

Community-based Hospice and Palliative Care Services in Southern Metro Manila and Neighboring Provinces in the Philippines: A Cross-Sectional Survey

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Background: The rising Philippine population results in a proportionate increase in the aging population and its health care needs.

Objective: In order to determine the demographic characteristics and needs of palliative and hospice patients in southern Metro Manila and surrounding provinces seeking care in a non-institutionalized setting, a chart review of 399 patients from 2 community-based hospice and palliative care programs was undertaken.

Results: Results show that the usual demographic profile of a patient seeking hospice and palliative care in the community setting of southern Metro Manila and neighboring provinces is female, 51-60 years old, with a diagnosis of cancer, breast cancer being the most common. Majority had undergone prior chemotherapy or radiation therapy. Hypertension was the most common co-morbidity associated with the primary diagnosis, and pain was the most common symptom reported. The children were the primary caregivers of these patients at home, and written advance care directives were unavailable on initial consultation. The most common spiritual concern of patients was not the fear of death, but being a burden to their family members. Complementary services may be needed in order to help patients and their families cope with the terminal illness. These may include social work to help connect the family to other institutions that provide free medicines, counselling sessions both for the patient and family, respite care or providing a day off for the caregivers, and skills training for the primary care givers.

Key words: hospice care, palliative care

INTRODUCTION

The Philippine population is steadily rising to more than 100 million based on the 2015 Population Census.

In the southern part of Metro Manila and the neighboring provinces of Cavite, Laguna, and Batangas, dramatic increases in population density were seen in the last twenty years. Of the 81 provinces in the country, Cavite was the most populous in 2015 with 3.68 million, followed by Bulacan (3.29 million), and Laguna (3.04 million).¹

The increase in population also results in a proportionate increase in the aging population. It is also expected to result in escalating concerns regarding proper medical care at the end of life. According to the Philippine

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Commission on Population, the population of Filipinos 60 years and above, or senior citizens in the Philippines, increased from 3.2 million in 1990 to 4.6 million in 2000, then to 6.2 million in 2010.²

To address this phenomenon, an investigation of the population attributes leading to the provision of hospice and palliative care services must be made. The Philippine Cancer Society³ established the country's first home care program for indigent, terminally-ill cancer patients led by a multidisciplinary team made up of a doctor, nurse and social worker. A number of non-governmental organizations (NGOs) and private groups followed suit and put up similar services. However, support from the government still leaves much to be desired due to inequity.⁴ According to a study by Lynch, the Philippines belongs to Group 3a, that is, *Isolated Palliative Care Provision*. This means that palliative care exists but is not well-supported in the country.⁵ There is also limited availability of opioid drugs for pain relief⁶, and only a few training institutions are available for hospice and palliative care.

Palliative and hospice care at home is not confined to cancer patients only. A study done at the Philippine General Hospital in 2005 revealed that around 5% of patients discharged from the Department of Medicine required home care services, and not all of them are cancer patients. The top five indications for home care were the presence of decubitus ulcers, debilitation from cerebrovascular disease (CVD), presence of indwelling catheter, cor pulmonale, and presence of a nasogastric tube (NGT) for feeding. The top five diseases necessitating palliative care referral include diabetes mellitus, pneumonia, congestive heart failure, hypertension, and chronic lung disease. The children were the most common primary caregivers and financial supporters of these home-bound patients. The average length of stay of the patients in the hospital was also increased for those needing home care services. It was mentioned that one of the factors that increased the length of stay of these patients in the hospital was fear of providing care at home without medical supervision.⁷

Since there are only a few studies in literature to assess the demographics and special needs of patients

with chronic and life-limiting illness among non-institutionalized patients in the Philippines, there is a need to look into the demographic characteristics of hospice and palliative care patients seeking medical attention at home.

The goal of this study was to identify the attributes of patients with chronic and terminal illness seeking home health care in the community by looking into their demographic and epidemiologic profiles.

After identifying the demographics and attributes of patients with chronic and terminal illness seen by health professionals in their home, we may have the information we need to address the needs of hospice and palliative care patients in the community setting.

METHODOLOGY

A review of charts dated January 2011 to December 2016 from two community palliative and hospice care providers in the Southern part of Metro Manila (The Ruth Foundation for Hospice and Palliative Care in Alabang, Muntinlupa; and Canossa Health and Social Center in Silang, Cavite) was done. This does not reflect, however, the totality of hospice and palliative care services in the Southern part of Manila and neighboring provinces, as a number of private physicians and agencies also provide hospice and palliative care services in the area.

A total of 399 patient charts were reviewed. Data were tabulated and summarized using Microsoft Excel 2007. Only the first 2 consultation visits were assessed in order to reflect the initial needs and concerns of patients before any significant intervention has been undertaken.

RESULTS

Most of the patients seeking hospice care were female (267 out of 399, or 67%). Majority of patients belonged to the 91 to 100-year-old group (83, 21%), because during the early years of the Ruth Foundation, they actively sought out elderly patients nearing 100 years old because

of the monetary benefits given to centenarians by the Philippine government.⁸ The 51-60 age group was next (80, 20%). Only 42 of the 399 patients were 40 years old and below.

The most common diagnosis on initial visitation was Cancer (179 out of 399, or 45%), followed by Sarcopenia (86, 22%) and Cerebrovascular Accident (42, 11%)(Figure 1). Of the 179 cancer patients, 128 (72%) underwent chemotherapy or radiation therapy in the past.

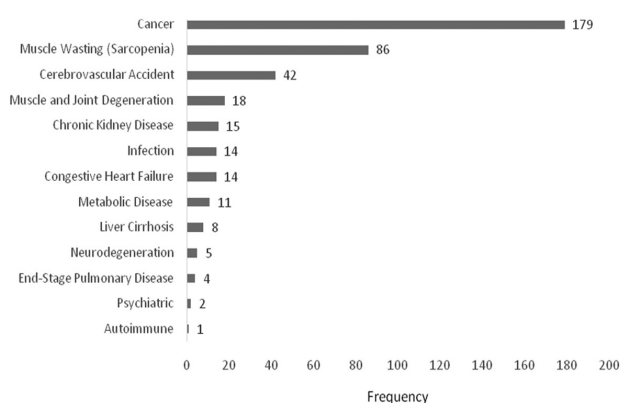


Figure 1. Summary of patient diagnosis on initial home visit.

Forty-eight out of 179 patients with cancer (27%) had breast cancer. Fifteen percent (26 of 179) had colorectal cancer, and 12% (22 out of 179) had cervical cancer. Pulmonary, head and neck, and uterine/ovarian cancers had 19, 17, and 14 cases, respectively.

Most community-based hospice patients with cancer were found to be in stage 4. Some patients (46 out of the 179) had undetermined stages because no diagnostic tests to determine cancer stage were reflected in the charts. A large number of patients also had muscle wasting or sarcopenia, defined as "...a syndrome characterized by progressive and generalized loss of skeletal muscle mass and strength with a risk of adverse outcomes such as physical disability, poor quality of life and death".⁹ Six out of fifteen chronically-ill patients with End-Stage Renal Disease (ESRD) underwent hemodialysis.

Majority of patients (156 out of 399, or 39%) were categorized under the Palliative Category. These patients may have a few symptoms that need to be controlled. They ranged from being generally ambulatory to being wheelchair-bound, and could still care for themselves. However, these patients could no longer do their usual activities of daily living. One hundred fifty one out of 399 (38%) patients were already in hospice category.

Among the co-morbidities, hypertension was the most commonly reported (111). This was followed by pulmonary infections (36) and diabetes mellitus (30). Joint diseases necessitating pain control and cognitive impairment were also common (19 cases each). The most frequently encountered symptoms on initial consultation included pain (233, 58%), arm and leg weakness (185, 46%), weight loss (180, 45%), fatigue (177, 44%), and poor appetite (162, 41%)(Figure 2).

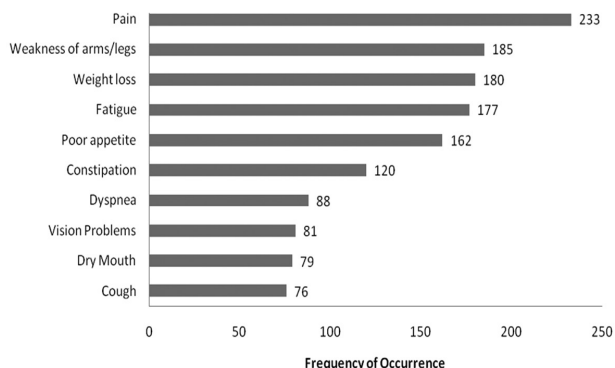


Figure 2. Most common symptoms on initial consultation.

Of the 399 patients, 34% reported having a history of substance abuse. They included alcohol beverage drinkers (57), smokers (54), both alcoholics and smokers (19), and metamphetamine users (4). None reported the use of *Cannabis*, a controversial herb that may have positive effects for pain alleviation. A significant number of charts (58 out of 399 or 15%) had no data on substance abuse.

Only 46 out of 399 patients (11%) reported using herbal and multivitamin supplements in addition to standard treatment prescribed by physicians. Other complementary and alternative therapies, such as acupuncture or faith healing, were not reported.

One hundred seventy out of 399 (43%) reported children as the primary caregivers of the patient. This was followed by the spouse (85, 21%), siblings (38, 9%), and professional caregivers (32, 8%).

Only 75 out of 399 patients (19%) had a written ACD on initial consultation. Of the 324 patients who did not have ACDs, 120 (37%) preferred oral directives to their family members. Ninety six (30%) were not ready to make written ACDs. One hundred eight (33%) did not have any idea about advance care directives.

Although majority of the patients and their families were aware of their diagnosis, 89 out of 399 (22%) felt that their knowledge regarding their disease condition was inadequate. Fifty-one (13%) of patients and their families requested not to be informed of the entire details of their illness, while 20 (5%) patients and their families reported confusion on why their condition was deteriorating.

Coping with the illness was a dilemma reported by a majority of patients (242, 61%). Anxiety (129, 32%) and sadness (55, 14%) were also seen. Majority of the patients reported having financial difficulties. Difficulties with adjustment and coping with change due to changes in roles in the family were also seen.

In this study, 59 patients (55%) felt they were a burden to their family. Twenty-five (23%) felt hopeless in their condition, and 16 (15%) reported fear of death.

DISCUSSION

The preponderance of elderly hospice patients is not simply due to the healthy status of younger age groups. Pediatric hospice care is not very common in the Philippines. It may be harder to accept an end-of-life condition in a young person, so referrals to hospice care are scarce.¹⁰

Patients with incurable cancer are offered the option of palliative chemotherapy, an intervention that is unlikely to result in a major survival advantage. However, it can improve tumor-related symptoms, and palliative care positively impacts quality of life. Patients receiving palliative care treatment may also be given inaccurate information about the survival gain of palliative chemotherapy.¹¹ Many patients with advanced cancer prioritize survival over quality of life¹², so healthcare professionals may accede to their wishes to do something active about the disease.¹³

The undetermined cancer stage in some patients is mostly due to financial constraints. Patients are diagnosed in the advanced stages of the disease, and are likely to suffer physically and psychologically because of the limited resources for early diagnosis and treatment.¹⁴

The PCST (Palliative Care Screening Tool), developed by The Ruth Foundation, is a combination of validated palliative care evaluation tools: the Edmonton Palliative Performance scale¹⁵, Eastern Cooperative Oncology Group Scale¹⁶, and Palliative Performance Status Scale.¹⁷ This was used to categorize patients as belonging to supportive care for observation only, palliative care, or hospice care. The tool helps the patient care staff determine the goals of care for each patient, and organize scheduled of visits.

Delayed referral to hospice care is common.¹⁸ Reasons that need to be explored include: 1) doctors may not be aware of palliative and hospice care service at home; 2) doctors do not want to refer patients to another care provider for fear of losing them; 3) doctors view a referral to palliative and hospice care as a personal failure in management; and 4) the patient was already advised by their doctor regarding palliative and hospice services but the family opted to delay consultation.

Managing co-morbid conditions in patients with life-limiting illness require an active review of drug therapies to balance the problem of diminishing benefits with increasing side effects. Some drugs may need to be discontinued as systemic changes occur. Data on number needed to treat can be used to arrive at decisions. As

prognosis worsens for a given condition, the number needed to treat usually increases.¹⁹

The Philippine Health Insurance Corporation (Philhealth) has a program that provides for a maximum of 90 sessions of hemodialysis per calendar year.²⁰ Patients with ESRD are candidates for palliative care, because they face certain death unless they receive active treatment in the form of renal replacement therapy (RRT).²¹ In spite of the continuous improvement of dialysis technology and pharmacological treatment, mortality rates for dialysis patients are still high.²² Integrating hospice and palliative care into ESRD management is necessary to address the needs of an aging ESRD population.²³

Early identification of behavioral risks for addiction in patients receiving opioids for chronic pain is essential in order to improve clinical outcomes. However, the possibility of addiction must not hinder a hospice and palliative care practitioner from prescribing opioids when needed.²⁴

Many herbal medications contain bioactive compounds that can be helpful in the treatment of multiple medical conditions. However, the increasing popularity of over-the-counter (OTC) herbal preparations presents a unique set of problems, such as toxicities due to contamination, and interactions with mainstream medications.^{25,26} A patient's reluctance to disclose their use of herbal supplements to their physicians or pharmacists increases their risk for herb-drug interactions. Contamination of herbal products with heavy metals such as lead is also a major concern.^{27,28}

A primary caregiver has the main responsibility to oversee care for patients who could no longer carry out activities of daily living such as bathing, eating, and grooming. With a Filipino culture of having a tight-knit and extended family, single children, even if employed, prefer to stay with their parents. They also bring this culture with them even when they migrate overseas and become overseas workers. Children prefer to take care of their aging parents and chronically ill relatives over sending them to nursing homes.²⁹

The low number of patients having advance care directives upon initial home visits may reflect the Filipino

culture of avoiding discussion of death in the family. This may lead to more stress in the family members as the impending death arrives. Advance care directive (ACD) planning improves end-of-life care, patient and family satisfaction, and reduces stress, anxiety, and depression in surviving relatives.³⁰ Despite the many benefits of helping prepare the family and patient an advance care directive, the low result of having an ACD may also reflect a possibility that health care professionals contribute to this problem. Reasons could include time and skill limitations in conducting care directive discussions; nurses and doctors may not be confident to discuss this topic. Legal ramifications may also discourage health care practitioners from conducting advance care directive counselling.³¹

Emotional conditions of patients with chronic diseases are often overlooked, and most of the time health professionals miss out on the incidence of depression. Apparently, doctors may be good in managing biomedical conditions but have difficulty in dealing with the psychological, social and cultural dimensions of health and illness.^{32,33} Majority of patients actually do not fear death. But the prospect of losing control of what one does, experiencing uncontrollable symptoms, being unable to work, losing independence, and becoming more dependent on activities of daily living are the most difficult aspects of terminal illness to accept. When one could not accept the inevitable, anxiety or sadness may be manifested. For those who could not cope, depression may set in.

Traditionally, spirituality was always connected to the religious aspect of one's life. As different religions grew, a shift in its meaning was observed. Spirituality now deals more with the meaning of life and one's purpose for being, without touching on the sensitive issue of God.³⁴

It is important to note how patients see their life in light of their current illness, and how they can still contribute to their family.³⁵ As the illness progresses and roles change, from being a physically independent member of the family to someone totally dependent even in aspects of feeding and daily hygiene, the condition takes a toll on how the patients see themselves. This situation may eventually

lead to more problems: non-compliance to medications, isolation, and hastened deterioration of the patients.

Institutions and palliative care practitioners should give more attention to non-physical aspects of illness; the services of counselors, psychologists, and psychiatrists must also be utilized. Palliative care education should not only focus its attention on controlling physical symptoms but also empower health care professionals and care givers to address these issues. This will result in better quality of life outcomes.³⁶

CONCLUSION

The usual demographic profile of a patient seeking hospice and palliative care in the community setting of southern Metro Manila and neighboring provinces includes: 1. female, 2. 51-60 years old, and 3. with a diagnosis of advanced cancer, most commonly breast cancer. Majority of the cancer patients had already undergone prior chemotherapy or radiation therapy. Hypertension was the most common comorbidity associated with the primary diagnosis. Pain is the most common symptom reported, and patients do not usually subscribe to complementary and alternative therapies. Children are the primary caregivers of these patients at home. There is often no written advance care directive on initial consultation. The usual problems encountered at home include coping with the illness, sustaining the financial needs of the family, and the patient's feeling of being a burden to family members. Most of the referrals for community hospice and palliative care are from relatives or neighbors of previous patients. It is recommended that a concerted effort between government and non-government organizations be put into place in order to strengthen community-based hospice and palliative care and address the needs of these patients at home.

REFERENCES

1. Philippine Statistics Authority. Highlights on Household Population, Number of Households, and Average Household Size of the Philippines (2015 Census of Population).
2. Crisostomo S. Pinoys living longer, but in poor health. The Philippine Star. Mar 1; Headlines. Available from: URL: 2015. <http://www.philstar.com/headlines/2015/03/01/1428816/pinoys-living-longer-poor-health>
3. Philippine Cancer Society. Philippine Cancer Society Annual Report 2014.
4. Asia Pacific Observatory on Health Systems and Policies. The Philippines health systems review. Health Systems in Transition, 2011; 1:2:116-24. Available from: URL: http://www.wpro.who.int/philippines/areas/health_systems/financing/philippines_health_system_review.pdf
5. Lynch T, Connor S, and Clark D. Mapping levels of palliative care development: a global update. J Pain Symptom Management 2013; 45(6):1094-106. doi: 10.1016/j.jpainsymman.2012.05.011.
6. Javier FO, Magpantay LA, Espinosa EL, Harder SM and Unite MA. Opioid use in chronic pain management in the Philippines. Eur J Pain 2001; 5: 83-5. doi:10.1053/eujp.2001.0286.
7. Calibuso JS, De Dios JA, Ramirez JM, and Dela Vega SF. Profile of patients discharged from the medical wards requiring home care. Phil J Int Med 2005; 43:151-7.
8. Congress of the Philippines. Republic act no. 10868 – an act honoring and granting additional benefits and privileges to Filipino Centenarians and for other purposes. Sec. 2b p. 2.
9. Delmonico MJ, Harris TB, Lee JS. Alternative definitions of sarcopenia, lower extremity performance, and functional impairment with aging in older men and women. J Am Geriatr Soc 2007; 55: 769-74.
10. Koenig BA, Davies E. Cultural dimensions of care at life's end for children and their families. In: Field MJ, Behrman RE, (editors). When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families. National Academy Press; Washington, DC: 2002; 509-52.
11. Suzanne A, Julian A, Blazeby JM, Falk S, and Campbell R. What oncologists tell patients about survival benefits of palliative chemotherapy and implications for informed consent: qualitative study. Br Med J 2008; 337:a752.
12. Matsuyama R, Reddy S, Smith TJ. Why do patients choose chemotherapy near the end of life? A review of the perspective of those facing death from cancer. J Clin Oncol 2006; 24: 3490-6.
13. Archer VR, Billingham LJ, Cullen MH. Palliative chemotherapy: no longer a contradiction in terms. Oncologist 1999; 4: 470-7.
14. Payne S, Chan N, Davies A. Supportive, palliative, and end-of-life care for patients with cancer in Asia: resource-stratified guidelines from the Asian Oncology Summit. Lancet Oncology 2012; 13:e492-500.
15. Bruera E, Kuehn N, Miller MJ, Selmser P, and Macmillan K. The Edmonton Symptom Assessment System (ESAS): a simple method of the assessment of palliative care patients. J Palliative Care 1991; 7:6-9.
16. Oken MM, Creech RH and Tormey DC. Toxicity and response criteria of the eastern cooperative oncology group. Am J Clin Oncol 1982; 5: 649-655.

17. Ho F, Lau F, Downing MG and Lesperance M. A reliability and validity study of the palliative performance scale. *BMC Palliative Care* 2008; 7, 10. <http://doi.org/10.1186/1472-684X-7-10>
18. Teno JM, Shu SE, Casarett D, Spence C, Rhodes R and Connor S. Timing of referral to hospice and quality of care: Length of stay and bereaved family members' perceptions of the timing of hospice referral. *J Pain Symp Man* 2007; 34(2): 120-5.
19. Stevenson J, Abernethy AP, Miller C and Currow DC. Managing comorbidities in patients at the end of life. *Br Med J* 2004; 329(7471): 909-12.
20. PHILHEALTH CIRCULAR No. 022-2015. New Philhealth Dialysis Package. Available at https://www.philhealth.gov.ph/circulars/2015/TS_circ022-2015.pdf
21. Laudico AV, Lumague MRM, Medina V, Mapua CA, Valenzuela FG, Pukkala E. 2015 Philippine Cancer Facts and Estimates, Philippine Cancer Society-Manila Cancer Registry Department of Health-Rizal Cancer Registry in cooperation with the Department of Health-Disease Prevention and Control Bureau Rizal Medical Center.
22. O'Connor NR, Dougherty M, Harris PS and Casarett DJ. Survival after dialysis discontinuation and hospice enrollment for ESRD. *Clin J Am Soc Nephrol* 2013; 8(12): 2117-22. <http://doi.org/10.2215/CJN.04110413>
23. Chandrashekar A, Ramakrishnan S and Rangarajan D. Survival analysis of patients on maintenance hemodialysis. *Indian J Nephrol* 2014; 24(4): 206-13. <http://doi.org/10.4103/0971-4065.132985>
24. Compton P, Weaver MF. Responsible opioid use. *J Pain Palliative Care Pharmacother* 2015; 29: 166-8. doi: 10.3109/15360288.2015.1037522
25. Sh, S, Klotz U. Drug interactions with herbal medicines. *Clin Pharmacokin* 2012; 51(2): 77-104.
26. Izzo AA, Borrelli F and Capasso R. Herbal medicine: the dangers of drug interaction. *Trends in Pharmacological Science* 2002; 23(8): 358-91.
27. Ernst E. Toxic heavy metals and undeclared drugs in Asian herbal medicines. *Trends in Pharmacological Science* 2002; 23(3): 136-9. doi:10.1016/S0165-6147(00)01972-6
28. Gunturu KS, Nagarajan P, McPhedran P, Goodman TR, Hodsdon ME and Strout MP. Ayurvedic herbal medicine and lead poisoning. *J Hematol Oncol* 2011; 4: 51. doi:10.1186/1756-8722-4-51
29. De Guzman EA. Living arrangement of the Filipino elderly. An information flyer on the Filipino elderly. Demographic Research and Development Foundation Inc. (DRDF) and the University of the Philippines Population Institute (UPPI) 1999.
30. Detering KM, Hancock AD, Reade MC and Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *Br Med J* 2011; 340:c1345. doi: 10.1136/bmj.c1345
31. Karnik S and Kanekar A. Ethical issues surrounding end-of-life care: a narrative review. *Healthcare* 2016; 4: 24. doi:10.3390/healthcare4020024
32. Turner J. Emotional dimensions of chronic disease. *Western J Med* 2000; 172(2): 124-8.
33. Fine R. Depression, anxiety and delirium in the terminally ill patient. *Baylor University Medical Center Proceedings* 2001; 14(2): 130-3.
34. Boyero A, Leombruni P, Miniotti M, Rocca G and Torta R. Spirituality, quality of life, psychological adjustment in terminal cancer patients in hospice. *European J Cancer Care* 2016; 25(6): 961-9. doi: 10.1111/ecc.12360
35. Egan R, Macleod R, Jaye C, McGee R, Baxter J, Herbison P and Wood S. Spiritual beliefs, practices, and needs at the end of life: results from a New Zealand national hospice study. *Palliative and Supportive Care* 2016; 14(78): 515-6. doi:10.1017/S147895151600064X
36. Grant E, Murray S, Kendall M, Boyd K, Tilley S and Ryan D. Spiritual issues and needs - Perspectives from patients with advanced cancer and nonmalignant disease: A qualitative study. *Palliative and Supportive Care* 2004; 2(4): 371-8. doi:10.1017/S1478951504040490