End-of-Life Health Care Disparity: A Case Study

A YOUNG WOMAN of 18 years named Ms. L., an undocumented immigrant from Central America, discovered that she had acute lymphocytic leukemia while living in the Southeastern United States. Due to her immigration status, lack of insurance, and inability to pay, she was unable to seek care. By the time she was admitted to the medical intensive care unit (MICU), she was no longer conscious to recount her story. Any experienced ICU nurse could tell within the first sentences of her story that Ms. L.’s situation was what we call a “slow code,” meaning that she was dying slowly, kept alive by medical technology. She was on an oscillator, septic, and neutropenic, with vasopressors titrating up to near-max levels. She was in multi-organ failure and decompensating. We were waiting for family to tell us that we could stop; a cardiac arrest was on the horizon, and we hoped that we could avoid the futility of chest compressions and broken ribs.

A family conference was called with a medical interpreter to speak with her partner, a young man named Mr. J. He was her only representative, as Ms. L.’s family was in her home country and could not be contacted. The resident explained to Mr. J. that his partner was very sick and that it was very unlikely that she would survive. Mr. J. began to cry, and wailed that God was going to save her. When the resident asked if he wanted us to do everything we could, Mr. J. cried “yes” and repeated that God was going to save her. The resident asked specifically about CPR, with the same result. The resident then agreed to the plan that Ms. L. would be a “full code,” meaning that all measures would be taken to keep her alive.

Ms. L.’s heart stopped the next day and she died after several rounds of CPR. I struggled to understand how a situation like this could arise and still be considered ethical. It seemed wrong she was refused treatment for her disease due to her inability to pay, yet was later offered expensive rescue care when it was too late. Furthermore, it didn’t seem ethical to require Mr. J. to make a decision about CPR. Of course he would ask us to do everything we could, but was he really positioned to understand the implications of the decision he was making? On the other hand, wouldn’t it be paternalistic for the physician to assume that he wasn’t? Additionally, given the language barrier and cultural difference, did the communication with Mr. J. provide him with the emotional support and information he needed to make an informed decision? Moreover, why did Mr. J. have all the decision-making power?

End-of-Life Health Care Disparity

Ms. L.’s story is an example of health care disparity both at the end of life and within the U.S. medical system more broadly. The Emergency Medical Treatment and Labor Act requires a hospital to rescue and stabilize a patient before transferring him or her to another hospital, regardless of the patient’s ability to pay (Chapple, 2010). This rescue care is guaranteed to everyone, but it merely casts the illusion of fairness, as this care is only available to the uninsured when they collapse (Chapple, 2010). Furthermore, researchers have found ethnic minorities receive higher-intensity care, increased length of stay, and more interventions at the end of life (Barnato et al., 2006; Smith, Earle, & McCarthy, 2009).

It is difficult to know if these differences at end of life are due to preferences or to inequities or biases (Smith et al., 2009). For example, the advance directive (AD), which guides decision making for individuals when they are no longer able to speak for themselves (Schmid, Allen, Haley, & Decoster, 2010), is often used as a measure of health care disparity at end of life. Numerous researchers have shown religion, socioeconomic status, health literacy, ethnicity, and cultural preferences are associated with variance in the number of documented ADs (Fischer, Saaaua, Min, & Kutner, 2012; Johnson, Kuchibhatla, & Tulsky, 2008; Kwak & Salmon, 2007; Muni, Engelberg, Treese, Dotolo, & Curtis, 2011; Smith, Sudore, & McCarthy, 2009; Volandes et al., 2008). Cultural values influence preferences at the end of life in a variety of ways. ADs express the value of autonomy for individuals to continue to make decisions at the end of their lives in the form of a written living will. Korean families prefer family-based decision making and discussing end-of-life issues indirectly and nonverbally, although they recognize AD as a tool once it is explained (Kwak & Salmon, 2007). In a separate study, African Americans were found to decline hospice, have lower levels of documented ADs, and prefer aggressive end-of-life (EOL) care (Smith, Earle et al., 2009). Nevertheless, cultural and religious preferences do not entirely explain the variance in the number of ADs, indicating there are other causes yet to be discovered (Smith, Earle et al., 2009).

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NOTE: If you would like to share your own narrative or experience in regards to the “Dignity of Death Imperative,” we invite you to submit to nejrnl@ajj.com.
Culture and Language

There is only limited research on understanding and improving EOL care in the Latino community and in many studies the sample size was too small to be significant (Smith, Sudore et al., 2009). Latinos often want to pursue life-prolonging care even if they only have a few days left to live, though rates of hospice for Latinos are similar to those of Whites (Smith, Earle et al., 2009). In a study by Fischer and colleagues (2012), it was found that there were fewer conversations and discussions with Latino patients about ADs and EOL care, and that language barriers did not explain all of the disparity. These authors suggested low health literacy and inadequate provider communication as possible causes (Fischer et al., 2012). Identifying Latino needs and preferences at end of life and how to bridge the education gap is an important area for future study.

In the case of Ms. L., her partner spoke only Spanish and required an interpreter for conversations with medical providers. Physicians communicate less information and provide less emotional support when interpreters are used in EOL family conferences (Thornton, Pham, Engelberg, Jackson, & Curtis, 2009). Given the barriers of language and culture, there is a higher chance for misinformation, which can directly affect the quality of care (Norris et al., 2005). Studies have recommended physicians should meet with the interpreter prior to and after difficult discussions to prepare the interpreter for the conversation and allow the interpreter to provide information about the patient, family, or culture (Norris et al., 2005). It is unclear if the resident in this case study had experience or training with the use of an interpreter for EOL discussions and if such training could have improved the experience for the Mr. J.

Palliative Care

Family conferences most often occur in the ICU when the prognosis is poor. Baggs and colleagues (2012) argue these discussions about limitations of treatments often occur late and “not uncommonly in a crisis atmosphere” (p. 60). This can contribute to emotional distress and difficulty in making decisions (Curtis & White, 2008). Furthermore, these discussions can be complicated by the fact medical technology has made it difficult to know when a patient is dying. The terms “medical futility” and “medical torture” have arisen in the medical community to describe prolonged deaths (DelVecchio Good et al., 2004, p. 950).

A landmark study, SUPPORT (1995), is frequently referenced in EOL literature. The study included 9,105 patients with a 47% mortality rate within 6 months. Researchers found do-not-resuscitate orders were made within 2 days of the patient dying, half of patients spent 8 or more days comatose or on a ventilator, and that pain was poorly controlled. Moreover, despite a predictable course of events, discussions and decision making came late (Support Principle Investigators, 1995).

Family conferences are an event during which goals of care are discussed, and decisions about shifting from life-sustaining treatment to supportive care can be made. Palliative care consults are often requested at this time. Palliative care is a holistic approach to treating emotional, spiritual, and physical symptoms of serious illness, and may be given in concert with curative care or alone and at any point after the diagnosis of a serious illness (Freysteinson, 2010). Unfortunately, palliative care is often confused with hospice, which has a similar philosophical approach but excludes curative treatment, and is only available when patients are estimated to have fewer than 6 months to live (Freysteinson, 2010).

An important benefit of palliative care is that it may be started earlier in the disease process. Family members and patients alike are given the opportunity to develop a relationship with the palliative care team and receive emotional, physical, and spiritual support over an extended period of time (Freysteinson, 2010). The palliative care practitioners have an opportunity to build relationships and learn about the important values of the patient and family. They can teach the family about the dying process and help them navigate the decision-making process (Freysteinson, 2010).

In the case of Ms. L. and her partner, they would have benefited from palliative care support. If they had the benefit of supportive relationships with a palliative care team much earlier, the team might have better understood Ms. L. and her partner’s values and been able to help them navigate the decision-making process. They might have helped Mr. J. understand Ms. L.’s prognosis and this could have eased his emotional burden and informed his decision making. The involvement of palliative care earlier on in Ms. L.’s care might have changed the trajectory of her hospital stay. It could have been possible for Ms. L. and her partner to say goodbye.

Decision Making

An important piece of the ethical challenge around Ms. L.’s dying process was the decision-making process. There are three predominant models of decision making: (a) Informed choice, in which the physician gives information to the surrogate decision maker (usually a family member) about the treatment options and the surrogate makes the final decision; (b) Paternalism, in which the physician shares a minimum amount of information and makes the decision without eliciting patient preferences (Curtis & White, 2008); and (c) Shared decision making, a collaborative process of giving information about the prognosis and treatment options, eliciting patient or surrogate
values and beliefs, and making a joint decision (Levin, Moreno, Silvester, & Kissane, 2010). Shared decision making has been identified as the preferred decision-making method (Curtis & Tonelli, 2011).

In the case of Ms. L., the resident used the informed choice decision-making model, which is common. Deep, Griffith, and Wilson (2008) found most residents used an informed choice model for decision making about life-sustaining treatment. However, there was not enough information given to families for decisions to have been considered “autonomous” and “informed” (p. 881). Furthermore, residents were implicitly influencing the decisions and were not using a shared decision-making model (Deep et al., 2008).

The act of giving total control in the decision making to Mr. J. may have been an indication of a normative behavior in the hospital. In a study that compared two academic medical centers with different levels of intensity (defined as either low or high intensity), different patterns of behavior and ways of thinking about life-sustaining treatment and decision making were discovered (Barnato, Tate, Rodriguez, Zickmund, & Arnold, 2012). In the high-intensity environment, the physicians “externalized the locus of control” to patients, families, and referring providers (p. 1893). They saw family member requests during EOL decision making as mandates, instead of a normal part of an evolving process (Barnato et al., 2012).

**Ethics Consultations**

While the resident in the case study was trying to satisfy the partner’s request by keeping Ms. L. full code, it may not have been the most ethical choice. It wasn’t too late to request a palliative care consult or an ethics consult. An ethics consult is appropriate when “key stakeholders are engaged in discussions of what might be deemed inappropriate or futile care, and discord exists around refusals to cease treatments” (Carter & Wocial, 2012, p. 148). An ethicist is an outsider who may facilitate communication or offer a recommendation. It may have been helpful to have an outsider assist in clarifying the goals of care and to “give permission to stop doing everything to save a life” (Carter & Wocial, 2012, p. 149).

According to Carter and Wocial (2012), the history and culture within a hospital influences the tendency to request a palliative care or ethics consultation; these requests were uncommon and sometimes resisted in the hospital in question. In Ms. L.’s case, either of these could have been appropriate.

**Conclusion**

In summary, there are many factors that influence the quality of EOL care and the experience of death and dying. These include health care system and societal inequities, individual preferences, cultural values, literacy, language, decision-making processes and communication, as well as the culture, history, and norms of the hospital in which care is provided. EOL care may be improved through efforts to understand the experiences and values of others. Earlier palliative care consults may allow for the development of stronger relationships between consultants, patients, and families, and make a difference in the dying process. Understanding cultural norms within institutions and their impact on care delivery may make way for a change in practice.

**REFERENCES**


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