life care.

Individual Action

As individuals, and as a society, we would benefit by becoming more comfortable with death. This seems too obvious to even mention. Death is a certainty for all of us. However, for too many of us, death is still a subject we avoid discussing even with our closest loved ones. It is difficult, if not impossible, to be adequately prepared for death if we are reluctant to discuss it. If, as individuals, we seek autonomy over our healthcare decisions, we must be prepared to accept responsibility for the directives we make in connection therewith.

Advance directives are often promoted as a means for achieving patient autonomy (Kass-Bartelmes, Hughes, & Rutherford, 2003). Yet, research indicates that patients (and/or their appointed healthcare surrogates) are not following through with the directives contained therein. A recent research study indicates that advance directives are actually completed and signed by less than 25% of most patient groups (Perkins, 2007). Some of the reasons cited for not completing advance directives were avoiding death related discussions, lack of awareness, lack of understanding, and poor support from healthcare personnel requesting completion of the forms (Perkins, 2007).

It is important to note that, given the low completion rates and other implementation limitations, there remains considerable room for improvement of the advance directive (Perkins, 2007). For example, one advance directive

“implementation problem is poor proxy representation” (Perkins, 2007, p. 53). The lack of unambiguous, regular, or recent instructions between the patient and proxy (i.e., family member or designated significant other) may result in overwhelming emotional anxiety and flawed decision-making by the proxy (Perkins, 2007, p. 53). This underscores the importance of family members or significant others to reach out and initiate the end-of-life discussion if it has not been initiated by the patient.

Notwithstanding these limitations related to advance directives process must be emphasized over outcome. The process of discussing a patient’s wishes and their options with a healthcare provider, as well as their family, at early and regular intervals can be immensely valuable in reducing potential uncertainties among family members and healthcare providers and, consequently, more closely aligning end-of-life care decisions with a patient’s true intentions.

Healthcare Provider Action

With respect to healthcare providers, two potential areas for consideration arise: (1) improving communication between the healthcare provider and patient; and, (2) improving the delivery of palliative-oriented care.

Effective communication requires active involvement by all relevant participants. Whereas we have noted the value of a patient being willing to discuss end-of-life matters with their healthcare providers, it is of equal, if not greater importance, for the healthcare provider to be a good listener and advisor in this communication process. In evaluating “what matters most” to patients during their end-of-life care, “having trust and confidence” in their doctors was “most frequently rated as extremely important” in a recently completed study of seriously ill patients (Heyland, Dodek, Rucker, et al., 2006, p. 635).

Research suggests that a patient’s “trust and satisfaction” levels may be dependent on their doctor developing “relational closeness” with the patient (Breen, Wan, Zhang, et al., 2008, p.159). To support the healthcare provider in fostering this closer relationship, addressing the nature of patient centered dimensions of care may be helpful. As described by the Picker Institute, based on more than 350,000 patient survey interviews, patient-centered dimensions of care include the following: “(1) respect for the patient’s values, preferences, and expressed needs; (2) access to care; (3) information and education; (4) emotional support to relieve fear and anxiety; (5) involvement of family and friends; (6) continuity and secure transition between healthcare settings; (7) physical comfort; and (8) coordination

and integration of care” (Breen, Wan, Zhang, et al., 2008, p. 156). The same study noted that almost four of five physicians could potentially improve their delivery of care by more effectively adopting “patient-centric” dimensions of care (Breen, Wan, Zhang, et al., 2008, p. 156). Another recent quantitative study also found that “increasing communication between patients and their physicians is associated with better outcomes and with less expensive medical care” (Zhang, Wright, Huskamp, et al., 2009, p. 487).

Another area that warrants further consideration among healthcare providers is palliative care. There is an increasing amount of research based on the perspective of patients and family members that indicates a potential to improve the quality of the end-of-life experience by greater consideration of multi-disciplinary palliative care (Teno, et al., 2004; Mitchell, 2002; Byock, Twohig, Merriman, et al., 2006). Research also shows that the improved quality of care can also be more cost effective (Byock, et al., 2006). An *Archives of Internal Medicine* study observed that when advanced cancer patients had candid end-of-life discussions with their doctors they experienced a reduction in acute care services and there was an observed negative association between quality of care and costs in the last week of life (Zhang, et al., 2009).

“An expansion of palliative care programs in hospitals” was one of the key policy recommendations of a recent study that could potentially result in lower healthcare costs while concurrently improving the quality of end-of-life care (Zhang, et al., 2009, p. 488). Whereas significant progress has been made in the acceptance and delivery of palliative care, the opportunity for additional improvement remains significant, particularly in the areas of healthcare provider and patient education, properly recognizing and discussing the futility of care, and in the delivery of coordinated palliative care in a multi-disciplinary manner (Chwang, 2009; Meier, Morrison, & Cassel, 1997; Mahmood-Yousuf, Munday, King, et al., 2008).

Government Action

Research suggests that a significant role exists for government in improving end-of-life healthcare. Effective policies and reform initiatives require an in-depth understanding of current outcomes and costs. There is a need to gather better healthcare utilization and cost data on the experiences of end-of-life patients (Wiener & Tilly, 2003). Improving information technology within the healthcare system offers the one potential means whereby to improve quality of care, efficiency, and lower costs (Chugh, 2009).

Whereas many advocate the expansion of the Medicare hospice benefit and greater use of palliative care services, additional evaluation may be needed on quality of life indicators as well as the cost effectiveness of palliative or hospice care. While improving accessibility to palliative services unequivocally provides greater choice and autonomy for the patient, the cost effectiveness of such programs remains unclear. Some studies, as stated earlier, report significantly lower costs for patients receiving palliative care while other studies have concluded that the comparative costs for hospice service were only marginally lower for cancer patients and higher for non-cancer patients (Campbell, Lynn, Louis, et al., 2004). This same study concluded that “overall, hospice users incur an estimated 4% greater [Medicare] costs than do similar patients who do not use hospice” (Campbell, Lynn, Louis, et al., 2004, p. 275). With respect to addressing the final wishes of the patient, a recent quality in end-of-life care study revealed that dying at home was not as important to patients as not being a burden to family (Heyland, Dodek, Rocker, et al., 2006). Government can assume a significant role in sponsoring greater research that is needed to better understand patient and family preferences, quality indicators of end-of-life care, and the relative cost effectiveness of palliative care versus traditional hospital services.

Another area that needs greater public policy attention is expanding access to more effective pain management. Research indicates that inadequate pain management remains a significant problem during end-of-life care (Imahof & Kaskie, 2008). A recent study concluded that both federal and state policies should be improved with respect to promoting more effective pain management during end-of-life (Imahof & Kaskie, 2008). Policy oriented pain management studies indicate that the greatest promise for effective policy reform in pain management are likely to begin with initiatives at the state level through the work of state attorney generals and state medical boards (Imahof & Kaskie, 2008; Edmondson, 2006). State attorneys general, in particular, may be in the best position to improve collaboration between “law enforcement and the medical community about the balance between effective pain management and the battle against diversion of prescription drugs” (Edmondson, 2006, p. 214).

Conclusions and Recommendations

Policy reform expectations for end-of-life care stemming from reform of the American healthcare system should be significantly moderated—there appears to be plenty of lower hanging fruit when it

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comes to systematic healthcare reform. While there may always be opportunities to improve the provision of end-of-life care, this remains an intensely personal issue. Many patients will experience a period of chronic illness before their death. Some dying patients may not lose hope until the very end, whereas others may accept their fate sooner. Patients deserve the autonomy to make these final end-of-life healthcare choices in their own right, in consultation with their families, and in consultation with their physicians. There is no “one-size fits all” end-of-life plan. Due to diverse medical and public opinions surrounding this issue, it is unlikely that public policy will be successful in finding a uniform, cost-efficient approach to end-of-life healthcare. This limited role for public policy suggests that healthcare providers and patients, in the first instance, must assume greater ownership and responsibility for end-of-life planning. As citizens, healthcare providers, family members, and future patients, we all should recognize that we have a responsibility to become more informed about end-of-life healthcare planning and to take the necessary steps to ensure that the final choices of patients are known and honored. Addressing this need to improve patient and healthcare provider awareness and accountability on this issue may be one of the areas where we may be best served in a non-intrusive, but supportive manner by public policy. The end-of-life planning provision in Section 1233 of H.R. 3200 may be a step in the right direction by providing education regarding advance directives and requiring periodic counseling and providing provider reimbursement for these services. It is unfortunate that the intention of the provision was not properly communicated in the midst of the heated debate surrounding healthcare reform. It is our hope that, in the event the measure does not mature into law, the issue be revisited again when calmer minds prevail.

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