CHAPTER 4

STRATEGIC SERVICE FRAMEWORK FOR PALLIATIVE CARE IN HOSPITAL AUTHORITY

The Hospital Authority

Palliative care (PC) is an approach that aims to improve the quality of life (QoL) of patients facing life-threatening or life-limiting conditions. PC emphasises alleviation of distressing symptoms (e.g. pain, shortness of breath), improves quality of care and supports a more peaceful dying process. Moreover, it helps families to cope during their loved one's illness and the bereavement period through a holistic and team approach.

PC services in Hong Kong are currently provided mostly by the Hospital Authority (HA) and are led by PC specialists under the specialties of Medicine and Oncology. In the past, HA PC services focused mainly on the care of advanced cancer patients. In the last decade, PC services have been gradually extended to cover patients with other diseases, such as end-stage organ failure (e.g. renal failure) and chronic obstructive pulmonary disease (COPD).

PC services offered by HA are provided by multidisciplinary teams of professionals, including doctors, nurses, medical social workers, clinical psychologists, physiotherapists, occupational therapists, etc. HA organises and coordinates its PC service on a cluster basis. Inpatient PC services provide care for people with complex conditions or people who are dying. A range of ambulatory PC services is also available, including outpatient clinics for the management of less acute and complex symptoms; day care services for rehabilitation and psychosocial care; and home care (community) services to optimise symptom control and empower informal caregivers. Families are also supported with bereavement care before and after the patients' death.

In recent years, HA has strengthened its PC service in a range of areas. For instance, HA has developed PC services for patients with end-stage organ failure, especially patients with renal failure, by working in collaboration with other specialty areas. PC day centres have been developed through collaboration with community partners to provide one-stop multidisciplinary care for patients living in the community. Psychosocial support and bereavement care have also been enhanced by strengthening the services provided by medical social workers and clinical psychologists.

To support terminally ill patients living in residential care homes for the elderly (RCHEs), Community Geriatric Assessment Teams (CGATs) in HA work with palliative care teams, as well as RCHE staff, to strengthen the care of RCHE patients at end of life (EoL) and to provide relevant training to RCHE staff.

BACKGROUND

DEVELOPMENT OF THE HA'S STRATEGIC SERVICE FRAMEWORK FOR PALLIATIVE CARE

In the Hong Kong context of a rapidly ageing population, coupled with a growing chronic disease burden, there is an urgent need to strengthen healthcare services to provide for increasing patient needs along the care pathway. To plan and further improve the quality and sustainability of HA's PC services, as well as to cope with increasing demand, HA proposed the Strategic Service Framework for Palliative Care (the Framework) in 2017. This was established to guide the development of PC services in the next five to ten years. As a consequence, strategic directions for improving adult and paediatric PC have been formulated.

The development of the Framework commenced in early 2016. With support from the HA Board and senior management, the Framework development entailed a wide-spectrum, consultative process within HA, covering all clusters, and the Head Office. A Taskforce and Working Groups were established to advise on future service models and system infrastructures that were considered to be imperative for adult and paediatric PC. Overall, a highly participative and broad engagement approach was adopted, with contributions from different clinical specialties and disciplines, cluster management, Head Office executives and patient groups.

Through the comprehensive review and consultation process, key areas for improvement of PC in HA were identified, which included the governance and organisation of services, care coordination, place of care and performance monitoring. With reference to international practices, local experience and advice gathered through the consultation process, the comprehensive Strategic Service Framework for Palliative Care was formulated.

FRAMEWORK STRATEGIES FOR ADULT PALLIATIVE CARE

The Framework recommends four strategic directions:

1. Enhance governance by dev nitoring for continuous quality improvement.

Under each strategic direction, strategies have been formulated with reference to identified areas of need or opportunities for improvement in order to address the service gaps and key issues. They are summarised in **Table 4.1** and discussed further in the next section.

Table 4.1 ***Summarising the HA Strategic Service Framework for Palliative Care***

AREAS FOR IMPROVEMENT	STRATEGIC DIRECTIONS (WHERE WE ARE GOING)	STRATEGIES (HOW WE WILL GET THERE)
Governance and service organisation	Enhance governance by developing cluster-based services with the collaboration of medical and oncology PC specialists	» Strengthen collaboration between medical and oncology PC specialists to develop cluster-based services » Reinforce the role of Cluster Coordination Committee on Palliative Care Services to support cluster-based service organisation
Care coordination	Promote collaboration between PC and non-PC specialists through a shared-care model according to patients' needs	» Stratify patients' PC needs for shared care » Integrate PC into the care pathway for early identification of patients in need and initiation of Advance Care Planning (ACP) » Strengthen specialist palliative consultative service in non-PC settings
Place of care	Enhance PC in the ambulatory and community settings to support patients and reduce unnecessary hospitalisation	» Refine and align PC day service » Expand palliative home care service » Enhance PC support to elderly patients in care homes » Enhance medical–social collaboration to support PC in the community
Performance monitoring	Strengthen performance monitoring for continuous quality improvement	» Enhance data collection with standardisation of data capture and alignment of measurement tools » Identify key domains and develop indicators for evaluation and monitoring of clinical outcomes and service quality

Enhance governance by developing cluster-based services with the collaboration of medical and oncology PC specialists. Enhancing the governance of adult PC services is the cornerstone of the overall service development. This is oriented at cluster-based service organisations to improve service accessibility and coordination of care.

Adult PC services in HA have traditionally been provided by PC teams located in 16 hospitals. The teams are led by PC specialists who are either from the Department of Medicine (medical PC teams) or the Department of Clinical Oncology (oncology PC teams). Collaboration between different PC teams is limited, and the accessibility to PC services is variable, particularly for hospitals without an in-house PC team. Due to the historical emphasis in HA on cancer patients, PC coverage for non-cancer patients has been less overall than that provided for cancer patients. Medical and oncology PC teams provide services to cancer patients, while non-cancer patients are generally provided for by medical PC teams.

At HA Head Office level, PC services come under the clinical governance of the Central Committee on Palliative Care, comprising members from medical and oncology PC teams (doctors, nurses and allied health). Moreover, at cluster level, Coordination Committees on Palliative Care Services have been established to oversee these services. However, there remains room to further strengthen coordination of different PC teams and service development at cluster level.

Recommended strategies include:

1. ***Development of cluster-based services through strengthening the collaboration between medical and oncology PC specialists.*** PC services are delivered through a coordinated network of both cancer and non-cancer patients in all cluster hospitals. This enables pooling of expertise and optimal use of resources and facilities for more accessible PC.
2. ***Reinforcing the role of the Cluster Coordination Committees on Palliative Care Services*** to support cluster-based service organisations and improve implementation, coordination and monitoring of PC services at the cluster level.

Promote collaboration between PC and non-PC specialists through a shared-care model according to patients' need. Care coordination is indispensable in PC, given that patients often receive care from different medical specialties based on their needs. However, the majority of non-PC specialist teams focus on providing disease management, and there may not be as much collaboration as there could be between PC and non-PC teams. The provision of comprehensive care near the end-stage of life thus heavily relies on PC specialist teams, which may limit patients' access to holistic and patient-centred PC. Moreover, there is generally limited awareness and knowledge of PC among non-PC specialists. As a result, referrals to PC teams are often made at the very end-stage of the patients' disease trajectory, which can affect the timeliness and accessibility of PC.

In order to improve EoLC, enhancing collaboration between PC and non-PC specialists and the integration of adult PC into the care continuum are important areas for further service development. Instead of simply adding a layer of specialist PC for every patient with a life-threatening or life-limiting illness, a shared-care model should be adopted, supported by training and skills transfer between specialties. The aim is to ensure the provision of timely and appropriate care according to the needs of patients and their families/carers.

Recommended strategies include:

1. ***Stratifying patients*** according to their PC needs and disease complexity, as well as the professional competency of the PC teams.
    a. The majority of patients who do not have complex PC needs should be managed by the parent team.
    b. Patients with complex PC needs but who also require disease modifying treatments should be co-managed by both the parent teams and PC specialists through consultative support, case conferences, joint clinics, etc.
    c. Patients with highly complex PC needs or difficult-to-manage symptoms, should be managed by PC specialists in a PC setting.
    d. Dynamic changes frequently occur in a patient's condition, as well as their level of need. Responsive referral and coordination mechanisms therefore need to be established to acknowledge and address the changing needs of patients and the appropriate level of care required.
2. ***Integrating PC into the care pathway.*** It is essential for early identification of patients in need of initiation of Advance Care Planning (ACP), regardless of the specialties of the care team. With training and skill transfer, healthcare staff working in non-PC settings should be better equipped to identify the PC needs of patients and their families/carers. ACP could be conducted by the parent teams to address patients' and their families/carers' needs and preferences.
3. ***Strengthening specialist palliative consultative service in non-PC settings*** is a key component of the shared-care model. It is instrumental in providing proper support to the parent teams and to facilitate skill transfer in managing patients with PC needs. It is also a priority to develop PC consultative services to support hospitals with no PC teams.

Enhance PC in the ambulatory and community settings to support patients and reduce unnecessary hospitalisation. Patients approaching EoL, especially in the last year of life, tend to have high utilisation rates of hospital services, such as Accident & Emergency attendances and acute hospital admissions, even though many of these patients may prefer to spend their last stage of life in a familiar environment. Acute hospitalisation can be stressful to patients and families/carers, and it also puts significant and potentially unnecessary pressure on the healthcare system. The lack of PC services in the ambulatory and community settings in the past potentially account for this situation.

It is therefore important for HA to strengthen ambulatory and community PC services. This will support patients and their families/carers to facilitate the provision of appropriate care-in-place of choice and reduce unnecessary hospitalisation. The emphasis should be on enhancing day care and home care, support to residential care homes, and community partnerships.

Recommended strategies include:

1. ***Refining and aligning the PC day service model*** across clusters to provide a "one-stop-shop" for integrated and multidisciplinary care. Service components should be refocused to provide more programme-based services and therapeutic procedures for symptom management.
2. ***Expanding palliative home care services*** with a cluster-based arrangement and adopting a case management approach to support both cancer and non-cancer patients. Collaboration between palliative home care nurses and Community Nursing Service (CNS) nurses should be strengthened under the principle of shared-care models.
3. ***Enhancing PC support*** to RCHEs through expanding the EoLC programme provided by CGATs, working in collaboration with the PC specialties and RCHE staff.
4. ***Enhancing medical–social collaboration*** with community partners, such as non governmental organisations (NGOs), patient groups and volunteers in order to better mobilise community resources and also to complement the PC services of HA for more holistic support to patients and their families/carers.

Strengthen performance monitoring for continuous quality improvement. At present, there are limited data on the performance and outcome of PC services in HA. Most information is captured manually and it is not standardised. Quality indicators are yet to be developed for systematic performance monitoring, benchmarking across units and for informing service planning. It is acknowledged that systematic monitoring of the quality and outcomes of PC services is instrumental to drive service improvement.

Recommended strategies include:

1. ***Enhancing data collection*** with standardisation of data capture and alignment of measurement tools. Apart from throughput data, other useful parameters should be identified, and data definition and collection mechanism should be standardised.
2. ***Identifying key domains and developing indicators*** for the evaluation and monitoring of clinical outcomes and service quality. Selection of key parameters for benchmarking could assist in driving service development and improving consistency in service provision among clusters.

THE FUTURE SERVICE MODEL FOR ADULT PC

Under the Framework, HA is moving towards realising the vision of providing timely, coordinated and holistic PC to patients and families/carers in need. Specialist adult PC services will be organised in a cluster-based arrangement, with strengthened governance through closer collaboration between medical and oncology PC teams. Timely and coordinated PC should be achieved through shared care between PC and non-PC specialists. PC is integrated into the care pathway of patients suffering from a life-threatening or life-limiting illness regardless of the specialties of their care team. Moreover, ambulatory and community PC services should be enhanced to support care-in-place and reduce unnecessary hospitalisation. Overall, performance monitoring should be strengthened to facilitate service improvement. The new service model of adult PC in HA is illustrated in **Figure 4.1**.

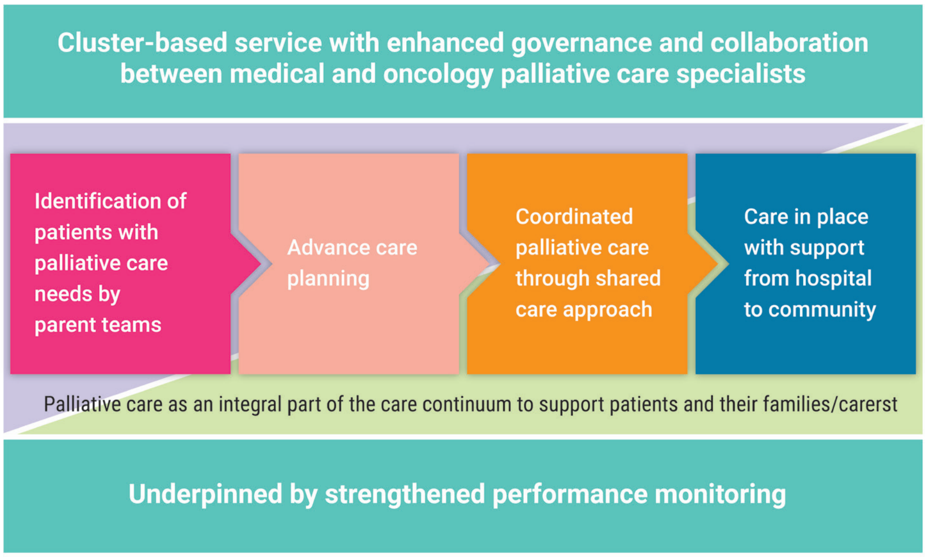

Figure 4.1 Future Service Model of Adult Palliative Care in HA

FRAMEWORK STRATEGIES FOR PAEDIATRIC PC

Specialist PC is currently not available in HA for paediatric patients. Children suffering from life-threatening or life-limiting illness are usually managed by a paediatric subspecialty team, which mainly delivers disease management. It may also manage the children's PC needs if required. Community support for these patients is generally limited, even though collaborations have been developed in recent years between paediatric departments in hospitals and NGOs to bridge service gaps. Overall, structured paediatric PC services are yet to be developed in HA.

The disease trajectories of paediatric patients facing life-limiting diseases are often very different from those of adult patients. The wide spectrum of serious paediatric illnesses, including inherited and congenital conditions, together with the fact that children are also growing physically, cognitively, socially and emotionally as they go through their illnesses, are particular features that increase the complexity of paediatric PC services. Moreover, as serious illnesses are not common among children in a developed economy such as Hong Kong, service demand and availability of specialised expertise for paediatric PC in HA is considerably lower than for adults.

Taking into consideration existing service gaps, factors limiting the development of paediatric PC and learnings from overseas experiences, a dedicated framework has been formulated to underpin the establishment of structured paediatric PC services in HA. There are three strategic directions for paediatric PC:

1. Establish territory-wide paediatric PC services in HA
2. Promote integrated and shared care with the parent teams
3. Enhance community support for children and families in need of PC

Establish territory-wide paediatric PC services in HA. A future service model for paediatric PC should include territory-wide paediatric PC services under single clinical governance. A centralised paediatric PC team should be established, led by paediatricians to coordinate the development of age-appropriate and family-centred care that caters for the special needs of paediatric patients facing life-limiting and life-threatening conditions. Services should be in the best interests of the children. The centralised team should work with the designated care team of doctors and nurses at regional level to provide comprehensive PC services oriented to the needs of children. The latter plays a significant role in coordinating care with community partners, special schools and local paediatric subspecialty teams, and also in the provision of palliative home care service in local communities. The centralised PC team should be based in the Hong Kong Children's Hospital. A continuum of paediatric PC services should underpin service delivery, covering inpatient, outpatient and home care support to schools and bereavement care.

Promote integrated and shared care with the parent teams. Paediatric PC teams should work closely as partners with paediatricians and other members in the parent teams who are managing the patient's condition. PC should be integrated into paediatric services, taking a shared-care approach to meet different levels of patient needs. Under the territory-wide service model, local care provision should be supported if patients and families wish to receive services at home or close by.

Enhance community support for children and families in need of PC. Children often prefer to be cared for at home when they are sick. Moreover, most families opt to care for their children at home if feasible. School is another familiar environment to children, providing a sense of reassuring rhythm to normal life with education and social life. As such, community-based services are an integral part of paediatric PC. Support and empowerment should be given to patients, their families and carers in schools to allow patients to live as fully as possible in their communities.

Paediatric palliative home care services should be further developed to support patients and families at home. In particular, support should be provided to special schools and residential schools. Training and skills transfer may be required for nurses who may serve as care coordinators, as well as school staff. Community partnerships for paediatric PC need to be strengthened. Relevant NGOs and patient groups should be engaged to provide complementary support to patients and their families. **Figure 4.2** summarises the future HA service model for paediatric PC.

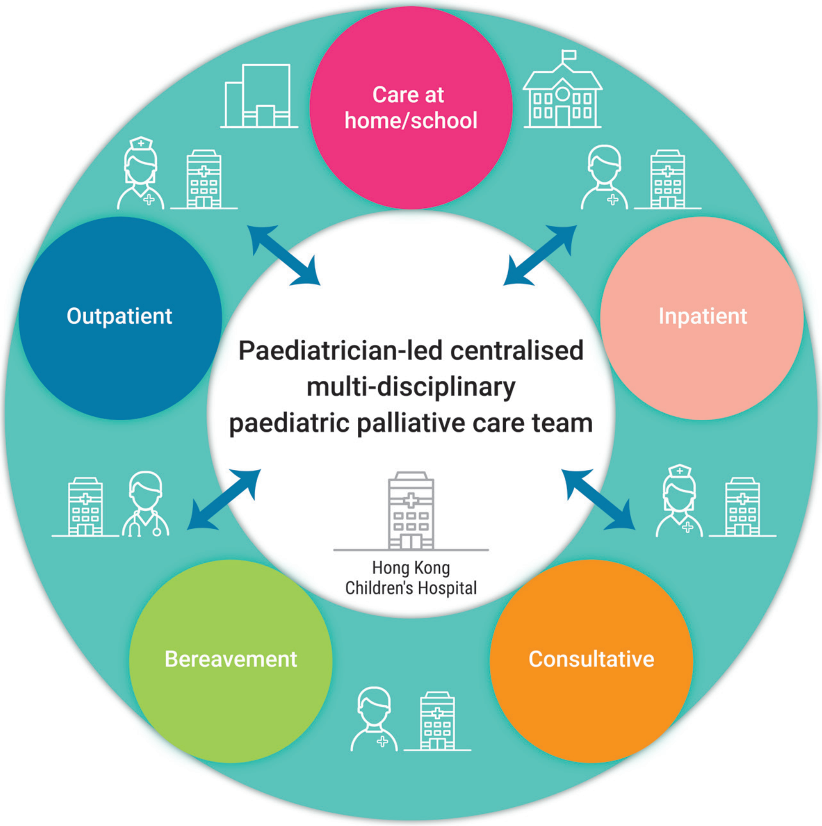

Figure 4.2 The Future Service Model for Paediatric PC

OTHER ORGANISATIONAL ISSUES REQUIRED AT BOTH ADULT AND PAEDIATRIC LEVELS

In order to facilitate the development of best practice PC service models and to support effective implementation of the Framework strategies for adults and children, a number of key enablers are essential. These include manpower and training, facilities, logistic support in hospital wards, information technology (IT) support and transport.

MANPOWER AND TRAINING

Training is fundamental to drive system and cultural change in integrating PC into the care continuum. It must be conducted by taking a systems approach and by targeting healthcare staff from both PC and non-PC settings, with collaboration between HA, academia and professional organisations.

First, basic training for all healthcare staff across disciplines and specialties is required to raise general knowledge and awareness of adult and paediatric PC. It covers the basic principles and ethical concepts of PC and ACP, as well as communication skills and practical care to enable patients to be supported along their disease trajectory.

Second, more advanced training is needed for non-PC teams working directly with adults and children who are suffering from life-threatening or life-limiting illnesses. Emphasis should be placed on skills transfer to enhance the competency of the teams to provide shared care with PC teams. Training should be focused on developing skillsets to initiate ACP discussions, symptom management and bereavement care.

Third, specialist training programmes should be consolidated to provide specialist PC services system-wide. These are provided by the Hong Kong College of Physicians and the Hong Kong College of Radiology for the training of medical and oncology PC subspecialties, respectively. For nurses, the Institute of Advanced Nursing Studies in HA organises a Post-Registration Certificate Course in Palliative Care Nursing. There are also designated training programmes for allied health professionals working in PC settings, coordinated by HA's Institute of Advanced Allied Health Studies.

In addition to this, however, detailed workforce planning is vital for doctors, nurses and allied health professionals to enable them to meet the escalating service demand. A cluster-based perspective of workforce planning and deployment is required to support the cluster-based Framework. Manpower standards must be established for inpatient, ambulatory and community PC to inform service planning and resource allocation. As well as manpower strength, reporting lines and career paths for professional development are also important areas for consideration.

FACILITIES

The physical design of environments in which to deliver adult and paediatric PC should be incorporated into hospital development and redevelopment projects in HA. Home-like, peaceful and soothing environments are essential design principles for PC facilities to relieve stress and improve patients' and families' perception of the quality of care.

It has been suggested that single rooms for patients approaching EoL provide more privacy. Moreover, interview rooms where patients and families/carers can engage in more intimate discussions should be made available if possible in both PC and non-PC settings in all hospitals. The design of mortuaries is another area to be improved on. This will affect the experiences and memories of patients' families/carers. Modernisation of the overall design of mortuaries is also required to better suit operational workflow and the needs of families/carers.

In addition to the design, capacity planning covering inpatient and ambulatory facilities for PC should be put in place to cope with projected service demand. This needs to take account of changes in the service Framework. The Central Committee on Palliative Care should work with cluster management to align future planning to the Framework.

LOGISTIC SUPPORT IN HOSPITAL WARDS

The logistics and operations of hospital wards should be designed to cater for the needs of patients and their families/carers. Consideration should be given to individual patient's conditions, including their psychosocial and emotional needs, especially during their last phase of life. For instance, flexible visiting hours should be considered so that patients can spend more time with their loved ones. Arrangements can also be made for families/carers to stay overnight with patients, if hospital operation allows.

IT SUPPORT

Better IT support is required to enable implementation of the Framework. IT systems need to be enhanced to support workflow, communication and care coordination across disciplines, specialties and care settings along the PC journey, especially between PC and non-PC specialists, as well as between home care teams and CGATs. Establishing a common platform to document ACP is also important for clinical communication and ongoing reviews. A database of PC patients is required to identify patients, document care management and monitor performance at both clinical and system levels. Furthermore, the development of tele-care, mobile apps and website support should be explored to support care-in-place and empower patients and families/carers.

TRANSPORT

In line with the development of better and more streamlined ambulatory care, transportation support for patients such as Non-Emergency Ambulance Transfer Service (NEATS) must be strengthened. This will help patients attend day care programmes more easily and use day services better. Moreover, transportation support is also important to facilitate hospital discharge and the transfer of patients between hospitals or to RCHEs.

SUMMARY

PC is an integral part of the care continuum. All patients facing life-threatening or life-limiting conditions, and their families/ carers, should receive timely, coordinated and holistic PC to address their needs. They should have greater participation in planning their care, be aware of the choices they can make and have the best possible QoL until the end of the patient's life journey. The HA Framework outlines strategies to achieve this vision.

The Framework strategies will be implemented in stages and will consider the service needs and organisational readiness at both clinical and cluster levels. Short, medium and long-term implementation plans have been developed and will be executed under the leadership of the Central Committee on Palliative Care. For those strategies that require additional resources, these could be sought through HA annual planning processes to support implementation. Many changes have already begun, and these will continue with the momentum generated from the processes taken to develop this Framework and through the concerted efforts of all in HA.