"Fostering Medical-Social Collaboration in Achieving Quality End-of-life Care"

Executive Summary

People are living longer, but not necessarily better

With a laudable life expectancy that ranks top in the world, Hong Kong's population is ageing rapidly. Greater longevity and the steep increase in co-morbidity in the elderly population has called for increased territory-wide attention on not just the quality of life, but also of death.

In 2018, Our Hong Kong Foundation ("OHKF") published the research report "*Fit for Purpose: A Health System for the 21st Century"* that advocated for the urgent need to reorient our currently hospital-centric, treatment-focused health system towards an integrated, primary care-led system (OHKF, 2018). In stressing the importance of care and not just cure, we emphasise the need to take a holistic approach in health service provision that should address the multidimensional needs of individuals throughout the entire life course; including the final stages of life.

Whilst **palliative care**, a concept that embraces **end-of-life care** (EoLC), is affirmed by the World Health Organization (WHO) as a core component of health systems (WHO, 2016), Hong Kong is clearly under-performing. In the "Quality of Death Index" launched by *The Economist* in 2015 that measures the quality of palliative care, Hong Kong was ranked 22nd of 80 selected countries, the lowest amongst its Asian counterparts including Taiwan (8th), Singapore (12th), Japan (14th) and South Korea (18th) (The Economist Intelligence Unit, 2015a). In particular, Hong Kong's score in the sub-category "community engagement" that assesses the level of discussion and awareness of end-of-life choices in communities, was below the global average of 80 countries (The Economist Intelligence Unit, 2015b).

OHKF recognises the continuous efforts of local institutions in both the public and private healthcare sectors in advancing palliative and end-of-life care services in Hong Kong. OHKF also acknowledges the Government's latest public consultation on EoLC (Food and Health Bureau, 2019) as a good effort to push end-of-life care development forward in Hong Kong.

Building on an expansive local literature in the past decade that has already revealed the palpable need to reinforce EoLC development, OHKF takes a progressive approach to explore views held towards EoLC in the community, specifically through the lens of potential EoLC service end-users reached in a telephone polling exercise. The polling, commissioned by OHKF and conducted by the Hong Kong Institute of Asia-Pacific Studies at The Chinese University of Hong Kong, was executed through telephone interviews with 1,001 Hong Kong residents between 26 November and 6 December 2019. Through understanding public perception and practice related to end-of-life care services in local communities, this study concludes that focusing on EoLC at a community level is vital not just for

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moving towards a more sustainable health system but importantly, for facilitating a better, and more dignified end-of-life journey for Hong Kong citizens.

Study Highlights (1)

A demonstrated need to enhance public education and advocacy on "end-of-life care"

Survey Questions

End-of-life care remains an ambiguous concept to most people in Hong Kong. According to the study, **55.1%** of respondents regarded themselves as having limited, little, nil or uncertain confidence in managing EoLC and its associated arrangements. Respondents also had a vague understanding of EoLC components. "Funeral assistance" proved to be the most understood component, to which **63.6%** of respondents responded positively; the other most-acknowledged EoLC parts being psychological counselling (**58%**) and social support (**43.7%**). While methodologies of EoLC have historically accentuated an integrated approach which encompasses physical, psychological, social and spiritual support. While most respondents proved to have some understanding of EoLC, most people in Hong Kong do not appear to be familiar with the vast and holistic scope of the concept. Instead, study findings point to a relatively disjointed understanding of EoLC and its individual components.

Q1

Q2

Findings also illustrate that sources of information on community EoLC services are scattered, where healthcare professionals in hospitals (**32.2%**) were found to be the most common channel of information dissemination. More concentrated efforts should be placed on public education and advocacy so that citizens will be able to understand the concept of EoLC and learn about related services in the community in a less fragmented manner.

Q9

Study Highlights (2)

Current end-of-life care services in communities have room for improvement, particularly in enhancing service comprehensiveness

At the time of study administration, only **23.4%** of respondents were able to identify end-of-life care service provision points in the community; of which **30.9%** had direct experience in using related services. The average service satisfaction score among users is a moderate **3.88** out of 6 where enhancing service comprehensiveness (**65.1%**), increasing promotional intensity (**48.2%**) and improving the performance of service providers (**42.8%**) were recognised by users as key elements that would contribute to the betterment of existing community EoLC services in Hong Kong.

Q3

Q4

Q5a

In contrast, a majority of respondents who had no prior experience in using EoLC services indicated reasonable price levels (**50.7%**) and accessibility of services (**45.9%**) as major considerations for future service acquisition. In comparison, service comprehensiveness becomes the most important consideration for past users of EoLC services. Reiterating the crux of this report, there is a need to review EoLC service provision at a system-level. Policies that lessen potential barriers on service

Q5b

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acquisition and enhance the motivation of our citizens to seek appropriate care that meet holistic needs should be in place.

Crucial factors to maximize end-of-life stay in the community include an enabling environment, and accessible support for individuals and families to facilitate end-of-life journeys. Such services exist but are fragmented, and our study further affirmed that people are largely unaware of available assistance in the community.

Understanding factors that will affect decisions to seek EoLC is also important in planning the expansion of related services. Respondents expressed multi-faceted needs when facing the final stages of life. For instance, **48.9%** of respondents stressed on the importance of a comfortable environment, **41.1%** indicated the significance of professional guidance and **38.0%** pointed towards the need for regular community healthcare services. We put forward that existing community initiatives should be scaled up in meeting the all-rounded needs of our citizens in handling end-of-life related matters. Q6

Study Highlights (3)

Sufficient support could realise wishes to stay in the community towards the end of life

Up to **86.1%** of respondents stated their preference for staying in the community [Note 1] until the end of their lives. When further reiterating the availability of sufficient community support, the percentage of people willing to stay in the community reached close to **90%**. This reveals public preference and readiness to receive community-based EoLC, and a promising opportunity to shift care burden from hospitals into the community. Findings substantiate the need to expand EoLC services, particularly at the community-level so that preferences of citizens are realised and concurrently, relief is brought to overstretched public hospitals. Q7

More than half of the respondents opted for relatives and acquaintances from non-religious affiliations as their most trusted type of personnel for non-medical EoLC support (**55.2%**). Healthcare professionals in the community were the next most popular option (**40.8%**), followed closely by hospital-based healthcare professionals (**39.6%**). However, a notable mismatch exists between preferred and actual channels of information on EoLC services; this was particularly noticeable for sources of support outside of hospitals and in community settings (**40.8%** vs **8.8%** for medical professionals in the community; **24.0%** vs. **12.8%** for social workers; **16.6%** and **4.8%** for religious acquaintances; and **30.8%** vs. **21.2%** for relatives or non-religious acquaintances). This further demonstrates that our primary care system has great potential for further development and that we are yet to optimise our utilisation of community resources to meet citizens' needs and expectations. Q8 Q9

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Conclusion: a holistic capacity planning blueprint and policy framework on end-of-life care is due

Hong Kong's elderly population will increase to one million plus (Census and Statistics Department, 2017) in the next twenty years. Rapid population ageing will see an emerging prevalence of caregivers, and a rising need for EoLC services in Hong Kong. Our study indicates that today, already **11.2%** of respondents needed to provide daily care to the elderly, or to individuals with chronic conditions within their own household. The role of caregivers will become increasingly prominent and the need for EoLC services will continue to rise. Q10

OHKF welcomes the current legislative proposal on promoting advance directives and dying-in-place in Hong Kong. Concluding our study findings, however, the key development areas of end-of-life care for the Government's reflection include: the lack of education and advocacy, the low engagement level of citizens in community end-of-life care services, as well as the fragmentation of current service provision.

Most importantly, it is evident to us that a solid vision and comprehensive policy framework should be devised in order to facilitate the realisation of a 'good death' in Hong Kong. Our health system shall take on a holistic approach in health service provision so that needs of individuals are consistently met throughout the entire life course; including the final stages of life. As we move towards a primary care-led, person-centred, integrated health system, community resources should continuously be leveraged upon as we shift care burden from our currently overstretched public health system into the community. Fragmented service provision should be overcome with policies that encourage integration throughout the system to enable the provision of quality, comprehensive and continuous care throughout all stages of life as we move towards a more dignified end-of-life journey for all Hong Kong citizens.

NOTE 1: The term 'communities' is understood as outside of hospitals, including nursing homes and individual homes.

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OHKF Phone Survey: Needs & Knowledge of End-of-Life Care in Communities

1. **Are you confident in handling end-of-life care and making end-of-life arrangements for yourself or family and friends? How would you rate your confidence on a scale from 1 (least confident) to 6 (most confident)?**

2. **Do you understand the following concepts related to end-of-life care? (can choose more than one option)**
   i. Advance directives
   ii. Dying in place
   iii. Symptom management
   iv. Psychological counselling
   v. Social support
   vi. Spiritual support (e.g. related to religion)
   vii. Funeral arrangement assistance
   viii. Do not understand any of the above

3. **Apart from hospitals, do you know where to seek end-of-life care services in the community you reside in?**
   i. Yes (jump to Q4a) ii. No (jump to Q5b)

4. **a. Have you ever engaged in or used available end-of-life care services in the community you reside in?**
   i. Yes (jump to Q4b) ii. No (jump to Q5b)

   b. Are you satisfied with your experience of end-of-life care services in your community? How would you rate your satisfaction on a scale from 1 (least satisfied) to 6 (most satisfied)?

5. **a. (For people with former experience) Which factor(s) contribute(s) to your dissatisfaction of end-of-life care services received in the community? (can choose more than one option)**
   i. Insufficient venues of service provision
   ii. Service hours are too short
   iii. Services are not comprehensive enough
   iv. Incompetency of service providers
   v. Over-priced services
   vi. Lack of service promotion and education
   vii. Others

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b. (For people without former experience / satisfied with current services) Which is/are the main factor(s) you will consider in your decision on whether to use end-of-life care services? (can choose more than one option)

i. Reasonable price
ii. Convenient access to services
iii. High familiarity with service providers
iv. One-stop shop service provision
v. Advice from professional personnel
vi. Fulfilling personal needs

6. What is/are the most important form(s) of support you need for you to handle end-of-life matters (for yourself or for family and friends)? (can choose more than one option)

i. Professional advice on end-of-life arrangements, e.g. making advance directives
ii. Regular healthcare services at the community level
iii. Medicine and equipment for symptom management
iv. Practical knowledge of caregiving, such as physical assistance and supporting skills
v. Psychological counselling
vi. Comfortable environment
vii. Others

7. a. If possible, would you want to maximise your time spent in the community (i.e. outside of hospitals, e.g. at home, in elderly centres) in the last stages of life?

i. Yes ii. No

b. (For those who do not wish to stay in the community as indicated in 7a) Would you want to maximise your spent time in the community in the last stages of life if there was sufficient support available?

i. Yes ii. No

8. When facing an end-of-life situation, who would you seek non-medical support from? (can choose more than one option)

i. Medical professionals in hospitals
ii. Medical professionals in communities
iii. Social workers
iv. Religious acquaintances
v. Relatives or non-religious acquaintances
vi. Others

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9. **Where did you learn about community end-of-life care services? (can choose more than one option)**
   i. Medical professionals in hospitals
   ii. Medical professionals in communities
   iii. Social workers
   iv. Religious acquaintances
   v. Relatives or non-religious acquaintances
   vi. Promotion from the Government
   vii. Others

10. **Are you a caregiver for elderly members or chronic disease patients within your own household?**
   i. Yes ii. No

Note: If there is any inconsistency or ambiguity between the English version and the Chinese version, the Chinese version shall prevail.

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