

# HONG KONG'S GROWING NEED FOR PALLIATIVE CARE SERVICES AND THE ROLE OF THE NURSING PROFESSION

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## ABSTRACT

This viewpoint paper explores the growing emphasis and social need for palliative care from a global perspective, juxtaposed against the Hong Kong status quo and its increasing need for such services. It further highlights that the role of nursing within palliative care is central to patients receiving the best quality of care. Hong Kong's current delivery models are generally insufficient and can be improved by the adoption of five recommended policy changes, which reinforce the position of nurses as vital to creating a better service. These recommendations will enable nurses to take the lead in future palliative care delivery frameworks, enabling more efficient planning of future management of patients' pain and other symptoms, social, spiritual, or emotional needs that arise during assessment. Its value may extend to other countries and settings.

## KEYWORDS

Palliative care, Quality of life, End of life, Hospice, Recommendations, Health outcomes

## INTRODUCTION

Palliative care was first conceptualized nearly 50 years ago as an approach to health care delivery, underpinned by the core values of empathy and compassion for both patients and their caregivers. The World Health Assembly recently issued a call for its place within comprehensive lifetime health care to be reinforced. This paper responds to that call by investigating whether current means and modalities of delivering palliative care services meet the increasing need for such services in Hong Kong.

A Quality of Death (QOD) report prepared in 2015 revealed that the quality of End of Life (EOL) care in Hong Kong trails behind comparable countries and regions. [1] The report

assessed palliative care across eighty regions, including several in the Asia-Pacific. Taiwan was ranked 6th place, Singapore 12th, Japan 14th, South Korea 18th, and Hong Kong was ranked 22nd. Multiple factors contributed to this relatively low ranking including insufficient spending, flaws in policy, under-capacity, and lack of engagement with and knowledge of such services in the wider community. [2] The QOD report findings suggest that palliative and EOL care services in Hong Kong are due for reevaluation and overhaul.

In this paper, we formulate recommendations for changes to the palliative health care policy and provision in Hong Kong in response to the above-mentioned appeal by the

World Health Assembly (WHA) to cement palliative care within the health care continuum. [3]

## THE GROWING EMPHASIS ON AND SOCIAL NEED FOR PALLIATIVE CARE

A recent review of global studies on palliative care needs and experiences conducted on over 1.2 million older individuals found that non-beneficial treatments had been administered to 33% to 38% of patients during their last six months of life. [4] This situation aligns poorly with the World Health Organization (WHO) definition of palliative care as:

an approach that improves the quality of life of patients [adults and children] and their families facing the problem[s] 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, and spiritual. [5, p. 5]

Hong Kong's first hospice services were established in 1982, and the model of hospice care has since served as a launchpad for a wider palliative care provision. Over the past few decades, palliative care in Hong Kong and elsewhere has left behind the EOL bunker and widely permeated the health care system. It is now a routine part of the treatment of disease at an earlier stage. [6]

According to WHO estimates, only 14% of the 40 million current EOL patients requiring palliative care receive it. [5] In this context, the WHA resolved in 2014 that greater emphasis should be placed on palliative care within the comprehensive health care that is delivered "throughout the life course". [7] The Assembly called on member states to study the development, reinforcement, and implementation of palliative care at all levels of health care delivery, a call for action reflected in the "Strategic Service Framework for Palliative Care" drawn up by the Hospital Authority (HA) of Hong Kong in 2017. [8]

Improvements in the provision of palliative care differ across health care systems. The US health care system, for example, has overseen a rapid improvement in provision of palliative care services for EOL patients: whereas palliative care teams were employed by only 25% of US hospitals with over 50 beds in 2000, that proportion had risen to 75% by 2015. [9] Data on terminal cancer patients in Hong Kong for 2012 and 2013 show that around 68% were given palliative

care [8] and palliative programs have been systematically made available to patients in the advanced stages of other diseases since 2010, principally those with neurodegenerative conditions (e.g., motor neuron disease), heart failure, end-stage renal failure, and advanced chronic obstructive pulmonary disease. Similarly, findings of a cohort review commissioned by the Central Committee on Palliative Care of the HA suggest that 44% of end-stage renal-failure patients were offered palliative care. [8] Despite these encouraging figures, however, gaps remain in provision. In particular, patients suffering illnesses that are non-malignant but nevertheless life-limiting (for example, advanced heart failure) have little access to such care—a serious consideration given the aging population.

## THE CONTEMPORARY SYSTEM OF PALLIATIVE CARE SERVICE IN HONG KONG: AN OVERVIEW

Presently approximately 360 hospice beds across 16 HA-run hospitals offer the full range of palliative care programs, from symptom control through counseling for EOL patients and their caregivers and family members. [9] Given that the population of Hong Kong was 7.41 million in 2017, this provision works out to approximately 4.8 inpatient hospice beds per 100,000 residents. The number of HA beds is almost matched by those provided by voluntary and charitable organizations. The Haven of Hope Christian Service runs 124 palliative-care and hospice beds, while a further 30 mixed public/private beds are sponsored by the Jockey Club Home for Hospice and run by the Society for the Promotion of Hospice Care. The largest non-HA provision is made by the Hong Kong Anti-Cancer Society Jockey Club Cancer Rehabilitation Centre, under whose auspices 180 beds are made available for cancer or other seriously ill patients. [10]

As of 2011, the palliative care sector in Hong Kong employed approximately 300 nurses. [11] Palliative care nursing is not a compulsory module in nurse training programs, so nurses who wish to take up this specialization are required to take postgraduate or diploma courses, such as the program in palliative care nursing accredited by the HA Institute of Advanced Nursing Studies, a diploma in oncology and palliative care for health care professionals, or a higher diploma in community health care for older patients. Other organizations working in the sector, such as the Hong Kong Anti-Cancer Society, the Society for the Promotion of Hospice Care, and the

Federation of Medical Societies of Hong Kong, also run palliative care training workshops. [12]

Palliative care is categorized by setting, with the four principal types being inpatient, outpatient, home, and day care [13], each of which is recommended for particular patient groups.

- Patients with symptoms ranging from moderate through serious/unstable are recommended for inpatient care in the form of daily treatments carried out in hospitals or, when resources permit, nursing homes or other facilities. Rehabilitation treatment is part of inpatient palliative care programs for patients in the later stages of illnesses, aimed at enabling them to maintain daily living activities for as long as possible. Inpatients in acute units are visited by medical staff from the specialist palliative care team for support and consultation.
- Post-discharge outpatient care can be provided for patients whose symptoms are stable, as well as for late-stage patients who require specialized treatment and those with psychological issues.
- Home care is for patients who are too weak to attend outpatient clinics, and is delivered by teams who visit the patient's home to offer consultancy, therapy, and monitoring, while also giving sensitive support and counseling to caregivers and other family members preparing for a death at home. This aspect of the service continues after the patient's death, when necessary.
- Day care is for patients whose symptoms are stable but require daily monitoring, and encompasses counseling, psychological support, and social activities aimed to promote QOL. Day care facilities frequently operate as resource centers for caregivers seeking information or medical equipment.

Palliative care provision in Hong Kong is growing, both in terms of the number of beds available and the range of services delivered. However, Hong Kong continues to trail behind to comparable regional economies. The QOD Index, which was developed by the Economist Intelligence Unit, further observed that Hong Kong's spending on health care and policy evaluation was relatively low. Moreover, public awareness remains limited. Yet, given the demographic changes whereby the proportion of older adults within the population is continuing to grow, as well as the prevalence of chronic diseases, there is a clear requirement for long-term palliative care planning from all

stakeholders, including the government, hospitals, hospices, palliative specialists, and the community.

Moreover, the above overview has highlighted the fragmentation of the current system of palliative care in Hong Kong: care is provided by a range of individual organizations with limited capacity, with little cooperation noted between public- and private-sector providers. It is therefore recommended that policies be formulated addressing issues including financial support, training, how to engage the community, and the wider culture within which palliative care is embedded in order to facilitate improvement and standardization in provision.

## **RECOMMENDATIONS FOR CHANGES TO PALLIATIVE HEALTH CARE POLICY: STRENGTHENING THE ROLE OF NURSES IN THE DELIVERY OF PALLIATIVE CARE**

The fundamental principles of palliative care involve both multi- and interdisciplinary approaches to holistic care. Palliative teams consist of diverse professionals who possess specialist skills. They operate under the shared goal of enhancing the quality of life of patients who are suffering from serious illnesses by providing psychological, medical, and practical assistance. They work closely with both the patient and his or her family members and caregivers. While the composition of a palliative care team will vary from region to region, the majority of teams consist of the patient and his or her family and caregivers, palliative care nurses, physicians, social workers, pharmacists, appropriate religious representatives, health clinicians and complementary therapists.

Palliative care nurses facilitate a multi-disciplinary approach to caring for the patient. First, they instruct, expedite, and model thorough palliative care evaluations, making sure that the goals of care, any advance care planning requirement, and the end-of-life care planning is performed in a timely manner. In addition, they assist in synchronizing suitable and well-timed care in the locations at which the care needs to be delivered; for instance, in a hospice, home, residential, or hospital setting. Palliative care nurses undergo dedicated training to develop enhanced communication skills and have the expertise required to administer complex symptom management. They spend the majority of their working time directly caring for a patient. As such, they are ideally placed to offer additional members of the palliative care team informed insights into the needs of the patient and the family.

Palliative nurses are also able to foster a strong relationship of trust and support between medical professionals and the patient and his or her family members and caregivers. This can serve to enrich the quality of life in various care settings. Nurses can also delineate which patients may require hospital admission to assist with the management of symptoms. By collaborating with professionals from various medical fields, palliative care nurses ensure that any modifications to the care plan are documented, and all relevant professionals are kept informed of any changes. This helps to ensure the patient's condition is managed in a smooth and consistent manner.

Reinforcing the professional, advocacy, and communication skills of nurses within the provision of palliative care will be a vital part of ending fragmented service delivery. Moreover, nursing practice within palliative care delivery already draws on the ethical principles and values embedded in the code of the American Nursing Association. Inter-setting, inter-disciplinary, and inter-level collaboration among nurses and their partners in multi-disciplinary care teams must be encouraged and leveraged, given the abundance of expertise available in the nursing profession. Nursing care, like palliative care, takes a holistic approach to patients' and caregivers' needs, which encompasses physical, emotional, and spiritual aspects of wellbeing. Furthermore, due to the nature of their practice, nurses are positioned to note changes in health status, which suggest palliative care should be initiated. The recommendations laid out in the next sections will enable nurses to take the lead in future palliative care delivery frameworks.

### Establishing guidelines to assess palliative care need

Several steps are necessary to develop and implement a new and improved delivery framework for palliative care, including public consultation and the approval of high-level directives. Specifically, screening criteria must be formulated to guide nursing teams in drawing up palliative care plans in anticipation of need. It is recommended that assessment should be carried out twice: first, when patients are admitted and again, during hospitalization. [14] Guidelines for these assessments are necessary, with screening criteria classified as primary (basic needs) and secondary (high probability of requiring palliative care). During the initial assessment under primary criteria, nurses must assess: inter alia, frequency of hospital admissions, complexity of care requirements, and decline in body function. Secondary criteria call for assessment of: inter alia,

age and cognitive function, whether patients have been admitted from a long-term care facility, social background to determine support available, and presence of chronic disease.

During the second assessment, primary criteria must include: whether patients struggle to control physical and psychological symptoms, whether they have been admitted to intensive care and for how long, and the occurrence of professional or familial conflict or uncertainty in patients themselves or their caregivers. Secondary criteria during this later assessment range from organ transplantation through emotional or spiritual distress displayed by patients and their loved ones.

Devising robust guidelines of this nature will enable nursing teams to take timely action when issues are identified in triage patients according to their palliative care needs, including referrals to specialists. This will allow for more efficient planning of future management of patients' pain and other symptoms, as well as any social, spiritual, or emotional needs and issues that come to light during assessment.

Given the nature of their role and practice, and the fact they are present across most health care settings, nurses are the natural advocates of palliative care. Indeed, they are already professionally trained in advocacy, being the representatives and communicators of patients' needs and wishes within multi-disciplinary teams, a role which increases in importance the more serious the condition of the patient concerned. Equally, they are frequently the members of the care team who explain and discuss treatment options with patients and caregivers. Knowledge of advance care is not yet widespread among patients or in the wider community, and nurses are best placed to inform patients and their families of the options available, discuss their relative benefits, and talk through any concerns about medical, practical, social, or psychological issues.

### Expanding professional education and training

It is also recommended that a palliative care module should be made a compulsory part of nursing training. Currently, health care workers interested in working in this field must take diploma courses or training workshops run by the University of Hong Kong School of Professional and Continuing Education and the School of Continuing and Professional Studies of The Chinese University of Hong Kong. The Hong Kong College of Gerontology Nursing and Hong

Kong Association of Gerontology certificate programs offer a model for hospice and palliative care nurse training which should be expanded. Moreover, a government-approved register of specialized palliative care nurses should be created to replace the current system of lists of diploma and certificate holders. This professionalization of the sector would make it more attractive to health care personnel and thus aid its expansion and further development.

Moreover, on-the-job training courses are recommended, which should focus on communication skills and advise on how service providers can most sensitively address the issue of death with patients and their families. Nurses should be trained to initiate and guide discussion with patients and families on EOL issues, including the provision of palliative care services, when patients are first hospitalized, rather than leaving such discussions until the illness has reached a very advanced stage. Moreover, training should equip nurses to identify the right moment for referral to palliative care specialists, and clearly explain the care options available. This type of training would be of particular value to those specialist areas and care units that currently show little engagement with or knowledge of palliative and EOL care.

### Improving public knowledge and enhancing patient education

It is necessary to engage the public in discussions of palliative care in order to deal with any fears and misunderstandings and encourage earlier and wider engagement with the sector. To this end, government-level promotions are encouraged, which could take the form of public talks and workshops in the community and disseminate information and messaging via social media. A prominent display of posters, educational leaflets, and links to further resources at community hospitals would be a useful first step to ensuring that necessary information reaches patients and their relatives.

It should be remembered that relatives are frequently involved in discussions about health care options and may well press for medical treatment in an attempt to prolong their loved one's life. Making palliative care training a compulsory part of nurse training and publicizing palliative care options in community settings may encourage both nursing trainees and the wider public to elicit and respect patients' own wishes and priorities around EOL care. It can also help shocked or grieving loved ones accept that death is a part of life, and that medicalizing the process of

death, or prolonging life at all costs, is not necessarily the best option. "Death Cafes," which are organized non-profit organizations in many regions and countries, invite participants to talk openly about death and grief, and to voice their concerns and fears. Organizing public talks on other cultures' approaches to bereavement and death can also foster discussion and widen perspectives on the place and value of palliative care.

Communication lies at the heart of palliative care provision and nurses offer a pool of skilled communicators who can bring empathy and knowledge to discussions with patients and their loved ones regarding prognoses, care options and goals, advance care planning, and other issues raised by advanced disease and the prospect of death. Leveraging the intimate knowledge of patients that they gain through their practice and the sphere in which they work, nurses are the best practitioners to communicate supportively, conveying difficult and complex medical information in the most appropriate and sensitive way and listening to the concerns and values of all involved. Hence, nurses able to assess palliative care needs in advance are well placed to initiate the necessary discussion of goals and treatment options.

### Increasing funding for palliative care services

In 2017/2018, health care funding in Hong Kong across both public and private sectors amounted to only 5.8% of Gross Domestic Product (GDP) [15], in contrast to the 10.7% and 9.6% of GDP respectively devoted by Japan and the UK to health care. Moreover, the proportion of health care expenditure in Hong Kong allocated to palliative and EOL care is small. This paper proposes that this type of specialist care should be made a policy priority and its proportion of funding should be increased to enable the expansion of specialist personnel and facilities.

It is recommended that all private and public hospitals should have a special palliative care department to oversee patient referrals, manage communication among multiple medical and social care stakeholders, and deploy the necessary infrastructure, including transport for patient transfer. HA provision of palliative care services should be complemented by non-profit organizations as well as the private sector, and funding must be made systematic and system-wide, rather than ad hoc and small-scale. These changes could enable the various actors involved to provide sustainable services to care for and bring comfort

to patients at home and in hospital or other health care facilities.

### Promoting nursing research on palliative care

A final area of improvement within palliative care is nursing research, which should be actively encouraged and incentivized. Currently, there is scant data on the effects of both palliative and EOL care on patients and caregivers, and much of the limited research available has been conducted in contexts where findings may not be generalizable to Hong Kong. Hence, it is recommended that the Hong Kong government funds and encourages systematic local research into supply, demand, and impact, with a view to enhancing current service delivery, and fostering innovative change to enable improvement.

## CONCLUSION

The centrality of nursing within palliative care rests on the nurse being a skilled coordinator across all levels of the health care system. The nurse communicates between and connects all medical practitioners involved, as well as the patient and their caregivers, hence playing a vital role in ensuring each patient receives the best quality of care. Although a range of nursing skills is called on in the provision of palliative care, it is this central position and skillset which suggest that nurses are best situated to deliver its primary aspects, such as communication, advocacy, and symptom management.

Given the growing proportion of older adults in the population and the prevalence of chronic disease, nurses' position must be reinforced as a key element in the provision of palliative care. As Hong Kong's provision of such care expands to include more patients at earlier stages and with more types of disease, the current delivery models are insufficient. With the current delivery system flawed by fragmentation across multiple small-scale operations and both public- and private sector provision, reinforcing the vital role played by nurses can boost positive health outcomes and create a better service. This development can be promoted by adopting these policy recommendations: (1) establishing guidelines that will ensure that palliative care needs are appropriately and accurately assessed; (2) expanding and enhancing the professional education and training that is currently available in this area; (3) developing and implementing a campaign designed to enhance public knowledge and education; (4) ensuring adequate funding for palliative

care services; and (5) promoting and supporting nursing research in palliative care.

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## CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

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