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Overview

Integrative Palliative Cancer Care in Hong Kong: An Overview and an Example from the East

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Abstract

Cancer is the most common cause of mortality worldwide. Although recent advances of multiple modality cancer management have significantly improved the cure and control rates, a significant proportion of patients are still refractory to the standard and available treatments. Early initiation of palliative care can reduce cancer suffering, improve health-related quality of life and possibly prolong survival. It also allows patients and their caretakers to perceive the trajectory of their cancer, so that better and advanced care planning can be contemplated and implemented. The traditional beliefs and perceptions of cancer also differ significantly between the East and the West, which may also affect the preferential approach to palliative care. This review provides an overview of palliative care services in Hong Kong, as compared with other parts of the world. In addition, we shall also explore how cancer perceptions affect the decision-making on palliative care.

Key words: Cancer; end-of-life care; hospice; pain control; palliative care; radiation therapy

Introduction

Holistic palliative care always constitutes an important element of cancer care, as cancer is the most common cause of death in most developed countries and regions. Yet the shortage and scarcity of board-certified palliative care physicians is always a challenge to healthcare policy makers, physicians, patients and their families or caretakers [1,2]. Palliative cancer care may be perceived as a subspecialty of low income generation, which may not appeal to the new generations of physicians. It also receives little funding and hospitals have a low incentive to provide this dedicated and highly personalised service. Also, the prolonged physical, social and psychological suffering of patients and their families when patients gradually deteriorate may also upset the physicians. Currently, oncologists often prioritise radical management of patients, leaving insufficient time to address the complex needs of palliative patients. Therefore, the vast majority of these patients are usually co-managed by oncologists, generalists and specialists in areas other than palliative care. In the West, a structured palliative care and end-of-life team consists of palliative care physicians, nurses, psychologists, physiotherapists, medical social workers and other allied health professionals in a network, which is crucial to the improvement of access and continuum of cancer care to patients with grave conditions and prognosis [3]. National and institutional guidelines on palliative care and symptom management are needed to provide and improve quality care across settings [4].

Palliative care is defined by the World Health Organization (WHO) as a management modality that 'improves the quality of life of patients (adults and children) and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, or spiritual' [5]. It has been shown that early initiation of palliative care can improve quality of life, relieve patient suffering and engage them and their

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families in devising personalised patterns of palliative care and advanced care planning through conversation [3,6].

Indeed, we are facing an unprecedented challenge of unmet need for palliative cancer care secondary to the soaring incidence of cancer and an aging population worldwide. The WHO estimated that only 14% of 40 million patients received palliative care during the end-of-life period [5]. Another recent systematic review pointed out that an average of 33–38% of patients received non-beneficial and substandard care in the final 6 months of their life [7]. Luckily, such an undesirable situation has gradually improved over the last two decades. For instance, 75% of hospitals in the USA provided a palliative care programme in 2015, as compared with just 25% in 2000 [8]. Unfortunately, such service gaps are much wider in the less developed countries and regions, especially for non-malignant diseases.

Furthermore, improved access to radiation facilities and effective medication for symptom relief also play an active role in alleviating many symptoms, together with a well-established palliative care team in conjunction with a collaborative approach between palliative care and specialist team members. Numerous studies have shown that radiation therapy is effective in controlling and relieving symptoms from tumour bleeding and obstruction, superior vena cava obstruction, disseminated brain and leptomeningeal metastases, acute spinal cord compression and painful bone metastases. Unfortunately, radiation facilities and radiation workers are still a critical scarcity in many parts of the world. Datta *et al.* [9] revealed that the low–middle income countries (LMICs) only have one-third of the global radiation equipment, but treat almost 60% of the world's cancer patients [9]. Moreover, LMICs also have a high incidence of common cancers and some endemic cancers, e.g. nasopharyngeal carcinoma. Cancers in patients living in LMICs usually present very late at diagnosis, which often precludes the chance of curability. Even so, recent evidence has suggested that the relative survival for nasopharyngeal carcinoma improved with availability of radiation therapy and personnel, based on the data from GLOBOCAN and the Directory of Radiotherapy Centers of the International Atomic Energy Agency (IAEA) [10]. The IAEA, through the Programme of Action for Cancer Therapy (PACT), has been actively taking the initiative to collaborate with business sectors and LMICs to expedite the installation of radiation facilities [11].

Access to symptom-relieving medication is also of paramount importance in palliative cancer care. Opioid analgesics, adjunct analgesics and sedatives are prerequisites of effective control of cancer pain (especially neuropathic pain), dyspnoea and restlessness, etc. A recent study even revealed that a shortage of parenteral opioid analgesics prolonged patient suffering with pain [12].

Pattern of Palliative Care in Hong Kong

Development of Palliative Healthcare System in Hong Kong

The public healthcare system in Hong Kong takes care of more than 90% of cancer patients in Hong Kong. In total, there are seven public oncology centres looking after a population of more than 7.3 million people, under the management of the Hospital Authority, a statutory healthcare organisation that receives public funding from the government. There are two types of oncologist in Hong Kong, namely clinical oncologists and medical oncologists. Clinical oncologists, constituting 80% of all oncologists in Hong Kong, receive structural training in conjunction with the current British training system for the Fellowship of the Royal College of Radiologists (FRCR) of the UK. They still need to undergo 2 more years of higher specialty training and pass the exit examination before becoming a specialist under the Hong Kong College of Radiologists (HKCR) after passing the FRCR examination. On the other hand, medical oncologists receive subspecialty training in medical oncology after passing the first examination of the Royal College of Physicians of the UK. After passing the final examination of the Hong Kong College of Physicians (HKCP), they are board-certified medical oncologists who can prescribe anticancer treatment other than radiotherapy. Palliative medicine was established as an independent subspecialty of the HKCR and HKCP in 1998 and 2002, respectively.

In Hong Kong, a territory-wide patient-oriented electronic health records (eHR) sharing system was launched in March 2016. Essentially, the system stores the patient medical data from both the private and the public sectors and a very sophisticated computer software is incorporated into this system to ensure data security. Every time a private doctor or primary care physician enters the system with the patient's identity number and the password supplied by the patient, the patient receives a SMS message that the doctor has viewed his/her medical records. So far only doctors in the private sector can gain access to the medical data stored in public hospitals if they have joined this programme, but doctors in the public sector receive very little information of treatment details in the private sector as private hospitals have relatively low incentive to upload the data into the system. With eHR, every doctor knows clearly all the treatment details of every palliative care patient when they visit any public/private hospital or doctor a distance away from their home. This is welcomed by all healthcare professionals as very few patients, especially those who are elderly and terminally ill patients, can fully remember their past medical history, as well as the treatment and prescription details.

An extensive public outpatient and inpatient palliative and hospice care referral and healthcare network has gradually developed in Hong Kong over 30 years. Clinical oncologists and palliative care physicians are responsible for providing territory-wide comprehensive palliative and end-of-life care to terminally ill patients. Those who are unwell at home or in an institution can immediately telephone the nurses in the respective palliative care clinic during office hours for expedited assessment and hospital admission if needed. However, ambulance services to the nearest Accident and Emergency Department (AED) of acute public hospitals of the Hospital Authority are often needed if patients suddenly deteriorate. In fact, the vast majority of terminally ill patients are sent to the nearest acute hospitals with an AED if they deteriorate during the night or on public holidays, as they are the most easily accessible, usually within a 15 min drive, and they are the only healthcare access (apart from private hospitals) open during public holidays. They charge a fairly low rate (only HK$180/£18/US$23) for every visit to the AED.

On the other hand, family doctors or primary care physicians play a small role in taking care of terminally ill patients for various reasons. They are often overwhelmed by the extremely large number of patients seeking medical care for communicable infections or chronic illnesses. Second, they are not authorised to issue death certificates if patients pass away at home. Third, they often refrain themselves from giving sedatives or opioid analgesics to patients at home for medicolegal reasons, although they are licensed to do so. This significantly contrasts with Western countries or regions, where family doctors are often invited to give home visits or where access to an AED is not straightforward.

A weakness of the healthcare system in Hong Kong is the overloaded public system, with long waiting times and potential medical errors. The private system is prohibitively expensive and patients risk over-investigations and treatment that may occur in other parts of the world. As most patients are elderly with little savings/pension, they cannot afford to see family doctors. If they become very sick, they go to the AED but the waiting time can be more than a day for non-urgent cases, as determined by the triage system conducted in the AED. Social assistance is available for the very poor but the amount of money barely covers daily expenses due to the inflation rate of Hong Kong.

Patient Perception and Treatment Preference

The degree of perception and acceptance of terminal malignancy and death has gradually changed over the past 20 years in Hong Kong. Although terminal malignancy was often considered to be a taboo subject by earlier generations because of traditional Chinese precepts, it is now gaining more recognition and acceptance [13]. This probably results from a better perception of terminal illness by well-educated patients and their caretakers. Also, the comprehensive palliative care offered by a multidisciplinary team makes patients and their caretakers less fearful of it. A better understanding of their terminal illness can also facilitate the patients to make advance directives, as described below.

Although most terminally ill cancer patients receive an orthodox Western style of palliative care, including targeted therapy, radiation therapy and, perhaps recently, immunotherapy, a significant proportion of patients resort to traditional Chinese medicine as palliative treatment, in either the public or private sector, in particular those who have previously exhausted all available options of a Western style of active anticancer treatment. Acupuncture, with either manual or electrical stimulation, is a commonly used traditional type of Chinese medicine. Similar therapies, including acupoint injection, and other needleless procedures, like moxibustion and transdermal electrical nerve stimulation, are often adopted independently or in combination with acupuncture (see the review article on Chinese medicine in this special issue for more details [14]). A recent systematic review and meta-analysis conducted in Hong Kong showed that acupuncture or related therapies significantly relieved pain among patients with liver and gastric cancer [15]. In addition, acupressure exhibited significant efficacy in reducing fatigue in lung cancer patients compared with sham pressure. Similarly, a local study showed that a mild muscle relaxation programme, together with patient education, could better help patients cope with symptom management during palliative radiotherapy for their lung cancer [16]. This may be beneficial clinically and psychologically to those patients undergoing palliative radiotherapy for lung cancer, as clusters of symptoms, including anxiety, breathlessness and fatigue, may be aggravated during and after palliative radiotherapy [17,18].

The advance directive has also been explored in the public health sector in the past two decades in Hong Kong, following its emergence in the West in the mid-1970s [19]. It is a written statement in which a patient indicates, when mentally competent, the medical care he/she would prefer when he/she is no longer competent to make such a decision [20]. A previous study revealed that about 30% of elderly patients lacked the mental capability of making decision at the end of their lives when they were required [21]. Advance directives can certainly facilitate the healthcare professionals to autonomously exercise healthcare decisions even at a time when patients deteriorate and become mentally incompetent. The patient's advance directive can also let their family and doctors know about the patient's preferences for end-of-life care so that they can act in accordance with such wishes. Finally, in both the East and the West, advance directives can cut healthcare expenditure when the directive specifies the limits to end-of-life care [22].

Healthcare providers in Hong Kong are now more knowledgeable about advance directive education and documentation. A local study showed that 63% of patients provided advance directives. A patient's poor insight of their prognosis was the most important and significant factor facilitating advance directive engagement, whereas family objection was borderline significant [23]. A recently published phase II study in Hong Kong further identified condition factor, value system, process of advance directive, physical and illness factor, personal situation factor and socio-cultural factor as the keys to advance directive acceptance [24].

End-of-life Care

In Hong Kong, almost all patients and families would like death to occur in an institution or a hospital [25]. An obvious reason is that the end-of-life pathway is an essential component of palliative care in the public health sector. The hectic life of caretakers who are also the bread winners of the family make it difficult to take care of patients at home. The extremely crowded living environment with the family in a small flat can also make the caretakers embarrassed and uneasy to accompany their beloved through the last moments of their lives. The religious rituals carried out to pave the way for the patients to enter the next world may also cause nuisance to the neighbourhood.

A death in the house/flat will make it inauspicious and depreciate its price, which is a major asset of the family's wealth. The concept of a 'haunted house/flat' is not just deep-rooted in the mind of the family or the neighbourhood, but also in the minds of the banking sector, which causes great difficulty for landlords when applying for mortgage loans. Very few families want to keep the cremated remains in the house, again because of old Chinese traditional beliefs of ghost, misfortune, etc.

Integration of Palliative Care into Routine Oncology Services in Hong Kong: a Review of Experience in a Decade

In 2007, the Hospital Authority, the statutory body of provision of public healthcare, largely equivalent to the National Health Service in the UK, received a generous charity donation to set up integrated palliative care incorporated into routine oncology services. The programme was named 'Heart of Gold' [26]. In phase one, eight palliative care ambulatory clinics were set up in all Hospital Authority service clusters in Hong Kong. An integrative palliative and hospice care service model was introduced in all cancer centres. In phase two (2010), two more palliative care ambulatory clinics were set up. In phase three (2014), the Hospital Authority included the palliative care service in recurrent expenditure of public services. Pilot projects were launched to explore cross-hospital collaboration, as well as hospital–community collaborative palliative care services. The programmes also supported palliative care healthcare team training in collaboration with the headquarters of the Hospital Authority [27].

The early audit results of 'Heart of Gold' in 2016 were encouraging. The programme served more than 38 000 late-stage cancer patients with more than 430 000 attendances at ambulatory palliative care clinics during the period 2007–2016. There were more than 90 000 home care visits. More than 2500 children received bereavement support. All of these were provided by around 60 palliative care healthcare workers of the Hospital Authority and more than 3300 volunteers [27].

In 2018, a territory-wide review of this integrative palliative care model was carried out, which aimed to assess the impact of the model prospectively from 2006 to 2015 [28]. All cancer deaths within the Hospital Authority were screened. Random samples were selected from all seven service clusters of the Hospital Authority from 2006, 2009, 2012 and 2015 to form a representative cohort of cancer death. Through the review of detailed clinical records, palliative care coverage during the last 6 months of life and palliative care outcome indicators were recorded.

Palliative care coverage is defined as specialist palliative care provided by either palliative physicians or oncologists in palliative wards, hospice, outpatient ambulatory palliative care clinic or palliative care home care team. The length of palliative care provision was recorded from the date of first palliative care service contact to the date of death of the patient. The place of death of the patient, either in a palliative setting (designated palliative care beds or hospice) or a non-palliative setting, was reviewed.

In the decade 2006 to 2015, palliative coverage of advanced cancer patients steadily improved. The overall coverage increased from 55.4% in 2006 to 68.9% in 2015 ($P < 0.001$), despite the number of cancer deaths increasing by more than 22% (9057 in 2006 to 11 138 in 2015). For the duration of palliative care provision, the median was stable at 21–22 days for inpatient palliative care. For outpatient palliative care, the median time improved slightly from 53 days in 2006 to 70–96 days in subsequent years. Although there is still much room for improvement, such a duration of palliative care was similar to internationally reported standards – 21 days for hospitalised patients and 90 days for outpatients [29].

The length of stay of the last admission was strongly associated with palliative care coverage. In the first week of the last admission, palliative care coverage was 56.3%, which rose to 71.9% if the last admission length was longer than 21 days. A similar trend was observed in the chance that the patient could die at a palliative care facility (hospice/designated palliative care ward). If the patient died within 7 days of admission, the chance that the patient could die in a palliative care facility was only 32.3%. The chance increased to 60.8% if the last admission length was 22 days or above. This was probably related to the shortage of palliative care service in acute hospitals. The 'waiting time' for an inpatient palliative care consultation or transfer to a palliative care bed could be rather long. Rapidly deteriorating patients may die in acute ward settings during the 'waiting time' for a palliative care bed or consultation.

Palliative care coverage was remarkably heterogeneous in different service clusters of the Hospital Authority. Hospitals with both a multidisciplinary palliative clinic and designated palliative care beds (>10 beds) were strongly associated with better palliative coverage of 82%, whereas for hospitals with no palliative care unit or with a palliative outpatient clinic alone, the coverage was much lower at 33.4% and 31.7%, respectively.

For end-of-life care outcome indicators, the survey found that provision of a palliative care service was associated with an improvement in cardiopulmonary resuscitation rate (1.4% versus 6.7%), lower intensive care unit admission (0.9% versus 4.5%) and a decrease in chemotherapy or other systemic anticancer treatments (2.7 versus 7.3%, 4% versus 10%, respectively). The use of strong opioids was more common in patients who had received palliative care (45.8% versus 27.1%). All of these improvements were statistically significant.

Across the decade, end-of-life care outcomes on the rate of cardiopulmonary resuscitation and intensive care unit admission were stable. However, over the past 10 years there was a significant increase in the use of chemotherapy or systemic anticancer treatments in the last 30 days of life. This was observed in patients with or without palliative care service provision, which is consistent with the advancement in oncology that patients have had many more options for anticancer treatment in recent years.

For healthcare resource utility, palliative care provision was associated with increased clinic visits, similar AED visits and increased hospital stays in the last 6 months of life, although the duration of the last admission stay on an acute ward was shortened. Across the decade, the average utilisation of healthcare resources for palliative cancer patients remained stable. The high utilisation of resources was consistent with the hospital-oriented healthcare settings of Hong Kong.

Overall, the integrative palliative care model of the Hong Kong public oncology system has made remarkable achievements over the past two decades. Palliative care coverage improved significantly from 55% to 70%, despite the rapid increase in cancer service demand. The duration of palliative care provision also matches the international standard. However, service provision remained heterogeneous across the different hospital service clusters. In addition, the system is over-reliant on hospital-based service delivery.

Building on the solid foundation of an integrative palliative care model, the following directions of service improvement in Hong Kong were suggested. First, multidisciplinary palliative care teams and associated palliative inpatient wards should be set up in various hospital clusters to address the service heterogeneity. Second, ‘rapid response’ palliative teams should be set up to expedite early palliative care intervention for patients in acute units. Third, community care teams and integration of hospital–community teams should be encouraged to avoid hospital admissions. Finally, a continuous quality monitoring system should be set up to provide information feedback for service improvement.

Patterns of Palliative Care in Other Parts of the World

In mainland China, palliative cancer care is still underdeveloped, without a formal structural training programme for physicians and nurses. Only very few tertiary oncology centres have incorporated a palliative care service as an essential component of comprehensive and holistic cancer care. Also, many families prefer not to disclose the diagnosis to patients and urge oncologists to avoid mentioning the diagnosis and prognosis, for fear of psychological distress and breakdown. Death is even regarded as taboo. Patients are often told of treating benign diseases while they are prescribed targeted therapy for their bulky and unfavourably looking primary or metastatic tumours. Family members play an influential role in making end-of-life decisions. On the other hand, patients prefer doctors to consult their family members before making healthcare decisions.

The palliative care service is very well-established in the West and is provided as an independent specialty by a multidisciplinary team in tertiary cancer centres within a provincial network. New York enacted a Palliative Care Information Act in 2011, which mandates doctors to provide patients with information and counselling regarding palliative care and end-of-life options appropriate to them [30]. Violations of this law are subject to a fine or a jail sentence. Other states also implemented similar laws. Nurse-led models of palliative and hospice care are gaining popularity and acceptance in the West, which is exceedingly rare in the East [31–33].

On the contrary, access to symptom relief may not be so convenient in some Western countries. Radiation and medical oncologists work in separate departments in North America and many European countries. Referral for palliative radiotherapy for pain or other symptomatic relief may take some time in Canada, except in emergency situations like spinal cord compression or superior vena cava obstruction, for which rapid radiation clinics are available, as there is no private radiation oncology service. In addition, the sharing of health records is still rudimentary, even in some developed countries. There is a lack of a nationwide electronic health record system that allows effective transmission and sharing of health records.

Conclusion

In summary, there is still room to improve palliative care services worldwide. According to the WHO, currently less than 10% of patients who need palliative care in LMICs receive it. The WHO 2030 Agenda slogan ‘leave no-one behind’ means that the governments trying to achieve Sustainable Development Goal 3 must develop palliative care policies to provide such care to 40 million patients who require palliative care globally [34]. It is envisaged that the future demand for palliative care service is soaring because of a progressively aging global population and improved cancer survival. A tailor-made model of palliative care service is warranted to suit the needs of each region and country.

Conflicts of interest

None declared.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.clon.2019.06.001.

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