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Through the Eyes of Taiwanese Palliative Care Providers: End-of-life Treatment Decisions in the United States

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The growth of medical knowledge and enhanced technology has increasingly blurred the line between life and death. Resuscitation procedures and life-sustaining devices such as mechanical ventilators, defibrillators, hemodialysis, and parenteral nutrition were introduced just a few decades ago, but have brought significant changes to the treatment of EOL patients. These treatments have given physicians the ability to prolong the process of dying; yet, the decision of when and how to use them has become complicated. An understanding of these controversial life-sustaining procedures and knowledge of current legal guidelines in the American EOL treatment context is necessary when palliative care in Taiwan seems to follow the Western experience in legislation regarding life-sustaining treatment. In this article, how EOL decisions made in the United States is summarized through the eyes of Taiwanese palliative care providers.

Life-Sustaining Treatments

The major function of life-sustaining treatments (LST) is to prolong life rather than cure the illness [1]. Frequently used LST include: cardiopulmonary resuscitation (CPR), mechanical ventilators (MV), dialysis, surgery, artificial nutrition/hydration, blood transfusions, and antibiotics [2]. For terminally ill patients, LST neither reverses their clinical course nor improves their health. Therefore, an EOL treatment decision is referred to as “a decision to continue or to forgo LST.” To forgo LST means to withhold (not to initiate) or to withdraw (discontinue) futile treatments, allowing nature to take its course [1].

Making decisions regarding whether to forgo LST is legally justifiable, yet ethically debatable. For example, the intent of unplugging a ventilator or discontinuing tube feeding is legally justified because it is the patient autonomously gives up his/her burdensome treatment[3]. However, this decision, sometimes defined as “passive euthanasia”[4], is still a decision to hasten death, which is morally difficult to make. In addition, “making EOL treatment decisions” is not a clear concept to most people. Since numerous legal issues involved in EOL decision-making have focused on the discussion of physician-assisted suicide and euthanasia [5], some may mistakenly associate EOL treatment decisions with these issues.

The concept of how to forgo LST, either to withhold or to withdraw, is unclear to most people as well. The decision to withhold and/or to withdraw LST may be seen differently by patients and families, but legally, they are seen as equal actions. In many legal cases, courts suggest that it is equally justifiable to withhold (not initiate) as to withdraw (discontinue) LST [6]. Many people hesitate to discontinue LST because they have reservations about killing their loved ones [1].

Cardiopulmonary resuscitation (CPR), mechanical ventilator, and artificial nutrition (tube feeding) are three frequently used LST procedures in EOL practice. The following section briefly discusses decisions about forgoing these LST methods, because they not only sustain life indefinitely, but also create great ethical controversy [7].

Cardiopulmonary resuscitation (CPR) and Mechanical Ventilator

Cardiac and/or respiratory arrests usually occur unexpectedly. In order to save lives, collapse of circulation must be corrected immediately and healthcare professionals are trained to respond to quickly restore circulation. Emergency crews are essentially duty-bound to resuscitate dying patients if no document exists to provide instruction to do otherwise. In such a case, every attempt will be made to prolong life [8].

Because CPR is usually futile and causes much discomfort for terminally ill patients, in early days, physicians usually stopped aggressive treatment and let nature take its course [8]. However, currently “our health care system has become overzealous with achieving life’s continuum” (pp. 14) [9]. Evidence shows both patients and healthcare professionals over-estimate the success of CPR [10], and patients with severe diseases who are facing impending death are frequently resuscitated [11]. One national study reports that nearly half of the study participants suffer from aggressive modalities, including several futile resuscitations, ventilators and ICU care [12].

As most cardiac arrests occur in an emergent or life-threatening situations, decisions to decline CPR are difficult for patients' family caregivers to make, since they are not prepared for such a discussion [13]. In order to avoid unnecessarymedical treatment and relieve patients' suffering, it would be preferable for both patients and families to discuss possible EOL treatment options at an earlier time. Unfortunately, most CPR decisions have to be made in times of crisis, during which both patients and families are stressed.

The introduction of mechanical ventilators (MV) poses another EOL dilemma. Treatment benefits and burdens of MV are debatable because MV may significantly decrease a patient's quality of life [3]. In addition, once a MV is in place, it automatically pushes air and oxygen into a patient's lungs. Because the patient's life depends solely on the MV, emotionally it is difficult for caregivers to withdraw the machine.

Tube Feeding

For those who are unable to orally take food and fluid, artificial nutrition and hydration technology may help prolong terminally ill patients' lives. However, since dehydration and a decrease in appetite are natural effects of the dying process, artificial tube feeding and IV dripping may present more burdens than benefits [14].

The advantages of initiating artificial feeding or hydration continue to be debatable. Most cultures throughout history, offering food has been a sign of caring and hospitality [1]. John Paul II declared that it is "morally obligatory" to continue artificial feeding and hydration for people in a persistent vegetative state [15]. Family caregivers provide sustenance to show their loved ones that they are not being abandoned; as a result, in clinical practice many EOL patients are being tube fed [16] and family caregivers tend to initiate tube feeding [7]. Moreover, nurses from Chinese would feed the patients to keep the patients alive as long as possible [17]. However, there is no medical evidence that forgoing nutrition and hydration will lead to a more painful death or "starve" patients to death [1]. In addition, based on the current legal guidelines, it is justifiable to withhold or withdraw food and fluids for patients at the end of life [14].

It is clear that, from the above discussion, while various LST prolong EOL patients' lives, they also cause great ethical controversies. American society has been struggling with these controversies surrounding LST, as evidenced by the Quinlan and Cruzan legal cases involving persistent vegetative-state patients. After numerous appeals, the court finally recognized the patients' right to die and their legal guardians were granted authority to forgo life-sustaining treatment. As a result, the ventilator (for Quinlan) and artificial feedings (for Cruzan) were discontinued [18, 19].

Underlying American Values

Ethical principles and religious beliefs have long provided the basic guidelines for medical decision making. In American society, Western bioethical principles and Christianity have shaped the American culture and its values [20]. These values have affected both healthcare providers and receivers in the U.S. legal and medical system. Due to the great diversity of racial, ethnic, cultural, and religious groups inthe United States, it is debatable whether there exists a dominant American culture. Nevertheless, it is generally agreed that Americans do share some basic core ideas[21]; these basic American values, predominately Western and usually among the White Middle class, are often used as "Americanization markers" to assess an individual's or a cultural group's assimilation to the dominant American culture [22]. In a cross-cultural study [23], the trait of being "individualistic" has been used to measure the acculturation of Chinese American youths to the dominant American culture.

Individualism & Self-Reliance

It is generally accepted that individualism, the idea of individual freedom, is the most basic and most traditional of all American values [24]. Individualism can be traced back to early settlers' desire to establish a new country. As the power of the government and the churches was limited, an environment of individualism was created to put more emphases on the citizen (individual), not the authority [24].

Along with the value of individualism, American culture values "self-reliance", meaning each individual has to rely on him/herself. In order to acquire individual freedom, each individual has to take the responsibility for his/her own decisions, no matter how complicated they may be. Due to self-reliance, patients possess the ultimate right in deciding their own medical care. Self-reliance can be further interpreted as a desire not to burden others, especially loved ones. As a result, many terminally ill patients choose to forgo life-sustaining treatment as a desire for self-reliance and a concern to ease family burdens [25]

***Western Bioethics:** As ethical and value issues are primary concerns of EOL treatment decision-making, it is essential to understand how American values are influenced by four bioethical principles: autonomy, justice, beneficence and nonmaleficence [26]. Since rapid developments in medical technology and biomedicine may cause controversial consequences such as "life-manipulation" or "de-humanization", whether or not to forgo LST is indeed a bioethical concern.*

However, bioethical principles, originated from ancient Greek philosophy and mainly developed in America and Europe, are very Western in nature. They have long been guidelines in Western culture in dealing with medical decision-making. Among these four principles, preserving a patient's autonomy is a primary precept; various professional ethic codes have similar statements, such as "while treating patients, a health professional should not exploit his/her position of relatively controlling power [27]."

Patient autonomy and justice

American society called for more attention to the value of patient autonomy because from the mid 1960s, an increased emphasis was placed on consumers' rights. As patients in general were bettereducated and more capable of understanding medical information, the authority of physicians was furtherchallenged and reexamined [28]. As a result, physicians gradually lost the absolute power of making treatment decisions and were forced to consult patients and their families to come to an agreement regarding LST [8]. Eventually, more legal guidelines were developed to protect patient autonomy, and a patient-centered principle in EOL treatment decision-making evolved.

Justice, the other ethical principle, implies autonomy in its definition given that justice can be characterized as equally respecting each patient's individuality. For healthcare providers, to practice justice is to acknowledge each patient has an equal opportunity in choosing his/her own medical treatment. Both autonomy and justice values are congruent with the basic American value of individualism.

Beneficence and Nonmaleficence

Even though two other ethical principles, beneficence and nonmaleficence, purport to protect patient rights as well, in reality they may not respect patient autonomy or the principle of justice. Historically, beneficence and nonmaleficence are often equated with "physician paternalism"[3]. Physician paternalism, in the context of medical decision-making, implies that patients' preferences of treatment are not fully followed by physicians.

Healthcare professionals, often assume a parental role given by the society to take care of vulnerable patients. In early days, patients were presumed to be incapable of understanding medicine and considered unqualified to choose among complicated treatments. Therefore, physicians were expected to protect the patients, based on beneficence and nonmalficence, by choosing the most beneficial treatment for them. However, while patient autonomy is currently endorsedand promoted in American society, physician paternalism may still be problematic since what physicians consider the most beneficial treatment may not follow patients' wishes.

Many studies support the report that physician paternalism exists in America, despite the emphasis on patient autonomy and individualism. Recent studies have found that physicians still control the release of medical information. In a study, up to 20% of patients who have chosen a particular option will change their mind if the information is presented differently [29]. Physicians are found still overruled patients' explicitly expressed wishes [10]. Furthermore, studies have shown that many treatment decisions chosen by the physicians are inadequate and have imposed unnecessary or unacceptable burdens upon the patients and their families [12].

Perspectives from Christianity

Since the Western culture and American society has its religious roots in Christianity, Christian perspectives have influenced Americans' life and death decisions. Nevertheless, Christianity has contradictory teachings concerning EOL decision making.

As a mandate in Christianity, the value of "respect for individuality" is from the belief that human beings are made in the image of God (Genesis 1:27). Since human beings are a reflection of God, they are capable of making free choices. This religious belief further supports the value of patient autonomy. For example, if an individual is no longer able to render service to God or others, he/she is granted the right to choose to forgo treatment [30] because the Holy Bible states, "For none of us lives to himself along and none of us dies to himself alone. If we live, we live to the Lord; and if we die, we die to the Lord (Roman 14:7-8). "

However, another Christian belief emphasizes the sanctity of life, which restricts an individual's free will to choose to die. Life, as a gift from God, should be received with gratitude and should not be discarded at will [30]. Christians believe that God is the Creator and Sustainer of life, and matters of life and death are presumed to be in God's hands. The Bible again clearly states, "For in Him we live and move and have our being…we are his offspring (Acts 17:28)." As a result, many patients therefore may feel uncomfortable making life and death decisions, and experienceguilt over wishing for death as they forgo aggressive treatment [28].

As mentioned before, although these ethical and religious values have formed a dominant part of American culture, they only represent an idealstandard for a segment of society, and donot apply to every American[21]. Questions of cross-cultural applicability in making advanced EOL treatment decisions have been raised in previous research [31], and the appropriateness of applying Western bioethics on patients from other cultural backgrounds is debatable[32, 33]. It is therefore preferable for healthcare providers to explore patients' values and their cultural beliefs in order to truly practice beneficence and nonmalficence, prevent possible physician paternalism, and fully respect patient autonomy.

Guidelines& Actual Practice Related to EOL Treatment Decision Making

To supplement the explanation of social endorsement of patient autonomy in the U.S., the following section reviews current EOL literature of legal guidelines and the constellation of treatment decision maker(s). In addition, actual practice of EOL treatment decision-making in the States is briefly characterized.

Patient Self-Determination Act & Advance Directives

Health policies related to EOL treatment decision-making have been developed during the last decade for guiding all individuals involved in this process. Adoption and amendment of the Patient's Bill of Rights during the 1980s shifted patient autonomy from an ethical concern to a legal obligation of physicians [34]. The law states patients have the right to refuse any medical intervention or treatments, and their physicians have the correspondent legal responsibility to document and follow patients' wishes. Furthermore, the subsequent Patient Self-Determination Act (PSDA) effective in 1991 introduced the idea of Advance Directives (AD), which laid more emphasis on EOL patients' autonomy in treatment decision making [35].

All Medicare and Medicaid funded healthcare facilities arerequired by PSDA to provide written information about adult patients' legal rights upon admission. AD, addressed to family and healthcare providers, include: a) patient's living will of treatment preferences under certain clinical situations, and/or b) an appointed proxy directive such as durable power of attorney for health care (DPOA). It is worth noting that the DPOA serves as a surrogate to make health care decisions for the patient including the decision to forgo life-sustaining treatment [36].

Although patient autonomy assumes freedom as part of its definition, competency and/or mental capacity to participate in EOL discussion is a pre-requisite. Therefore, AD is made in advance before patients become incompetent—it does not go into effect if patients are proven competent and capable of expressing his/her own treatment preferences [4].

Due to legal regulations, healthcare providers are mandated to document AD and to provide related AD education, such as information about LST, to patients and their families. It is expected that increasing awareness and knowledge of AD will instigate patients, families, and their health care providers to discuss EOL treatment preferences prior to the crisis.

However, research has found AD largely ineffective, and current practice falls far short of the ethical ideal of patient autonomy [10]because: a) patients' wishes regarding their own EOL treatment are still disrespected [37] even though contemporary ethics and health policies have supported self-determination in forgoing LST, b) interventions have failed to increase patients' knowledge regarding EOL treatment decisions, and patients and their families still lacked knowledge of their health condition and information about LST, c) patients'satisfaction has not increased by gaining more education on self-determination [11], and as a result, d) the goals to initiate early EOL discussion and to complete AD upon admission have never been reached [37].

Studies have also revealed that although both physicians and EOL patients agree with the idea of making advanced treatment decisions [6, 28] and the majority of the elderly patients desire to be involved in discussion, EOL treatment decisions are indecisive and delayed [10]. Although most EOL patients although recognize their rights in making treatment decisions, they still felt unprepared to take such a heavy responsibility. There is substantial evidence that approximately half of terminally ill patients do not want to bear the responsibility of EOL decisions[38] and reasons include: a) they believe another person, fate, or GOD should make EOL decisions, b) they think that AD are only for people about to die, and/or c) patients find it difficult to articulate treatment preferences. Making life and death decisions is too overwhelming a burden to most EOL patients. Similarly, family surrogates feel theextra burden of guilt, conflict of interest, and legal responsibilities from hearing to make these decisions [28].

It is not surprising that most commonly, an EOL treatment decision is never made." When reviewing literature about EOL treatment discussion, only a few patients reported to have had EOL discussions with their physicians [39], and those discussions were mostly overly optimistic. Another study revealed that 50-63% of patients who preferred forgoing resuscitation did not communicate wishes to their healthcare providers because they waited for the physicians to initiate the discussion [40]. As a results, as stated previously, unnecessary life-prolonging procedures are thus frequently employed since physicians are reluctant to initiate EOL treatment discussion [37].

Another cause of delayed treatment decisions is that patients and families do not want to give up hope for fear that an early-made decision to forgo LST may decrease patients' chance of survival [10]. Both patients and families may worry about not having done everything "technologically" possible [28].

To conclude, gaps between contemporary ethical standards and actual clinical practice indicate insufficient EOL care in the United States. These gaps also imply that current ethnical and legal standards are not adequate because they may not meet patients and families' needs in making EOL treatment decisions.

Surrogate Decision Making

The importance of including family in EOL treatment decision-making iscross-culturally indisputable (Last Acts). Since patients are in social relationships and are not isolated individuals, ideally EOL treatment decisions should be made in supportive consultation with family members and close friends.

Presently legal standards in the U.S. recognize family members as the primary surrogates, and a hierarchy of various family relationships is classified in surrogate decision making [41]. If patients decline to prepare AD or living wills, they are encouraged to enact a DOPA so that EOL treatment decisions can be made by a preferred family member, close friend, or loved one. When family members are not available, others, suchas relatives or close friends who know the patient's values and preferences, may help the physician in making treatment decisions [1]. However, in this case, neither the friends nor the physicians can function as the legal decision maker(s) since they are not officially appointed DOPA.

Because family participation is encouraged in the U.S., complex issues are involved in family surrogate decision-making. In clinical practice, families often have difficulties reaching a consensus about patients' wishes, and conflicts often arise between patients and families. Evidence shows that although family members are generally thought to be in the best position to know patients' values or treatment preferences, EOL decisions that family members make are generally no better than guessing [42]. Families are not good proxies since systematically they report lower quality of life and greater suffering that patients' self-evaluation [43], in addition, families often assume EOL patients are too stressed or too emotional to be capable of making a rational EOL treatment decisions [28]. Therefore, it is not surprising that patients may worry families opposing their wishes [6].

Substitute Judgment

It is worthwhile to review two types of frequently employed surrogate decisions: "substitute judgment" and "best interest". These are applied when patients become incompetent or patients' preferences on EOL treatments have not been documented [1].

Substitute judgment decisions can be made either a) by the spouse, family members, or close friends, or b) by a family consensus [3] based on patient's previously known values and beliefs. Ideally for the whole family to make a best substitute judgment, they must weigh both the patient's clinical state as well as his/her values. In other words, a moral substitute judgment decision attempts to mirror what the patient would have done if competent [28]. However, this ideal is thwarted by the fact that all surrogates bring their own values into any EOL discussion, so the family judgment may not adhere to the patient's wishes.

Best Interest Judgment: If neither AD/DOPA nor a consensus of substitute judgment decision can be made, another option is "a joint decision" made by family, physicians, and other healthcare providers based on the "patient's best interest." Conflicts among families and physicians have been commonly seen in making such decisions. Given that understanding in EOL knowledge and best interests is different among all involved individuals, physicians reported having difficulties reconciling the wishes of patients and the families [6]. In addition, physicians feel they are caught in the middle of highly emotional situations when they have to reach a consensus with family members[28].

Many families, on the other hand, are concerned that physicians may overrule their wishes [28] because it is clear that physicians have little information on patients' treatment preferences (Drazen, 2003). Physicians are no better surrogates than the families either because they consistently underestimate patients' symptoms and distress [43]. One study [44] showed that while more than 50% of the patients preferred to forgo CPR, these preferences were misunderstood, and as a result, authorized resuscitations were performed. Interventions aimed to increase physicians' knowledge of patients'treatment preferences were ineffective [11], and treatment decisions were not mainly based on patients preferences but by the individual characteristics of the physicians [45]

Ethical Consultation

In order to solve the above ethical controversies, the Joint Commission on the Accreditation of Health Care Organization (JCAHO) in America has required all hospitals and health care facilities to provide ethics consultation services [46]. Ethical committees are developed with the intention of dealing with uncertainties or disagreements during the EOL treatment decision-making process. However, not all hospitals have invested enough attention and resources into ensuring the quality of this intervention, although ethical consultation service has proven effective in minimizing conflicts among physicians, patients, and families [47]

In summary, although complete patient autonomy is the gold standard for making EOL treatment decisions in Euro-American countries, shared decision-making and collaboration amongst patients, families, and physicians, is preferred in Asian culture. Although the legal standards encourage advanced patient participation in EOL decision-making, such participation does not often occur in reality in the states and has frequently resulted in futile treatment as well. In Taiwan, it also holds true that when EOL patients become incompetent, physicians and families are often called upon to make surrogate decisions based on their various understanding of the patients' values and best interests. Even after The Legislative Yuan has recently approved the third reading of a reformed bill to the Hospice Palliative Care Regulation, following the American experience highlighting patient autonomy, the dynamic of the decision-making process that leads to actual EOL treatment decisions remains legally and ethically complicated in Taiwan.

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