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## OVERVIEW OF PALLIATIVE CARE SERVICE IN HONG KONG

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# **ABSTRACT**

Palliative care service is a growing trend for patients with terminal illnesses. The purpose of palliative care service is to improve the quality of life for the patients and their family by providing comprehensive care such as symptoms control, pain relief and counselling support. More and more people prefer to spend the final stage of their life in a comfortable environment with adequate care. Palliative care service in Hong Kong is inadequate and enhancement of the service is needed. This review paper aims to evaluate the current development of palliative care service in Hong Kong and suggest improvement of the service.

Literature review of published research studies has been conducted. Compare to other countries or regions, the existing palliative care in Hong Kong is lagging behind the international standards. This study reveals that the system in Hong Kong is lacking of comprehensive policy, thus limiting the organisations to provide the service in small-scale operations, and resulting in fragmentation of the co-operation between the public and private sectors. Factors such as professional training, community engagement, culture and financial issues are affecting the adequacy of palliative care service. To facilitate the development of palliative care service for patients who are in need, initiating palliative care guideline, expanding professional education and training, increasing government funding to organisations that provide palliative care and increasing public awareness about the service are recommended.

**KEYWORDS:** palliative care, quality of life, palliative care guideline, government policy

### 1 INTRODUCTION

The World Health Organization (WHO) defines palliative care service as "an approach that improves the quality of life of patients (adult 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." (World Health Organization, 2019). One of the most widely known life-threatening illnesses is cancer. According to the statistics of Hong Kong Cancer Registry (2018) under the Hospital Authority (HA), there were around 30,000 new cancer cases in Hong Kong in 2016, which was an increase of 3% as compared with the previous year. Apart from the conventional treatments like radiotherapy and chemotherapy in cancers, palliative care is an approach to manage symptoms and side effects of cancers and their treatments. According to the Hospital Authority (2017), around 68% of cancer patients in Hong Kong had received palliative care before death in 2012-2013. Often, the service is offered as soon as cancer is diagnosed, during cancer treatment or continued after treatment.

In addition to cancers' patients, palliative care also covers patients who suffer from other serious illnesses such as Parkinson's disease, dementia and chronic life-limiting diseases such as cardiovascular diseases, chronic respiratory diseases or AIDS (World Health Organization, 2016). In Hong Kong, 44% of patients with end-stage renal failure have received palliative care (Hospital Authority, 2017). Based on individual's needs, palliative care services may include pain relief and distressing symptoms like vomiting and shortness of breath, emotional support and counselling for both patients and their families, and helping them to explore their beliefs and values. It is a team approach to find the needs of patients and their families and offers a support system to improve their quality of life when facing problems associated with life-limiting and terminal illnesses (World Health Organization, 2019). The professional team provides psychological, emotional and social care, and thus palliative care is called supportive care or comfort care.

## 2 OUTCOMES OF PALLIATIVE CARE

Various empirical studies show that quality of life of patients with various illnesses and their family has improved through palliative care. A systematic review reported that there was an association between palliative care interventions and significant improvement in quality of life and symptom burden of patients (Kavalieratos et al., 2016). The results showed that there were consistent improvements in advance care planning, enhancement of patient and caregiver gratification, and reduction of health care utilisation associated with palliative care among 43 randomised controlled trials (RCTs) with more than 12,000 patients and almost 2,500

caregivers. A RCT conducted in three Hong Kong hospitals examined the effects of home-based transitional palliative care for patients with end-stage heart failure (ESHF) after their discharge from hospitals, with 43 and 41 subjects as intervention group and control group respectively. The intervention group received weekly palliative home visits or telephone calls in the first four weeks and monthly followed-up by a nurse case manager with the support of a multidisciplinary team until the end of 12 weeks. Patients in this group had a significantly lower readmission rate, higher clinical improvement in depression, dyspnea, and the score of Edmonton Symptom Assessment Scale than those in the control group (Wong, Ng, Lee, Lam, Ng, Ng and Sham, 2016).

### 3 DEVELOPMENT OF PALLIATIVE CARE IN HONG KONG

## 3.1 Public and non-government organisations

The first palliative care team and service in Hong Kong was established at Our Lady of Maryknoll Hospital in 1982. Currently, the service has expanded into 16 hospitals under the Hospital Authority with around 360 beds in total (Hospital Authority, 2017). These hospitals provide comprehensive care such as symptom control and psychological counselling for terminally ill patients and their family.

Apart from the Hospital Authority, non-government organisations (NGOs) also offer palliative care services, including the Haven of Hope Christian Service (HOHCS), Hong Kong Anti-Cancer Society (HKACS) and Society for the Promotion of Hospice Care (SPHC). HOHCS provides 124 beds for palliative and hospice care services, while the 30-bed Jockey Club Home for Hospice (JCHH) offers part-public and part-private services under SPHC. The Hong Kong Anti-Cancer Society Jockey Club Cancer Rehabilitation Centre (JCCRC) provides 180 beds to cancer patients or seriously ill patients (The D. H. Chen Foundation, 2015). Other NGOs and charitable foundations such as The Jockey Club Charities Trust and The Board of Management of The Chinese Permanent Cemeteries had invested substantial funding to enhance capacity building in the past years (Chan, Lee, Woo and Yi, 2017).

# 3.2 End-of-life Services

End-of-life (EOL) care is an integral part of palliative care and is the provision of care and support for patients who are approaching death. In order to provide quality and holistic EOL care services, the Hong Kong Government has launched a public consultation to obtain public views on EOL legislative proposals (Food and Health Bureau, 2019). The consultation aims to improve the quality of life of patients and remove barriers for implementing legislation

on advance directives (AD) and dying in place.

The Social Welfare Department (SWD) of the Hong Kong Government requires contract elderly care to integrate EOL care into their care services (Legislative Council, 2014). SWD has been adjusting the subsidy amount for contract residential care homes for elderly (RCHEs) for their service on palliative care. SWD aims to have all contract RCHEs providing EOL care services by the end of 2019-20 (Legislative Council, 2017).

As palliative care service is mainly provided by HA, it has supported the development of palliative care by issuing different guidelines, including Guidance for Clinicians on Advance Directives in Adults in 2010, Do-Not-Attempt Cardiopulmonary Resuscitation (DNACPR) in 2014 and Guidelines on Life-sustaining Treatments in the Terminal III in 2015. In addition, the Hong Kong West Community Geriatric Assessment Team of the HA, had initiated a EOL pilot programme for the RCHEs in cooperation with the Tung Wah Group of Hospitals Jockey Club Care and Attention Home since 2009 (Luk, Liu, Ng, Beh and Chan, 2011). The programme provides opportunities for RCHE staff to receive training in palliative care in Taiwan, and had in return reduced acute hospital admissions of their patients.

Having a multidisciplinary team for palliative care is important. HA has continued to offer health professionals in general hospital wards and staff in home cares, and professional societies more education and training in recent years in order to equip them with better skills and knowledge in palliative care (Legislative Council, 2016). Since 2012, a funding of around \$12 million per year has been initiated by HA to recruit clinical psychologists and medical social workers in the public healthcare sector, with the aim of addressing the psychosocial needs of patients and their family.

## 3.3 Types of palliative care

With the expansion of palliative care, there are mainly four types of care, including inpatient, outpatient, home and day care. Inpatient palliative care is suitable for patients with moderate to serious or unstable symptoms. They may have treatments daily, most often at hospitals, medical centres or nursing homes. Some patients who are suffering from late stage disease will have rehabilitation treatment to maintain their daily living activities. For patients who are staying in an acute unit, doctors and nurses from the Palliative Consultative Team will visit them to provide consultation and support (Hospital Authority, 2015).

Outpatient care is suitable for stable and discharged patients. Patients who are in latestage with specialty treatment or psychological issues are normally referred to outpatient care clinics as well (Hospital Authority, 2015).

Home care assists patients who are weak and cannot have follow-up care in the outpatient clinic. The home care team will go to the patients' home and monitor their health conditions. They also help patients and their family and relatives to plan and prepare the death at their home. The team will stand by and counsel families and relatives before and after the patients' death to manage psychological breakdown during the whole progress (Hospital Authority, 2015).

Day care is suitable for patients who are stable and require monitoring every day. It provides the patients social activities and group or individual psychological counselling service to improve their quality of life. Usually, there is a resource centre in the day care service that provides education material to family and relatives and, medical equipment for patients to use or practice (Hospital Authority, 2015).

# 3.4 Framework strategies for palliative care implemented by the Hospital Authority

In 2017, the HA developed an update framework, called the Strategic Service Framework for Palliative Care, to facilitate the development of both adult and paediatric palliative care services in the next five to ten years. It outlined strategies for enhancing the existing service model and addressed current issues. It also emphasised collaboration among different specialties from hospitals to community settings.

According to the updated framework, there are four areas for improvement in palliative care service for adults. The first area is to develop Cluster-based services with medical and oncology palliative care specialists for improving the governance. HA aims at strengthening collaboration between medical and oncology palliative care specialists in order to optimise the use of resources and facilities. Their clinical experience, facilities and resources could then be shared in both medical and oncology palliative care teams which could generate more inspiration of the services. In addition, Cluster Coordination Committee in each cluster shall evaluate and revise the role on palliative care service to enhance the accessibility of palliative care in all patients who need this service. They should coordinate the implementation and monitoring of the service as well as the resource bidding and service planning in their clusters. The committee shall involve different parties and specialists like management supports, Accident and Emergency Department, pain control, etc. (Hospital Authority, 2017).

The second area is to enhance collaboration between palliative care and non-palliative care by sharing the care model of patients' needs. Patients would be stratified according to the

complexity of disease, professional competence and level of needs. Cases which are complex but need continuing management by parent team would be cared by non-palliative care specialists for basic management and advance care planning. Cases which are highly complex or having complicated symptoms would be passed to palliative care specialists. This approach could provide a coordinated, timely and appropriate palliative care service to patients. Besides, specialist palliative consultation service could be extended to non-palliative care settings. It could support the parent team to treat other patients in non-cancer late-stage conditions such as organ failure as a co-management (Hospital Authority, 2017).

The third area is to enhance ambulatory palliative care service to support patients in the community to minimise unnecessary hospital admissions. HA has planned to expand the palliative day care to home care service. On-site assessment, phone consultation, intervention and carers' support would be provided. Palliative care support to elderly home, medical and social collaboration with the community would also be enhanced. Hospital Authority would cooperate with NGOs, patient groups and volunteers to organise supporting and empowering activities for patients and carers. They would also provide other services to support patients in their daily life such as escort service, bathing, meal preparation, funeral proceedings, peer support groups, etc. (Hospital Authority, 2017).

The fourth area is to improve the monitoring of performance on palliative care services. Some key domains and standardised indicators would be developed in order to evaluate and collect performance data. Once they are widely adopted across clusters, service quality and outcomes could be monitored and strengthen the performance monitoring for continuous quality improvement.

### 4 COMPARISON WITH OTHER COUNTRIES/REGIONS

Despite efforts in the development of palliative care in Hong Kong, Hong Kong only ranked at position 22 out of 80 regions in the 2015 Quality of Death Report published by the Economist Intelligence Unit. Compare to many other countries or regions in the Asia-Pacific region, including Taiwan (position 6), Singapore (position 12), Japan (position 14) and South Korea (position 18), Hong Kong is lagging behind and was ranked relatively low in the palliative and healthcare environment category in terms of spending on healthcare and policy evaluation, and the capacity to deliver palliative care services. Furthermore, Hong Kong ranked only at position 38 in the category of community engagement in terms of public awareness of palliative care and availability of volunteer workers for palliative care. These indexes have indicated that there are rooms for improvement in palliative cares services in Hong Kong.

## 4.1 Legislation on palliative care

Hong Kong is a relatively high-income city but performed more poorly than low- to middle-income countries such as Panama and Mongolia in terms of healthcare spending, research and capacity to deliver palliative care services. As mentioned above, SWD and HA are involved in improving and expanding palliative care service but legislation and system are not comprehensive. In Colombia, palliative care services are provided to patients with terminal, chronic, degenerative and irreversible conditions under a law enacted in 2014, which protects the patients' right on the access of the service and clearly outlined the obligation of the government and health authorities throughout the country (Leon, 2014). Meanwhile, Mongolia has included palliative care in its health and social welfare legislation and national cancer control programme by requiring all medical schools and social workers to receive palliative care training (Lim, 2016).

# 4.2 Qualified specialists

Registered nurses in Hong Kong are required to have at least 16 practice hours in oncology nursing and palliative care, which is the least practical time by comparing to other areas (The Nursing Council of Hong Kong, 2016). For those who are interested in palliative care, they can take postgraduate courses in tertiary institutions or symposium, or work in palliative care units to gain experience. Up to 2011, there were around 300 nurses engaged in the provision of palliative care (Chan, Lee, Woo and Yi, 2017). As there is no specialty registration in palliative care for nurses, Hong Kong Palliative Nursing Association was established in 1997 with 92 registered hospice nurses and promote hospice development. For registered doctors, they are required to pass a clinical examination with four years of advanced training of clinical oncology and palliative training in either the general physician or clinical oncology stream. There are 49 specialist palliative care physicians in Hong Kong (Yamaguchi et al., 2017), while palliative medicine is considered as a subspecialty and there are currently only 22 registered specialists in palliative medicine (The Medical Council of Hong Kong, 2018). In comparison, Australia and Taiwan have 300 and 562 palliative care physicians respectively. Hence, Hong Kong has a relatively low number of qualified specialists in Asia. The Quality of Death Report in 2015 commented that unlike Australia and Germany, where there are also voluntary hospice workers, Hong Kong has a shortage of supporting professionals in palliative care, such as psychologists and social workers.

# 4.3 Community engagement

In Hong Kong, the general public have limited knowledge and awareness of palliative

care services. They have even misunderstood the terms 'palliative care' as abandoning the patients and just leaving the patients to wait for death. The scoring for public awareness on palliative care was only 2 out of 5 in Hong Kong (Economist Intelligence Unit, 2015). It might be due to the Chinese traditions, and people find it hard to face and hence, avoid talking about death. However, at the same time, there is limited information for people to access through communities or even government portals. Therefore, it is important to build community and professional networks to promote palliative care and to encourage the public openly discuss about death and dying. In Costa Rica, it has developed an extensive network of day care centres and volunteers on palliative care service (Pastrana, De Lima, Wenk, Eisenchlas, Monti, Rocafort and Centeno, 2012). Spain has also implemented an integrated model that allows volunteers to receive training and get involved in fundraising. In the United Kingdom, the National Council for Palliative Care has established the Dying Matters Coalition to help raising public awareness of palliative care through community activities and events such as advertising on posters, distributing leaflets and DVDs, and promoting online (The Economist Intelligence Unit, 2015).

### 5 POLICY RECOMMENDATIONS

# 5.1 To establish a guideline to assess the needs of palliative care

To identify patients in need of palliative care accurately, a guideline with criteria assessment is needed to allow the medical team to screen patients for unmet palliative care in advance. Two assessment guidelines, assessment at the time of admission and assessment during day hospital should be developed (Weissman and Meier, 2011). Both guidelines should be divided into primary and secondary criteria to screen patients at basic needs and high likelihood of palliative care needs respectively. In assessment during the admission, the primary criteria should assess patients' frequency of admissions to the hospital, complexity of the care requirements, decline in body function and so on, while the secondary criteria should assess patients' admission from long-term care facility, age of patients, cognition condition, availability of social support, chronic disease and so on. During the hospital day, primary criteria should include difficulty of controlling physical or psychological symptoms, length of staying in intensive care unit, disagreements or uncertainty among patients, staff etc. Secondary criteria should assess transplantation of solid-organ, emotional or spiritual distress of patients, family etc. With a well-developed guideline, the medical team can respond effectively upon identification of issues and initiate referrals to doctors specialised in palliative care for consultation. Thus, the patients benefit from adequate management of pain and symptoms, and emotional, spiritual and social issues in advance.

## 5.2 Expanding professional education and training

Education on palliative care curriculum should be expanded and made compulsory in the training of health professionals. Currently education opportunity in palliative care is limited to the diploma and workshop provided by the University of Hong Kong School of Professional and Continuing Education and School of Continuing and Professional Studies of The Chinese University of Hong Kong. For nurses, apart from certificate programmes provided by the Hong Kong College of Gerontology Nursing and Hong Kong Association of Gerontology, more certification programs for both hospice and palliative care nurses should also be provided. Moreover, the Hong Kong government should enable nurses to be formally registered as specialised nurses in palliative care instead of being diploma and certificate holders. These measures will increase the incentives for professionals to work and develop in this field and to position themselves in their career.

There should be on-the-job training courses on improving communication skills and how to handle the topic of death with sensitivity and patients' needs. Doctors, nurses, social workers and other staff in hospitals should discuss EOL issues and palliative care service with patients and their family members during early hospitalisation period, but not at the very late stage of illness. They should be trained to identify the right timing to initiate referral to avoid any delay and to explain the care and treatment options clearly to patients and their family. In particular, such training should be promoted to specialties and units that are not interested in, or having low awareness or inadequate knowledge on palliative and EOL care.

## 5.3 Improving public knowledge and education

To clarify the concept of palliative care service and to avoid misunderstanding, the government should actively promote palliative care service to the public through regular talks, workshops and seminars in the community. In local hospitals, posters and leaflets about palliative care services should be displayed in order to let patients and their relatives obtain, understand and use information of the service. On the other hand, family members of patients often play an active role in making health-related decisions including medical treatment as they would want to prolong patients' life by all means. There are patients who would rather refuse discussing future care with family members to avoid tension.

Through education at schools and community activities, students and the public can learn how to respect the wish and preference of the patients and other people, some of whom may not want others to make the decision for them based on their own value. People can also learn to accept death as part of life and the ways to choose the right heath care services. To

encourage more people to talk about death and bereavement in the society, organising Death Cafes can allow participants to freely voice about their views and concerns over death with one another. Moreover, talks about different cultural perspectives on death can also educate the public to have a wider view on death.

## 5.4 Increasing funding on palliative care service

Since expenditure on public and private health care in the Hong Kong is only about 5.8% of the Gross Domestic Product (GDP) in 2017/2018 (Hong Kong's Domestic health Accounts, 2019), compared to other countries like Japan (10.7% of GDP) and United Kingdom (9.6% of GDP), the proportion for palliative and EOL care expenditure is relatively limited. Palliative care and EOL investment should not be set in a low priority. The government should provide sufficient funding on palliative care service by increasing the supply of specialists and facilities such as hospices and RCHEs.

A department responsible for palliative care in public and private hospitals should be setup to manage patients' referrals and communication between different healthcare and social services sectors. In addition, equipment such as vehicles and medical instruments for patient transferal service should be provided. Palliative care service should not only rely on the provision by HA but should be widely expanded to include NGOs and the private sector. Instead of one-off funding, continuous funding and charity programme to NGOs can support them to provide sustainable service in the community as well as designing a caring environment in patients' wards and arranging more home visits by care providers.

## 5.5 Research on palliative care

Research incentive is another area to be improved in palliative care. Research related to effects and impacts of palliative and EOL care services on patients and their family members have always been limited. Local data collection is important as data from other countries may not be applicable or culturally appropriate. Therefore, the government should provide research funding schemes and facilitate the setup of research centres in order to analyse the demand and supply of palliative care, and facilitate new interventions to improve the quality of service in the community. Organisations and hospitals can encourage patients and their family members to participate in research studies by providing them with clear explanation on ethics issues and informed consent.

### 6 CONCLUSION

Palliative care service in Hong Kong is becoming more comprehensive and diverse with the help of HA and NGOs. However, when comparing with other countries, Hong Kong is still lagging behind to meet international standard in palliative care. As reported by the Economist Intelligence Unit, Hong Kong was at low positions in terms of spending on healthcare and policy evaluation, and the capacity to deliver palliative care services, and public awareness of palliative care. With the growing ageing population and prevalence of chronic diseases, there is a service need to develop long-term care planning on palliative care system involving the government, hospitals, hospices and palliative specialists.

The most recent public consultation concerning EOL legislative proposals launched by The Food and Health Bureau (FHB) is to revise the current common law position in respect of AD. With a more comprehensive legislation on AD, conflicting regulations can be avoided and patients' right and interest on dying in place can be respected. The amendment of AD can also help to give an impetus on the development of more palliative day care centres, hospices and even palliative care home service as people may decide to remain at home when approaching the EOL.

Recommendations are given in the present review, including establishing an assessment guideline, increasing government funding and research, expanding education for professionals and the general public. Together with the advanced HA framework 2015 and the proposal on EOL legislations, further progress and improvement on the supply of palliative care should be achieved in the coming years.

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