

Case Report

Cite this article: Guarin GE, Dee EC, Robredo JPG, Eala MAB, Medina MF, Tanco KC (2023). End-of-life care for Filipino patients with cancer. *Palliative and Supportive Care* 21, 365–369. <https://doi.org/10.1017/S1478951522001183>


Received: 05 April 2022
Revised: 26 June 2022
Accepted: 20 August 2022

Keywords:

Palliative; Filipino; Cancer; End-of-life; Minority

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Abstract

Providing end-of-life care within the cultural context of a Filipino patient in the United States is a complex process for clinicians, patients, and their families. An inclusive approach is crucial, especially because a significant proportion of patients belong to minority groups such as Filipinos, who represent the fourth largest group of immigrants in the United States as of data available in 2019. The case provided in this paper highlights the importance of family, religion, and finances in guiding the best possible way of providing end-of-life care for Filipino patients with cancer. At the end of this review, we discuss concrete action points that may give a non-Filipino physician a deeper understanding of end-of-life care for Filipinos.

Case

An 80-year-old Filipino woman with stage IIIB (T4 N1 M0) lung adenocarcinoma status post 4 cycles of carboplatin and etoposide with concurrent radiation 2 years ago was admitted for worsening shortness of breath. She now required 6 L per minute of oxygen via nasal cannula to maintain adequate oxygenation. She continued to deteriorate, with Eastern Cooperative Oncology Group (ECOG) performance status 3. A repeat CT scan showed an increase in size and number of lung masses and now with metastases to the thoracic spine, adrenal glands, and liver. Her eldest daughter, who had been the designated caregiver since the passing of the patient's husband, wanted to discuss their options. The oncology team thoroughly explained the risks of undergoing another round of chemotherapy and introduced the possibility of comfort care. Unfamiliar with the concept, the patient and her daughter asked how much it would cost. They were informed that it would be covered by health insurance. Although momentarily relieved, they would soon encounter multiple issues to resolve.

Background

End-of-life care is a complex process for clinicians, and more so for patients and their families. Delivering bad news, caring for the terminally ill, and guiding families with end-of-life decisions on behalf of patients, all while upholding the dignity of the dying are among the challenges that many clinicians face. On top of these, there remains the hurdle of providing socially and culturally appropriate care.

Recognizing and understanding multiple nonmedical considerations in end-of-life care is critical, given the diverse societies in which we live and practice. It is important to pursue a culturally inclusive approach to end-of-life care, especially because a significant proportion of patients belong to minority groups. In 2019, there were 44.9 million immigrants in the United States, equivalent to 14% of the national population (American Immigration Council 2021). Although minority groups in the United States and United Kingdom are less likely to use palliative care services compared to white patients (Bajaj et al. 2022; Connor et al. 2008; Johnson 2013; Ngo-Metzger et al. 2008), lower rates of use may reflect lower access rather than lower need (Griggs 2020; Payne et al. 2005). Additionally, disparities exist in the quality of end-of-life care experienced by racial and ethnic minorities (Smith et al. 2007; Welch et al. 2005), underscoring the importance of culturally tailored care (Johnson 2013; Kwak and Salmon 2007).

In this paper, we draw attention to cultural considerations for end-of-life cancer care for Filipino patients and patients of Filipino descent. The Philippines is a large Southeast Asian country of over 100 million people. Additionally, the Philippines represents the 4th largest country of origin of immigrants in the United States in 2019, accounting for 4.5% of immigrant

population, and approximately 20% (Budiman and Ruiz 2021) of Asian Americans. We recognize that end-of-life care involves individualized patient discussions that consider each person's values. However, we believe there are themes that may be common among many Filipinos and members of the Filipino diaspora. These themes, namely financial considerations, family, and religious influences, guide end-of-life cancer care for this population.

Finances

In countries with less financial protection and high out-of-pocket (OOP) payment systems for health care, the combination of chronic disease and economic vulnerability (Sapkota *et al.* 2021) can have damaging socioeconomic and health impacts on affected households (Eala *et al.* 2022). This is a reality in the Philippines, a lower- and middle-income country (LMIC), where OOPs continue to be the dominant source of financing for health care.

Severe financial crises due to chronic diseases are common (Eala *et al.* 2022). Compared with more financially advantaged patients with past savings, poorer populations are unable to pay treatment costs and are left to choose between avoiding medical treatment and further impoverishing their families. Payments for goods and services significantly diminish household incomes, compromise the ability to access other essential needs, and paralyze financial activities altogether. Patients in rural areas (Sapkota *et al.* 2021) even experience more challenges in receiving treatments because facilities are more concentrated in urban communities. Travel, accommodation, food, and longer time of lost productivity for both the patient and the accompanying caretaker add to the already ballooning costs of treatment (ACTION Study Group *et al.* 2015). These families are thus disincentivized to seek care or are encouraged to resort to culturally acceptable alternatives.

Coping and adjustment strategies meant to minimize impacts of illnesses are costly and consequential in the long term as well, especially when they involve sale of assets and/or disinvestments in physical and human capital (Quimbo *et al.* 2008). As a result, low-income earning households, which make up a significant proportion of the Philippine population, tend to avoid medicines (Hodge *et al.* 2016), follow-up treatments, and further interventions so as to minimize costs. An in-depth interview with Asian Americans, which included Filipino Americans, also revealed that immigrants exhibit similar patterns of behavior. Despite a state's end-of-life care resources, some of these patients choose to return to their home country to die instead of going into hospice care (Becker 2002) because of traditional values or limited financial means.

Poorer health translates to less current and future wealth (Quimbo *et al.* 2008), as seen in direct effects of decrease in income due to lower productivity of the ill family member and the respective caregivers, and of increased payments for treatment of diseases. This shapes belief systems, behaviors, and outcomes, and creates a poverty trap that cuts across generations. Cultural values (Tuason 2010) of resilience, "pagpupunyagi" (or perseverance and resourcefulness), and "pakikipagkapwa" (reliance on others) are observed in marginalized groups but praying for change and surrendering to God have become intensified responses as well.

Inequalities in socioeconomic status also create disparities in outlook about one's health and one's future. Those with better access to education have better access to information, which improves critical thinking (Quimbo *et al.* 2008), helps in decision-making, and facilitates greater awareness, acceptance, and utilization of modern medicine and facility-based or institutional care. They are

also often more capable of actively seeking the type of care they deem adequate, which include aggressive medical treatment and palliative service.

Palliative care remains to be a relatively foreign concept in LMICs (Poudel *et al.* 2019), where there is lack of public funding for the service. In a 2015 Quality of Death study index, the Philippines ranked 78th out of 80 countries in terms of quality of end-of-life care and was listed as one of the worst places to die. Aside from the shortage of specialized professionals, this was attributed (Angara 2018) to limited public understanding and awareness of palliative care services, and limited number of government subsidies for individuals accessing them. There is therefore a need to prioritize and incorporate palliative (Poudel *et al.* 2019) and end-of-life care into health care and social development agenda to address issues of affordability and sociocultural belief systems of key stakeholders.

In our patient's case, the palliative care team was consulted. A family meeting was arranged with the patient's children, including those from the Philippines who attended through video conference. Two of them wanted to pursue further treatment, one was interested in comfort care and flying their mother home to Manila, while the eldest daughter was left confused. The patient wanted what was best for her family and did not want to burden her family any longer.

Family

Aside from finances, family largely influences attitudes toward end-of-life care among Filipinos. It is considered the foundation of their social life and is prioritized when making major life decisions.

In a typical Filipino family unit, the father is considered the head of the household, while the mother is the primary decision-maker in education, health, and finances of the family. In their absence or incapacity, the eldest child takes over the decision-maker role. It is then recommended to consult with the head of the family following the birth order, especially in discussing treatment and steps to care (Cantos and Rivera 1996; Spector 2000).

Beyond the typical structure, extended family members also actively participate in one's care. Filipino elderly seeks family members for guidance and support (de Guzman *et al.* 2009), and their constant presence is seen to aid coping and recovery. When Filipino patients are sick, they expect their family members to help them (Cantos and Rivera 1996; Luckman 2000). In turn, family members bear a sense of obligation to care for one another (Nishimoto and Foley 2001). This concept of filial piety inspires how the young honors the elderly in most East Asian cultures (Ikels 2004).

While it is usually offered for the terminally ill in the American health-care system, hospice care is rarely included in a Filipino's end-of-life care plan. There are limited studies that discuss Filipinos' preference for hospice. For patients with cancer, the majority chose home death, while the minority preferred hospital death or had no preference at all (Vidal *et al.* 2020). A large retrospective study in 2008 found that the use of hospice among Filipino patients dying with cancer, as well as other Asian and Pacific Islander ethnic groups, was significantly less compared to white patients (Budiman and Ruiz 2021). Filipino families find it unimaginable to leave the care of their dying family relatives to an institution (Sy 2012), and so they tend to the sick patient in the comfort of their homes.

Filipinos also struggle with advance care planning, which poses a challenge to health-care providers. In an ethnographic case study performed in a large private tertiary care center in Manila, Philippines, the advance directive completion rate was

10% (Manalo 2017). This statistic was found secondary to family members' refusal to give up on the patient and religious beliefs (Doorenbos et al. 2011). Meanwhile, based on a study conducted at the University of California, San Francisco School of Nursing, the overall attitudes of critically ill Filipino patients and their families toward advance directives were positive with higher scores among family members than patients (McAdam et al. 2005). However, the completion rate and their knowledge of advance directives were both low (McAdam et al. 2005).

Recognizing the family's influence and importance in a patient's attitude and advance care planning bridge gaps in the provision of end-of-life care.

Returning to the case of our patient, she had to wear a non-rebreather mask for worsening hypoxia as days passed. Intravenous fluids were also administered after developing acute kidney injury due to inadequate oral intake. Her condition continued to deteriorate, but her children still could not decide. Her eldest daughter at the bedside received instructions from the patient to find a priest for confession. She no longer desired intubation.

Religion

The role of religion in the Philippines and among members of the Filipino diaspora cannot be understated. Over 80% (Doorenbos et al. 2011) of Filipinos identify as Roman Catholics. Although religion and spirituality are often individual experiences, recent data suggest that even among young Filipinos in contemporary society, Catholicism is flourishing (Cornelio 2016). Additionally, 65–83% (Cherry 2013; Park 2009) of Filipino Americans identify as Catholic. Given the importance of religion and spirituality for religious people at the end of life, the Catholic faith plays a critical role for dying Filipino patients (Cessario 2006; Doorenbos et al. 2011; Steinberg 2011).

For many Filipinos, illness is seen as destiny bestowed upon them by God, and that the course of their illness including the possibility of death is part of God's will for them (Doorenbos et al. 2011). Although work is needed to further understand how this perception impacts Filipino patients at the end of life, it has been suggested that faith in God and dying as a surrender of the self to God's will can promote a peaceful death among Filipino patients (Doorenbos et al. 2011).

The influence of religion for Filipino patients is intimately intertwined with existential issues at the end of life. At least a quarter (Vehling and Kissane 2018) of patients with cancer experience existential distress – that is, distress that results from a persistent threat to life and the self (Kissane 2012). The alleviation of existential suffering constitutes an important aspect of reducing total suffering at the end of life and may be associated with a good death (Dee 2021). Additionally, for many people who identify themselves as spiritual, religion plays an important role in the alleviation of existential distress (Okon 2005).

Spiritual well-being may play a protective role against despair and depression at the end of life (Okon 2005). One such study found that spiritual well-being was the strongest variable studied that served as a predictor of less desire for hastened death, suicidal ideation, and a sense of hopelessness in the context of terminal illness (McClain et al. 2003). A study of US patients found that over 50% of older inpatients reported some form of religious practice, and 40% reported that faith was the most important factor that helped them cope with illness; nearly 90% used religion to cope (Koenig 1998). Another study found that in their cohort of patients with advanced gynecologic cancer, almost half grew more religious

since diagnosis, and 85% identified a religious affiliation (Roberts et al. 1997).

Although similar numbers among Filipino patients are not readily available, it is likely that religion plays a similarly important role in the experience of cancer and end of life for many patients. In support of this, a study of Filipino nurses who care for dying patients found that 4 of the top 20 most important nursing interventions from the nurses' perspective involved issues of spirituality and existential comfort, such as to "encourage patients to express spiritual concerns," "protect religious beliefs," "provide spiritual support," and "provide privacy for spiritual behaviour" (Doorenbos et al. 2011). A study among community-dwelling Filipino Americans similarly found that issues of spiritual concern, such as the preservation of hope, and finding meaning in existence and death were associated with dignity and the end of life (Periyakoil et al. 2010).

Of note, it is important to consider Filipino patients who do not identify with Catholicism. Although Catholicism is the majority religion in the Philippines, religious minorities exist, for example, people who identify as Muslims.

In Islam, death is viewed as a natural phenomenon. In the Quran, it is written "Every soul shall taste death, and only on the Day of Judgment will you be paid your full recompense," as well as "But never will Allah delay a soul when its time has come; and Allah is acquainted with what you do." Many see life being lived as a preparation for the next (Gentry 2022). At a time of illness, some Muslims prefer that an "imam," who is regarded as the leader of a mosque, be called to visit and pray for the sick. As imams also have secular jobs, others may request any Muslim to comfort them when they are sick. A patient may also request to be on a bed facing in the direction of Mecca (Gentry 2022). Regarding the end of life, decisions about ending the life of terminally ill patients at their request are deemed beyond a doctor's obligation (Sachedina 2005). It is written in the Quran 3:145, "It is not given to any soul to die, save by the leave of God, at an appointed time" (Sachedina 2005).

The complexities of the individual experience of faith may be influenced by societal pressures to profess religion, as is prevalent in the Philippines. Therefore, careful evocation of a patient's conceptualization of their own faith or lack thereof may guide approaches to care, especially in the context of approaching efforts aimed at mitigating an individual's existential suffering.

The patient in our case received comfort measures as she wished. A priest was called urgently to give final blessings to the patient. Her eldest daughter decided to simply honor her mother's request while the 3 other children were devastated to see their mother suffer and to see her only through video calls. The patient was given morphine intravenously every 2 h and glycopyrrolate for her secretions. She finally breathed her last in peace far away from home, with her eldest daughter holding her at the bedside.

Recommendations

Recognizing that end-of-life care is a very foreign concept for most Filipinos, providers must spend considerable time with patients and their families educating them about hospice and palliative care, including clarifying misconceptions and destigmatizing the field. Framing end-of-life care as supportive care (Fadul et al. 2009), and emphasizing symptom control, pain alleviation, and the prioritization of patient comfort, may make Filipino patients and their families more receptive. Providers must explain these concepts using familiar and culturally sensitive language, avoid medical

jargon, and ensure that patients and their families are provided with a safe space to freely ask questions without any judgment.

Religion and spirituality are important considerations when caring for Filipino patients throughout the entire disease continuum, but especially at the end of life. A clinical assessment of spiritual needs must be made at the onset and explored regularly, ensuring that these needs are properly documented and communicated with the rest of the health-care team (Okon 2005).

A spiritual history is essential and may be done using an open-ended or structured format. In the open-ended format, opening questions include the following: “Is faith important in your life?” “What roles does spirituality or religion play in your life?” “Does life feel like a gift or like a burden as you go through this illness?” “What brings meaning and purpose to your life?” On the other hand, the structured format involves using mnemonic tools to explore the following domains: character of transcendent beliefs, religious affiliation/membership, personal meaning and importance of faith and spiritual sources of strength, and impact of beliefs on medical decision-making and process of care. Mnemonic tools include HOPE (sources of hope, organized religion, personal spirituality and practices, effect on medical care and end-of-life issues), FICA (faith, importance/influence, community, address/apply), and SPIRIT (spiritual belief system, personal spirituality, integration with a spiritual community, ritualized practices and restrictions, implications for medical care, terminal events planning) (Okon 2005). Additionally, Filipino patients at the end of life may highly appreciate when they are provided the means to avail of appropriate religious services.

Treating a Filipino patient at the end of life means treating their family as well. This may go beyond the patient’s nuclear family and include in-laws, close friends, and even neighbors. It is therefore crucial for providers to understand their patient’s family structure and the relationships within the family unit to determine their “therapeutic allies.” This can be done through the creation of a family map (Colapinto 2018), an assessment technique used in structural family therapy.

At the onset, providers must ask their Filipino patients whether they would like their families to be involved in end-of-life discussions. If so, providers must establish who will be involved in these discussions and who will be expected to attend family meetings. More importantly, both the patient and their family members must be educated on the rules of consent and priority of next of kin for surrogate decision-making.

Finally, providers must consider financial concerns that Filipino patients and their families have which they may hesitate to bring up. High OOP costs and financial catastrophe due to health expenditure are perennial issues in the Philippines (Dayrit et al. 2018) that have shaped Filipino perceptions and attitudes toward health care, including end-of-life care. Therefore, informing patients of any available social support services, and referring them to appropriate agencies as necessary, may go a long way in alleviating financial worries.

Funding. Dr. E.C.D. is funded in part through the Cancer Center Support Grant from the National Cancer Institute (P30 CA008748).

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