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The Patient Self-Determination Act: 20 Years Revisited

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Evidence exists that the goals of the Patient Self-Determination Act (PSDA), which went into effect December 1991, have fallen significantly short of their achievement. The purpose of this paper is to explore the outstanding and controversial issues that continue to impact both health care providers and health care consumers today. A brief history of the PSDA and events that led to its passage are discussed. Further, the complex legal, ethical, and societal issues that have arisen in the almost two decades since its passage are explored for their impact on health care providers, health care consumers, families, surrogate decision makers, the economy, and society as a whole. Recommendations for addressing the barriers that impede PSDA goal achievement are also presented, such as education, policy reform, and effective communications among health care providers, health care consumers and others. Recommendations for future research are also offered.

Keywords: Patient Self-Determination Act; advance directives; health care decision making; autonomy; end-of-life

As its 20th anniversary approaches, the federal Patient Self-Determination Act of 1990 (PSDA) has provoked multiple social, political, legal, and ethical issues since its passage (Patient Self-Determination Act [PSDA], 1990). Passed as part of The Omnibus Reconciliation Act of 1990, the PSDA became effective December 1, 1991, amid intense public scrutiny and with great expectations that the law would "correct the balance of the relationship between health care consumers and providers," (Rouse, ¶ 3, 1991). Twenty years later it is important to evaluate whether those expectations have been realized and if a sense of balance has been achieved.

The goals for the PSDA legislation were to: (a) provide education regarding an individual's rights under state laws to make decisions regarding health care, including the right to refuse treatment; (b) promote greater formulation of advance directives (ADs) to be used if individuals become incapacitated; and (c) reduce end-of-life treatment costs by preventing unwanted and unnecessary care, in addition to what health care practitioners perceived as the need for defensive medicine (Heitman, 1992). The purpose of this paper is to explore the persistent and controversial issues that continue to impact both health care providers and health care consumers today. A brief history of the PSDA, its current status, and progress towards accomplishing its intended goals, as well as recommendations for the future, will be presented.

HISTORY OF THE PSDA

A significant impetus for the development and ultimate passage of the PSDA was a 1990 Supreme Court decision (*Cruzan v. Director*, 1990), in which hospital employees refused to honor a parental request to terminate nutrition and hydration from their comatose daughter, Nancy Cruzan. The issues in this case were compounded by the patient's incompetence. The Supreme Court recognized that there are constitutionally protected rights to refuse nutrition and hydration that would preserve life but these rights typically extended to the competent patient. The complexities arose in the context of whether a surrogate (e.g., parents) can make

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that decision under these particular circumstances. The question essentially becomes one of balancing interests amid clear and convincing proof of the patient's intent and desires. The impact of this case was a major contributor for laying the groundwork for the PSDA legislation. Although the Cruzan case was a catalyst for the passage of the PSDA bill, the legislative intent was to standardize patient information regarding health care decisions. Under the PSDA, health care providers were required to provide written information to patients regarding their rights to participate in decisions about their own health care, their rights to complete ADs, and the health care provider's policies regarding how they honor these rights. States, however, were free to develop legislation on the directive types, forms, and limits on the power of particular agents (such as surrogates).

While Cruzan was the most recent and influential case for the PSDA passage, the foundation was laid with earlier cases. Karen Quinlan was 21 years old when she was placed on life support due to respiratory arrest after having ingested alcohol and medications in 1975. Quinlan, as Cruzan, was incapable of making a decision as to health care treatments, and Quinlan's family petitioned the New Jersey Supreme Court to remove a ventilator so she could die with dignity. However, the physicians and hospital refused to honor the father's request to terminate the life-assisting apparatus (Dyer, 2006; Jackson, 1999). Ultimately, the New Jersey Supreme Court held that removal was permissible. Quinlan was removed from the ventilator but breathed on her own, living for yet another 10 years before dying from an infection (Dyer, 2006).

In 1985, the New Jersey Supreme Court once again considered an incompetent patient's rights of self-determination with regard to feeding tubes. The court decision distinguished elderly nursing home patients from those who were younger and in a vegetative state, such as Cruzan and Quinlan. The case involved Claire Conroy, an 84-year-old woman with severe dementia (Lo & Dornbrand, 1986). The court (*In the Matter of Claire Conroy, 486 A.2d 1209 [New Jersey, 1985]*) rejected the argument that artificial nutrition via tube feedings was considered to be ordinary life sustaining measures, and supported the tube feeding withdrawal on the basis that the benefits of the tube feeding did not outweigh the burdens, and continuing the tube feeding would have been inappropriate treatment (Lo & Dornbrand, 1986).

The *Brophy v. New England Sinai Hospital* case in 1986 heard the argument of Paul Brophy who suffered a ruptured cerebral aneurysm and became comatose, remaining in a persistent vegetative state (Davis, 2003; Jackson, 1999). His circumstances were different in that his life support was defined as artificial nutrition and hydration, while Quinlan's was respiratory support. Brophy had never expressed his intent regarding life-sustaining treatment but more than 12 family members argued that he would not want to continue his treatment. The Massachusetts Supreme Court reasoned that artificial nutrition and hydration was a medical procedure and as such it could be rejected as could any treatment. They found that removing the feeding tube was not the equivalent of suicide, reasoning that individuals have a right to death with dignity and a constitutional right to protection from nonconsensual invasion of one's body.

These cases highlight the complexity of legal and ethical issues inherent in situations in which there is no AD. They also highlight some of the problematic issues that arise in very difficult life-sustaining or life-terminating decisions without the benefit of an AD. The questions that continue to generate debate are whether these types of cases have changed since the implementation of the PSDA and whether the goals of the PSDA have been successfully accomplished in the last 20 years.

MISSING THE MARK: PROBLEMATIC ISSUES AND PROBABLE CAUSES

It is our premise that the PSDA has failed to meet its intended goals. Serious issues still prevail concerning AD completion rates, compliance with completed ADs, advance planning education, and the cost and utilization of end-of-life care. These issues, including discord between law and ethics, have seriously affected health care practitioners, health care consumers, surrogate decision makers, and others (Ulrich, 2001). Value system conflicts among the affected parties, varying approaches to interpretation and enforcement, and lack of adequate communication are all contributing factors to the disputes and continued struggles between the various stakeholders and constituents. A discussion of some of the problematic issues raised since the PSDA went into effect will be presented as they align with the goals of the PSDA: ADs, education, and cost-effectiveness of end-of-life care treatment.

Advance Directives

Advance directives became an important tool for determining patient intent regarding end-of-life care. The PSDA defined ADs as a written instruction, such as a living will or durable power of attorney for health care, that would be recognized under state law as proof of the patient's intent and desires should the individual become incapacitated (PSDA, 1990). The premise was that individuals should be empowered to make their own health care decisions and to exercise responsibility and authority in so doing through a clear expression of their intent (Ulrich, 2001). Before the passage of the PSDA, few people executed their autonomy in expressing their intent in health care decision making through the use of ADs (Winslade, 1991). While the PSDA provided legitimized opportunities for individuals to exercise their right to autonomy in health care decisions, practical concerns were expressed early as to how the PSDA would be operationalized and enforced (Weber & Kjervik, 1992). These concerns remain today and have been fully realized on several different levels. For instance, problems with PSDA interpretation have resulted in confusion surrounding implementation procedures in health care facilities. Inconsistencies in the recognition and honoring of ADs have created multiple and complex legal-ethical issues that have resulted in futile care. These controversies are largely due to differing attitudes, beliefs, and knowledge about the federal and state statutes used to interpret PSDA implementation. Also to blame are clashing value systems of patients, families, health care providers, and health care organizations within an environment characterized by a fear of potential accusations, litigation, and even threats to professional licensure.

Many states modeled their AD forms on the Uniform Health Care Directive Act (UHCDA) and combined ADs with living wills. Some states, however, refused to allow for ADs under state legislation requiring the judiciary to adjudicate by balancing the interests in each particular case, in many ways creating more Cruzan-type cases. Standler (2005) observed that decisions in some cases were based on the justification that death would be a result of natural causes and not on a decision to discontinue life or withhold artificial life support; however, "natural causes" can be open to interpretation and result in a different course of events as in the well-publicized case of Karen Quinlan.

Dilemmas and resulting actions regarding end-of-life care decision making frequently are more legally based than ethically based (Annas, 1995). State law covers implementation and enforcement issues. As such, the AD must be determined to substantially comply with the state law provisions for the validity of these documents. Accordingly, a physician or other health care provider that fails to comply with an AD, medical power of attorney, and living will may be subject to professional disciplinary action as well as possible civil litigation resulting in monetary damages. However, issues such as reasonable determinations, good faith, and similar justifications are all a part of the judicial interpretative process in adjudicating these issues. In addition, some states have "matter of conscience or another basis" exceptions for not complying with ADs and similar legal documents. The court cases where physicians have been sued (Pennsylvania and Ohio, most notably) involve complex factual determinations pertaining to informed consent, the nature of the treatment, the patient's condition, and so forth (Lynch, Mathes, & Sawicki, 2008). If claims are factually supported in the opinion of the court then it is possible for patients to receive compensation for health care expenses and emotional distress; although as a general rule, these types of cases are hard to sustain in court. Under the Death Act in Texas, a directive has no operative effect until a physician has certified in writing that a patient is "terminal or has an irreversible condition" (Texas Administrative Code, Section 405.61, 1996). A physician complying with a directive under Texas law is protected from civil and criminal liability unless there is a failure to exercise reasonable care (which is a complex factual determination). A physician who refuses to carry out a directive may not only be subject to criminal and civil liability but may also be subject to disciplinary action by the Texas State Board of Medical Examiners.

Though the PSDA was intended to decrease defensive health care practices (Heitman, 1992), fears of litigation brought by surviving families/surrogate decision makers continue to exist. Duke and Northam (2009) found that about 40% of physicians in a Texas community feared litigation, although Texas law states that "a person does not commit an offense...by withholding or withdrawing life-sustaining treatment from a qualified patient" (Texas Advance Directives Act [TADA], 1999, Sec. 166.047). Studies also indicate that physicians fear litigation by surviving surrogate decision makers or even by the legal system if they act according to an AD that may be in conflict with the law or is in conflict with the wishes of surrogate decision makers (Duke & Northam, 2009; Ferrell, 2006). Even when physicians are willing to follow a patient's AD, they often allow the surrogate decision maker to convince them otherwise (Badger, 2005), again usually due to either overt or covert threats of litigation. Families often have not had the luxury of time and thoughtful consideration to prepare for the impending death of a loved one; and when decisions must be made about life-sustaining or life-ending measures, conflicts may occur (Ferrell, 2006). However, the presence or absence of an AD or the passage of time sometimes has no effect on lessening the contention or preventing long and drawn out court battles. A widely publicized case of this nature was Terry Schiavo, whose husband and parents were involved in an acrimonious dispute about discontinuing artificial nutrition and hydration. Ms. Schiavo was in a persistent vegetative state for many years before her death. Based on the belief that she could eventually recover, her parents publically protested the plan to remove her feeding tube. After her death, autopsy results reflected brain damage well beyond any hope of recovery from her current state (Quill, 2005).

A provision in the PSDA calls for ensuring compliance with state laws governing ADs since state laws were intended to be the mechanism for enforcement and implementation of the PSDA (Clarke, 2009). However, information in the literature about operationalizing this compliance process is limited, and anecdotal information reveals that state law procedures are not being followed. Further, enforcement issues are problematic at the state level because limited consequences are in place when a patient's AD is not followed. The only known efforts addressing this are some state futile care laws, such as in Texas (Health and Safety Code, 1999) and in Ohio (Ohio Revised Code, 1998), that include the mandate that physicians either facilitate or not interfere with the transfer of care to a provider willing to comply with the wishes of patient and/or family/surrogate decision makers. Even this law is being contested by "right-to-life" activists (Shannon, 2009). Texas law also states: "A physician, or a health professional acting under the direction of a physician, is subject to review and disciplinary action by the appropriate licensing board for failing to effectuate a qualified patient's directive in violation of this subchapter or other laws of this state" (TADA, 1999, Sec. 166.045). Problems continue to arise with these laws, partially due to the multifaceted ethical issues involved, as well as the age-old problems of nonadherence and noncompliance.

Despite the advantages of autonomous health care decision making that have been shown with having an AD (Pautex, Herrmann, & Zulian, 2008), little improvement has been noted for AD completion rates (Bradley, Blechner, Walker, & Wetle, 1997; Braun, Onaka, & Horiuchi, 2002; Shapiro & Bowles, 2002; Wellbery, 2005). This is especially true for those individuals who are not critically ill (Jezewski, Meeker, Sessanna, & Finnell, 2007; Wellbery, 2005;). Further, a dichotomy exists between having positive beliefs and favorability of advance care planning and low completion rates in the lay public (Braun et al., 2002; McAdam, Stotts, Padilla, & Puntillo, 2005; Nolan & Bruder, 1997) and in health care providers (Duke & Northam, 2009; Duke & Thompson, 2007). Completion rates vary from 20% to less than 30% (Dobbins, 2007; Hampson & Emanuel, 2005; Wellberry, 2005), and have remained static for the past 15 years (Hampson & Emanuel, 2005).

Education

Several reasons for continuing low AD completion rates have been identified. One such reason relates to how consumer education is conducted. The PSDA states that persons should be educated about ADs on admission to health care institutions accepting Medicare and Medicaid reimbursement. However, interpretation of the education requirement is inconsistent. Education implies some type of interactive process between learner and teacher, which does not occur in the vast majority of cases. When education does happen, patients are often not in a receptive condition. Many of the institutions with adherence problems are inpatient facilities in which persons are admitted under conditions of urgency and stress, and at a time when cognitive abilities are not focused on something called a "living will." Even in outpatient facilities, clients may not have the mental fortitude to consider ADs. People are typically being asked to consider ADs under anxiety-provoking circumstances that are beyond their control. Very few health care institutions do more than provide written materials about ADs that are bundled together with a variety of other papers and forms through an admissions office.

Education-related barriers for AD completion by patients include procrastination (Butterworth, 2003; Matzo, Hijjaz, & Outwater, 2008), lack of readiness, denial, and unrealistic expectations about life-sustaining and life-prolonging futile care (Butterworth, 2003). Also, patients (Golin et al., 2000; Salmond & David, 2005) and health care providers (Butterworth, 2003; Smith et al., 2008) have expressed discomfort with discussing advance care planning. Additional barriers include institutional environmental factors, lack of effective communication between staff and patients, lack of understanding of benefits of ADs, and lack of trust in a designated surrogate decision maker and/or health care provider (Van Dorn, Swanson, Swartz, Elbogen, & Ferron, 2008). Furthermore, there is a widespread belief that ADs are only for the elderly and/or terminally ill (Larew, 1998).

Communication about ADs is recognized as a vital component of the education process for the lay public, yet ignorance seems to prevail. Patients who had formulated ADs stated that they learned about them from persons other than their health care providers (Duke, Thompson, & Hastie, 2007; Fairchild, 1998; Salmond & David, 2005). Often, individuals were assisted in the completion of ADs by attorneys or social workers

(Duke et al., 2007; Perry, Swartz, Smith-Wheelock, Westbrook, & Buck, 1996).

Studies show ethnic minorities have lower completion rates than do Anglo persons (Dobalian, 2006). A lack of basic education has been identified as contributing to the inability to understand future health care dilemmas, and may therefore interfere with the willingness to make informed decisions about end-of-life care preferences (Volandes, Ariza, Abbo, & Paasche-Orlow, 2008). Further, language translation issues are a problem and may interfere with AD completion. An accepting and informative attitude by health providers may be an important key to helping hard-to-reach vulnerable populations come to understand the importance of making their end-of-life wishes known.

Physician and nurse barriers include inadequate knowledge and attitudes (Duke & Thompson, 2007; Jezewski et al., 2005; Morrison, Morrison, & Glickman, 1994; Putman-Casdorph, Drenning, Richards, & Messenger, 2009; Shapiro & Bowles, 2002) and comfort levels (Morrison et al., 1994; Putman-Casdorph et al., 2009). Instances of not honoring ADs by the physician and other health care providers, the surrogate decision makers, or both, continue to be prevalent (Annas, 1995; Duke et al., 2007; Duke & Northam, 2009).

End-of-Life Treatment Costs

A goal of the PSDA was to reduce the end-of-life care treatment costs by reducing unwanted and unnecessary interventions and the perceived need for defensive medicine (Heitman, 1992). However, this goal has not been met since the costs of care have remained high as individuals near death. Hogan, Lunney, Gabel, and Lynn (2001) found that Medicare beneficiaries die at the rate of 5% per year, costing Medicare approximately $26,300 per person. A longitudinal survey compared the change in health care expenditures with age as people approach death as compared to expenditures when they were not close to death (Yang, Norton, & Stearns, 2003). Findings revealed that expenditures did indeed increase with age and the monthly health care expenditures were much higher when people were close to death. The cost of care for the last year of life represented 27.4% of all Medicare payments for the elderly. This percentage has remained constant for two decades (Hogan et al., 2001; Buntin & Huskamp, 2002).

The utilization of intensive care unit (ICU) services has remained high as well. In a retrospective analysis of administrative data of discharge databases, Angus et al. (2004) found that one in five Americans die using ICU services. Stated differently, 18% to 26% of the U.S. population use the ICU at the end of life with an average cost of $24,541 per person for terminal ICU hospitalizations. Dobbins (2007) also found that 42% of the patients in her study of older adults in a community hospital died in ICU. Interestingly, Hanchate, Kronman, Young-Xu, Ash, and Emanuel (2009) found that costs in the final six months of life for African Americans ($26,704) and Hispanics ($31,702) were considerably higher than for Anglo Americans ($20,166). Much of the cost differences were found to be due to greater end-of-life use of the ICU and other intensive procedures. In addition, aggressive and possibly futile care is more likely in ethnic minorities due to their lower AD completion rates (Dobalian, 2006) and decreased likelihood for having a "do not resuscitate" order (Levy, Fish, & Kramer, 2005). Little research was found that addressed the issue of lowering costly end-of-life care. However, promising research has been reported by Zhang et al. (2009) regarding the effectiveness of patient-physician discussions about end-of-life wishes of patients with advanced cancer. Factors such as use of the ICU, life-sustaining technology, length of stays, hospice services, and quality of life in days before death were also examined. Their findings indicated that patients who reported end-of-life discussions were less likely to die in the ICU, had greater utilization of hospice services earlier, and had 35.7% lower costs of care.

CONSEQUENCES OF THE PROBLEMATIC ISSUES

Advance directives were intended to decrease uncertainty for families and health care providers in situations where patients were unable to voice their wishes (Heitman, 1992).When ADs indicating no desire for aggressive treatment are not honored, harmful and sometimes tragic outcomes occur for the patient, loved ones, and health care providers. Patients may experience prolonged pain and suffering attributable to the disease process and/or continuing burdensome tests and treatment. Loved ones also suffer while watching the patient endure the trials and tribulations of aggressive care (Sibbald, Downar, & Hawryluck, 2007). Even when the patient is in a vegetative or comatose state, or not receiving aggressive care yet being kept alive with artificial nutrition and/or ventilation, the possibility of pain and discomfort remains an issue for that patient. Though we now have more knowledge about the perception of pain, there is much yet to be learned. The premise that a person who "looks peaceful" is not suffering cannot be assumed.

Moral distress on the part of health care providers is an additional adverse concern created by ethical dilemmas that may result from failure to honor an AD

(Austin, Kelecevic, Goble, & Mekechuk, 2009). Jameton (1984) defined moral distress as "when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action" (p. 6). Individuals come to the patient care setting with their own, and sometimes disparate morals, values, beliefs, and experiences. These diversities may become evident when life is prolonged and when little or no hope for any meaningful life exists, frequently resulting in conflict, anger, frustration, and ultimately, moral distress (Ferrell, 2006). Though moral distress has been noted in physicians, it is more often reflected in nurses due to power differentials (Hamric, Davis, & Childress, 2006). Nurses have less influence on decision making despite the fact they are more actively involved in direct patient care and spend more time at the bedside than any other health care provider. Moral distress leads to anger and frustration (Ferrell, 2006) and altered health care team functioning (Austin et al., 2009; Ferrell, 2006) at a time when collegial interactions and health care team support is needed for optimal patient care and for support of each other. Nurse retention problems are also a byproduct of moral distress (Corley, Elswick, Gorman, & Clor, 2001).

RECOMMENDATIONS FOR THE FUTURE

Addressing the identified issues requires targeting several areas: awareness, education, attitudes, AD completion, and compliance with the federal and related state statutes. Numerous interventions have been tested over the years to increase AD completion (Heiman, Bates, Fairchild, Shaykevich, & Lehmann, 2004; Ho, Thiel, Rubin, & Singer, 2000; Jezewski et al., 2007; Landry, Kroenke, Lucas, & Reeder, 1997; Myers, Moore, McGrory, Sparr, & Ahern, 2004; SUPPORT, 1995). However, a key factor that transcends these strategies is adequate communication among health care consumers, individual health care providers, family members, surrogate decision makers, and individual legal representatives. Further, these discussions should occur in appropriate settings and at more optimal times. The acute care setting is one of the most inappropriate places to offer information about ADs; yet, this is the most common setting. Decisions about end-of-life care takes considerable thought, including discussions with family and health care providers, and possibly legal and spiritual/religious advisors. A more appropriate strategy would be to have standardized education and discussions as a routine component of every primary health care visit to offices and clinics. The AD can be thought of as the "6th" vital sign in primary care, irrespective of age, with the topic addressed at each visit to ensure the "currentness" of one's AD wishes. Documentation in the medical record is critical along with appropriate discussions with surrogate decision makers and family. The movement toward establishing electronic medical records may facilitate universal communication of one's wishes.

Issues regarding enforcement of the PSDA and related state laws have been problematic and need to be addressed. For example, the existence of a written AD has not ensured that a patient's desires and intent were honored by family members, health care personnel, a hospital, or even the courts. By revisiting the language and wording of these statutes, perhaps any existing ambiguity can be minimized, resulting in less room for inconsistent interpretation. Understandable guidelines can be offered regarding the education component in terms of what comprises the education content, how the education is delivered, a means to evaluate patient/surrogate understanding, qualifications of individuals providing the education, and the setting in which the education occurs. Of these, the most critical may be the qualifications of the educator (business office staff typically have this role in acute care settings) and evaluating understanding (this is typically not done). Minimizing the threat of liability when a patient's AD is followed in cases where the patient's wishes are in conflict with surviving family and/or surrogate decision makers must also be addressed. When physicians and nurses are proactively key participants in AD discussions and these discussions are appropriately documented, more persuasive and convincing evidence exists regarding adherence to the patient's wishes, which may reduce the threat of liability. States that do not have specific policy protecting health care providers who act in "good faith" and as advocates for a patient with an AD should address this legislative gap. For those states that do have this in place, efforts should be made to ensure awareness and knowledge of this policy, and to explore factors that cause a continued fear of litigation.

Legislative policy has been partially addressed in most states concerning futile care. For example, the Texas Futile Care Law, as part of the Texas Advance Directive Act (TADA, 1999), states that a health care facility may discontinue life-sustaining treatment against the wishes of the patient or those acting on behalf of the patient if the treatment is thought to be hopeless or futile. Further, in Texas and other states, a physician must arrange transfer of a patient to a facility willing to render the type of care desired by the patient and/or surrogate decision makers when there is a conflict between surrogate decision makers and health care providers (TADA, 1999). As with the PSDA, problems with the way this law is worded and enforced interfere with optimizing patient autonomy and well-being. For instance, the law mandates actions to be taken by ethics committees when these conflicts occur. However, anecdotal evidence indicates that members of these committees are unprepared for such discussions and that some acute care facilities do not have a formal ethics committee in place. In these cases, an "ad hoc" group is called that is comprised of administrative officials and possibly an outside, usually legal, representative. Making decisions of this nature requires at least some knowledge of related laws and health care ethical decision-making processes. It is unlikely that all decision makers, especially "ad hoc" persons, have the skills and training needed to make these decisions. Policy formulation should be directed toward ensuring institutions have the appropriate resources for complying with these type of statutes. When considering the enormous impact of the decisions to be made, ethics committee member qualifications and education should be minimally standardized to facilitate chances for the best possible outcome in very difficult and complex situations. Ideally, an ethics committee should be interdisciplinary, representing physicians, nurses, social workers, spiritual/religious leaders, as well as lay persons and leaders in the legal, ethical, and philosophical areas of practice and expertise (Matzo & Ramsey, 2006). If an institution does not have qualified individuals to serve on an ethics committee, a plan should be established for access to a qualified external committee or advisory board with similar qualifications if and when necessary. Further, each institution should have access to a qualified individual who can act as an advocate for the patient's best interests in the event of conflicts between and among health care providers.

Research should be targeted toward intervention testing to improve AD completion rates among the health care providers and the public, especially among minority groups and with an emphasis on essential communications with individual health care providers and family. Without these discussions, honoring an AD may be less likely to happen. Because means are not in place for monitoring compliance with the related statutes, research should be targeted in this area so that data can be provided to legislators and health care administrators in order to better formulate solutions. For example, to what degree does any institution address in their policies, procedures, and in actual practice the requirements of a futile care law? A testable intervention may be appointing an advocate for patients without written ADs who may be receiving aggressive, futile care. A wide range of possibilities exist that need to be identified and tested in order to protect the autonomy, dignity, and respect of every single person who has and has not formulated a written AD.

CONCLUSIONS

While seeking plausible solutions and commonsense guidelines, this discussion has left many unanswered legal-ethical and emotionally laden questions. What are the consequences when an AD is not followed? How can threats of liability to health care providers be minimized? Further, how can the patient be protected in the case where hope for a meaningful life exists and efforts are being pursued to discontinue life-sustaining measures? Do futile care laws written as part of AD acts help to achieve the goals of the PSDA? Is the public aware of respective state laws regarding futile care? How can a person's autonomy and wishes be respected when there is no written AD?

Ethical dilemmas and conflicts arise in situations of existence and nonexistence of an AD, creating seemingly insurmountable problems among the health care team, family, and others. The importance of communications has been addressed, but also essential is having an interdisciplinary health care team who can communicate to facilitate successful outcomes. Working toward ensuring patient autonomy and advocacy calls for attitude changes for health care administrators, the nursing and medical professions, and other critical members of the health care team. All need to work together to eliminate the power struggles and hierarchical structures that often impede professional communications and collaborative decision making that could facilitate more positive patient and family outcomes. Further, in the face of related patient dilemmas, promoting patient advocacy means having the patient's best interests as the central focus of care. Therefore, it is critical that a sense of mutual trust and respect exists among health care providers. Strategies toward accomplishing this goal must be addressed in future studies using appropriate and credible resources. Until health care providers can agree that end-of-life efforts must be centralized around positive patient outcomes, other interventions will continue to fall short of addressing the problem of adherence to patient wishes for their final days.

Health care providers and society own the responsibility for ensuring each person is treated with a sense of respect and dignity in accordance with the desires and intentions of the patient. This can only be accomplished by working together in a unified direction toward effective policy, education, and practices that reflect patient advocacy and optimal outcomes while preserving the patient's right to self-determination.

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