

# **BARRIERS AND POTENTIAL SOLUTIONS TO PHYSICIAN REFERRALS TO PALLIATIVE CARE SERVICE IN THE PHILIPPINES**

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## ***Abstract***

Doctors play an important role in facilitating access to supportive and palliative care (SPC) services for people with advanced cancer and other serious illness. Early referral allows palliative care teams to provide early assessment and relief of pain and psychosocial distress and discuss advanced care planning. However, many patients are referred to supportive and palliative care services only in the last days of life. Lack of education about palliative care and lack of awareness of the availability of supportive and palliative care services can lead to patients not being referred at all. Moreover, confusion about physician roles, a lack of physician comfort with prognostication and end-of-life conversations, including the fear of depriving patients and families of hope can be barriers to timely supportive and palliative care referrals. Misperception about terminology and the intent and scope of supportive and palliative care, and concerns about cost and other financial considerations can also contribute to a reluctance to refer to supportive and palliative care. Recognizing the physician barriers to referral to supportive and palliative care can bring about changes in education and health care practices to achieve goals of providing timely palliative care to those in need.

Key words: barriers, palliative care, supportive care

## **INTRODUCTION**

When patients are diagnosed with a life-threatening illness such as cancer, they and their families face uncertainty about the future and anxiety about how to access treatment, the quality of treatment, and its affordability. In Asia, many patients are diagnosed with cancer are advanced in the disease and are therefore, not amenable to curative treatment even though they are likely to suffer pain and other symptoms as well as psychosocial concerns. Palliative care is patient- and family-centered health care that focuses upon effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care, according to patient/family needs, values, beliefs, and cultures. Palliative care can be delivered concurrently with life-prolonging care or as the main focus of care. The goal of palliative care is to anticipate, prevent and

reduce suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies (National Comprehensive Cancer Care Network, 2015).

Both as a philosophy of care and as an organized, highly structured system, palliative care involves an interdisciplinary team, including the professions of medicine, nursing, social work, chaplaincy, counseling, nursing assistants, and other health care professions. Supportive care is part of oncological care that involves the prevention and management of the adverse effects of cancer and its treatment. This includes physical and psychosocial symptoms and side-effects across the entire continuum of the cancer experience, including the enhancement of rehabilitation and survivorship. The terms "life-threatening" or "debilitating illness" are assumed to encompass the population of patients of all ages and a broad range of diagnostic categories, who are living with a persistent or recurring condition that adversely affects their daily functioning or will predictably reduce life expectancy. (EAPC, 2009).

Hospice and hospice care means different things in different countries—it is variously used to refer to a philosophy of care; to the buildings where it is practiced; to care offered by unpaid volunteers; or, to care in the final days of life (Doyle and Woodruff, 2013). However, the principles that underpin supportive and palliative care are broadly the same. (Watson *et al*, 2009). Traditionally, hospice care was reserved for those with incurable cancer. Increasingly, hospice care is provided for other patients such as those with AIDS and neurological disorders, including motor neuron disease, multiple sclerosis, and dementia.

Yearly, according to the Human Rights Watch's *Global State of Pain Treatment* (2011), tens of millions of people around the world with life-threatening illnesses suffer unnecessarily from severe pain and other debilitating symptoms because they lack access to palliative care, an inexpensive health service that aims to improve the quality of life of people with serious health conditions.

Untreated pain and lack of palliative care have several consequences. Moderate to severe pain, as well as other physical and psychosocial symptoms, have a profound impact on quality of life. Pain can lead to reduced mobility and the consequent loss of strength; compromise the immune system; and, interfere with a person's ability to eat, concentrate, sleep, or interact with others. A World Health Organization (WHO) study found that people who live with chronic pain are four times more likely to suffer from depression or anxiety. The physical and psychological effects of chronic pain can directly influence the course of disease and also reduce patients' adherence to treatment. Pain also has social consequences for patients and their caregivers, including

inability to work, care for children or other family members, and participate in social activities. At the end of life, pain can interfere with a patient's ability to bid farewell to loved ones and make final arrangements. As documented by Human Rights Watch, patients' suffering is often so intense they would rather die than live with their pain.

Supportive, palliative, and end-of-life care offer the potential to improve patients' quality of life and pain control, to reduce suffering for cancer patients and their families, and to give patients dignity in death. All patients should have access to such care, both for pain and symptom control and to address psychosocial and existential concerns. In resource-rich countries and regions these services should be integrated into oncology services, whereas in resource poor settings they should be the main focus of treatment. As such, the meaning of palliative care in Asia is closely linked to the economic resources available. (Payne et al, 2012)

Although the WHO considers palliative care an integral component of cancer care and has urged countries to improve its availability, too often palliative care continues to be the neglected child of the health care family, receiving low priority from health policy makers and health care professionals and almost no funding. This is despite the fact that experts estimate that 60 percent of those who die each year in the developing world—a staggering 33 million people—need palliative care. In part, this is because most cancer patients in developing countries are diagnosed when they are advanced in the disease and can no longer be cured, leaving palliative care as the only treatment option (Human Rights Watch, 2011).

Early referral to supportive and palliative care (SPC) allows palliative care teams to provide early assessment and relief of physical and psychosocial distress and discuss advanced care planning and is increasingly becoming recommended as the standard of care. WHO has recognized that “palliative care is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy.” However, despite these standards and recommendations, referral to SPC tends to occur late in the course of illness. Most patients are referred to palliative care services within 30 to 60 days of death, and many are referred in the last days of life (Wentlandt et al, 2012).

In a systematic review of the problems and issues of accessing specialist palliative care by patients, caregivers and health and social care professionals, Ahmed, Bestall and Ahmedzai (2004) reported that palliative care may not be reaching all of those that could benefit from it. Access or referral to specialist palliative care is not equitable for all. All eligible patients and their families should be referred to and cared for by relevant palliative care services, be that the GP and community team, in-patient

palliative care, a hospice, day care or other service. However, misinformation and lack of good published evidence about the benefits of palliative care in some situations means that some patient groups are denied an appropriate referral.

Moreover, the rapid and unplanned growth of hospices and other palliative care services has led to several problems that affect the way these services are perceived by both the public and medical professionals. These problems include:

- heterogeneity in what palliative care services in different localities offer;
- lack of understanding amongst professionals about whom to refer, and when;
- resistance by some professionals to share with or hand patients over to palliative care services even when it would be in the patients' interest;
- reluctance by many patients and their family caregivers to be referred for palliative care, because of misunderstandings of what it offers, or fear of its association with imminent dying;
- perception that palliative care is only for cancer patients; and,
- missed opportunities resulting from patients having certain cultural backgrounds, or being in institutional care.

These difficulties have led to many potential patients being doubly disadvantaged, not only because of their life-threatening disease and the distress associated with that, but also by being excluded from the benefits of palliative care. Currently, there is no standardized way of screening patients with a progressive cancer diagnosis, or chronic disease about their need(s) for specialist palliative care. Eligibility relies on the knowledge and resources of the patient and their family, the attitudes, knowledge and experience of the person referring and other factors relating to location and resources. This process of referral has been successful for some but it allows some people to slip through the gap where the knowledge and resources of the patient are few, where the referrer has less experience and knowledge, and where there may be few or no palliative care services in an area. (Ahmed et al, 2004).

This inequity and significant gap in the provision of palliative care has led the international palliative care community to develop strategies to improve access to quality palliative care using a human rights approach to urge states who are signatories to the International Covenant for Economic, Social and Cultural Rights (ICESCR) to meet human rights core obligations for the provision of palliative care in their countries. (Gwyther, 2014).

In the Philippines, a bill entitled, "The Palliative and Hospice Care Act" has been filed in Congress to improve the quality of life of the terminally ill. Under this legislative measure, all government and private hospitals and health centers are required to

provide palliative care and end of life services to all patients with life-threatening illness.

Through active advocacy efforts and practical models of provision of palliative care, it has been recognized that palliative care is an appropriate and compassionate response to the needs of patients with life-threatening illnesses. This is true for cancer patients and for those with other chronic progressive illnesses. However, there are significant inequities in the provision of palliative care worldwide. The Worldwide Palliative Care Alliance, in partnership with the International Observatory on End of Life Care at Lancaster University, UK, published a report that mapped palliative care development around the world in 2006 and an updated version 2011. The updated report showed that worldwide; 75 countries (32%) have no known palliative-care activities; 23 (10%) have capacity-building activities only but no services; and, only 20 countries (8.5%) had palliative care well integrated into their mainstream health-care provision. In Asia, countries with no known palliative-care activities include Afghanistan, Bhutan, North Korea, Laos, and many of the Pacific Island nations. Asian countries where palliative care is largely integrated into mainstream health-care provision include Hong Kong, Japan, Singapore, and Taiwan. In between, some Asian countries (e.g., Indonesia, Philippines, Thailand, and India) have isolated or patchy provision of palliative care services or preliminary integration into mainstream health-care provision (e.g., China, Malaysia, and Mongolia). In many countries, palliative care was first integrated as part of oncology care before being extended to patients with non-cancer diagnoses.

## **DISCUSSION**

According to the Country Report on the Philippines (Wright et al, 2008), the movement towards palliative and hospice services in the Philippines began in the 1980s and took a significant step forward when pain relief became incorporated into the government's 1990 Cancer Control Programme. The following year, in September 1991, the Philippine Cancer Society, Inc. started its Patient Outreach Services, founded the first home care programme and offered support to other interested groups. The Directory of the Asia Pacific Hospice Palliative Care Network (APHN) shows members registered since March 1, 2001. By May 16, 2014, the list included 32 Philippine organization or facilities with 18 located outside Metro Manila.

A 2008 Country Report on the Philippines identified and summarized the challenges to hospice and palliative care development in the country based on the following headings:

A. Palliative care and society: 1) The Philippines is a resource constrained country; 2) Lack of public awareness; 3) Provision is problematic in remote areas and patchy throughout the archipelago;

B. The health care community: 1) Lack of training among medical and nursing staff; 2) Low credibility/ interest in palliative care; 3) Low number of doctors with S2 licenses (essential to prescribe morphine) ; 4) Unwillingness of doctors to refer patients;

C. Government: 1) Lack of political will to support palliative care; 2) No government stream for hospice funding;

D. Service provision: 1) Maintaining a pool of trained and available volunteers; 2) Securing administrative support; 3) Funding; 4) Procuring; drugs, equipment and materials; 5) Training; 6) Becoming over attached to patients, particularly children.

**Potential Barriers To Physician Referrals to Palliative Care Service**

More than a decade after the establishment of the first supportive, palliative, and hospice care services and fellowship training program in the state-run University of the Philippines-Philippine General Hospital (UP-PGH), many patients with advanced disease still do not receive palliative care; while, some are referred too late in the course of their disease to benefit from treatment. The reasons for this may relate to the physician, the patient, the family, or to societal factors (Doyle and Woodruff , 2013).

Among private patients consulting at UP-PGH, and in private hospitals where such services already exist, lack of education about palliative care and lack of awareness of the availability of supportive and palliative care services can result in patients not being referred at all. Confusion about physician roles, a lack of physician comfort with prognostication and end-of-life conversations, including the fear of depriving patients and families of hope can be barriers to timely supportive and palliative care referrals. Misperception about terminology and the intent and scope of supportive and palliative care, and concerns about cost and other financial considerations can also contribute to a reluctance to refer to supportive and palliative care. (Table 1).

**Table 1. Barriers To Physician Referrals To Supportive And Palliative Care in Private Hospitals the Philippines**

<p><b>Non-referral</b></p> <ul style="list-style-type: none"> <li>• lack of education about palliative care</li> <li>• lack of awareness of the availability of supportive and palliative care services</li> <li>• lack of institutional standards for palliative and end-of-life care</li> </ul>
<p><b>Late referral</b></p> <ul style="list-style-type: none"> <li>• belief that they are well qualified and able to care for their patients and often referred only when symptoms became unmanageable</li> <li>• poor prognostication</li> <li>• lack of communication skills to break the bad news and discuss end-of-life issues</li> </ul>

**Reluctance to refer**

- misperception about terminology (e.g., hospice vs. palliative care)
- doesn't understand role of palliative care in relation to treatment intent, stage of the disease, and functional status
- reluctance by doctors, patients, and families to forego disease-controlling treatment
- doesn't believe in palliative care
- belief that it is their job to manage their patient's symptoms and to provide the psychological support to help patients cope with their illness, and referral to palliative care would be shirking their responsibilities as a good doctor and would be perceived as abandonment of their patient
- belief that they will be relinquishing control of the patient's care to a multidisciplinary team and that he or she will not be part of this team
- loss of income
- belief that referral will add financial burden to patient and family

**Non-referral**

The major reason for lack of access to palliative care is paucity of physician referrals due to lack of education about palliative care, lack of awareness of the availability of supportive and palliative care services, and lack of institutional standards for palliative and end-of-life care.

**Late referral**

Several health professional issues contribute to late referral to palliative care. Attending physicians largely feel that they are well qualified and able to care for their patients with advanced cancer and often would refer only when symptoms became unmanageable. Hence, to make appropriate referrals, doctors must be able to recognize when the patient is encountering difficulties or when the care is beyond their level of expertise.

Among the other reasons for the lateness of referrals include difficulty in making accurate prognoses even for patients with advanced cancer. Even if the prognosis is evident, the physician may be reluctant to "admit defeat" or to discuss the prognosis with the patient and family. The desire to minimize emotional damage to the patient or family, to maintain hope and not appear to abandon the patient often reportedly resulted in failure to refer appropriately. Ongoing, but ineffective, treatment may be fuelled by this non-acceptance of the prognosis by health professionals, patients, and families who would thus seek further treatment in the hope of cure or prolongation of life.

Longstanding relationships between doctors and patients sometimes made the decision to refer difficult, with concerns that referral may result in patients and families feeling abandoned by their attending physician. It was deemed unnecessary for patients to be

referred to another service when attending physician already had an extensive knowledge of the patient, and their physical and psychological problems.

Difficulty communicating bad news and end-of-life issues are important barriers. Poor communication around issues such as disease progression, prognosis, change in treatment intent, and end of life emanated from a number of sources including the clinician, the patient and their family. Failure by some patients and families to absorb and accept bad news and to communicate openly and honestly between themselves exacerbated the problems. However, patient understanding and acceptance depend largely on what patients are told and how they're told it.

While doctors might not find it difficult to identify when treatment should be changed to supportive management, a number might find it difficult to verbalize this with patients. Reportedly, complex treatments were sometime continued to avoid such painful discussions.

### **Reluctance to refer**

Attending physicians may be reluctant to refer patients to palliative care since they do not have a clear understanding of how palliative care can be helpful to their patients. While the presence or complexity of symptoms was most frequently reported as the trigger for referral, issues such as treatment intent, stage of the disease, and functional decline all played important roles in such decisions. Physical symptoms such as pain and discharge from hospital with a need for home care are catalysts for a referral. Functional decline, evidenced by decreasing mobility, loss of independence, and more frequent acute episodes needing admissions are also significant triggers for referrals for SPC. However, patients who appear well, do not complain and who appear to be functioning well at home would be perceived as not requiring SPC and would often be overlooked, despite being able to potentially benefit from SPC services in other ways.

Reluctance by doctors, patients, and families to forego disease controlling treatment contributed to a disinclination to refer people who could potentially benefit from SPC. Attending physicians erroneously believe that if they are administering cancer-directed therapy, palliative care cannot be offered at the same time. Attending physicians believe that it is their job to provide the psychological support to help patients cope with their cancer and to manage their symptoms, and to refer them to palliative care would be tantamount to shirking their responsibilities as a good doctor. They could also have the perception that referral to supportive and palliative care would mean that they would relinquish control of the patient's care to a multidisciplinary team that excluded him/her, which in turn could affect their income. Further, the attending physicians may



have the idea that referring a patient to palliative care entails additional expenses that would add to the financial burden of the patient and families.

### **Potential Solutions To Physician Referrals To Supportive And Palliative Care Service**

McAteer and Wellbery (2013) proposed that the supportive and palliative care specialist and team should clarify to the patient and attending doctor that decisions are flexible and are ultimately made in conjunction with them as well as the patient's family. Other solutions include: educating physicians about illness trajectories and prognostic indicator tools as well as a skills training for physicians that promote early, clear communication with patients and families, that contextualizes decisions in terms of goals of care, and that further advance care planning discussions. Part of the solution also entails an explanation that the cost of supportive and palliative care is likely equal to, or maybe even lesser than, that of usual care.

### **Best Practices in a Private Tertiary Hospital in Metro Manila**

Although the challenges are formidable, there are signs that palliative care continues to progress at both local and tertiary levels. The Medical City (TMC) is more developed since supportive and palliative care is already incorporated into standard-of-care cancer treatment approaches from the onset of the formation of a multi-disciplinary cancer team to establish goals and plan of care for a new patient with advanced cancer consulting at the Cancer Center (Wright et al, 2008).

There is adequate access to palliative measures, including early palliative care given in conjunction with curative therapy as part of a broader, guideline-directed management strategy. This private tertiary and teaching hospital in Metro Manila is accredited by the Joint Commission of International Accreditation (JCIA). It is implementing pathways that trigger supportive and palliative care referrals based on specific clinical features (e.g., repeated or lengthy hospitalization, prolonged ICU stay, decline in cognitive or functional status, unacceptable pain, emotional distress, lack of goals of care clarity and documentation, disagreements or uncertainty among the patient, staff, and/or family about major medical treatment decisions, and/or resuscitation preference, ethical concerns about end-of-life care) and palliative care utilization is a key quality measure. The institution's internal medicine residency training program and continuing medical education incorporate these elements in the clinical training of doctors, as well as that of the nurses. The School of Medicine and Public Health attached to the hospital (Ateneo de Manila University) likewise incorporate these essentials in its medical curriculum and provide its medical students with inpatient palliative care exposure.

## **CONCLUSION**

More than a decade after the establishment of the first supportive, palliative, and hospice care services and fellowship training program in the state run University of the Philippines-Philippine General Hospital (UP-PGH), many patients with advanced disease do not receive palliative care and some are referred too late in the course of their disease to benefit from treatment. On the other hand, a private tertiary hospital in Metro Manila has a supportive and palliative care service that is more developed. Other universities and hospitals are planning to start palliative care services and fellowship training as well. The National Palliative and Hospice Care Council of the Philippines (Hospice Philippines, Inc.) has become invigorated, exploring new ways of supporting its members, engaging with government, and seeking the means to encompass palliative care within the public health system. The Department of Health's commitment to increase the availability of morphine and other analgesic drugs, are indicative of a growing interest. (Wright et al, 2008). In the Philippines's House of Representatives, a legislative bill integrating palliative and hospice care into the Philippine health care system is currently under deliberation. If this House Bill is approved, all government and private hospitals are mandated to provide palliative and hospice care services. The Department of Health, in partnership with Hospice Philippines, shall formulate the rules and guidelines for accreditation to ensure a standard quality of palliative care services. As such, addressing physician barriers through adequate education and training are integral steps in furthering the effective provision of quality supportive and palliative care services in the Philippines.

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