賽馬會安寧頌
JCECC
Jockey Club End-of-Life Community Care Project

For Legislative Council Panel of Health Services Meeting, December 13, 2019 on "Legislative Proposals on Advance Directives and Dying in Place

1. The JCECC project was initiated by the Hong Kong Jockey Club Charities Trust aiming at improving the quality of end-of-life care, enhancing the capacity of service providers, as well as raising public awareness in the community. Partner organizations include 2 universities and 5 NGOs.

2. The JCECC Project generally supports the Government to provide clear legal provisions for Advance Directives (AD) and remove legal barriers by amending related Fire Services Ordinance and Mental Health Ordinance as well as the Coroners Ordinance to make possible the implementation of Dying in Place in Residential Care Home for the Elderly (RCHEs).

3. A full version of recommendations will be submitted to Food and Health Bureau as response to the public consultation. Below are our key points.

4. Expanding the Implementation of AD to Holistic Advance Care Planning (ACP)
   4.1 We advocate that preceding to signing AD, the patient, the family and the medical team should go through ACP, which is an indispensable ongoing communication process that addresses holistic needs, values and preferences of the patients prior to making medical decisions.

5. Enhancing the Readiness and Capacity of the Medical Systems in Providing End-of-Life Care (EoLC)
   5.1 Healthcare professionals, especially in areas outside oncology, geriatrics and palliative care are hesitated or unmotivated to initiate AD conversations with patients and family members due to practical constraints. We hope enough resources are pledged to support the continuation and enhancement for the quality trainings on palliative care or EoLC.
   5.2 In view of the tight manpower in the public health sector to handle the increasing demand for AD arising from the ageing population, we suggest collaboration of public and private hospitals in terms of ensuring the compatibility of AD forms used, and extending the above-mentioned professional trainings to medical staff in private hospitals, or even family physicians practicing in the community who know the medical histories and preferences of their patients well.

6. Making, Modifying and Revoking an AD
   6.1 We support that the making of an AD in written format and be witnessed to minimize disputes.
   6.2 We agree that revoke of a previous AD can be done anytime and allowing both oral and written revocation when the preference changes from withdrawal to acceptance of certain life-sustaining treatments (LSTs). However, given the higher chance for disputes when it involves a change from accepting (LSTs) to withdrawing such treatments, we recommend only written one with 2 witnesses is allowed.

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7. Streamlining the Storage and Access to the AD Document
   7.1 Considering that the eHRSS is still under staged development and medical staff in both public and private medical settings are still getting used to using the system, we support that original AD document be required as proof of a valid AD. However, related medical staff should educate and remind the individual/ family to store the original document in a consistent and easy to reach place or multiple originals be kept by key family members.
   7.2 However, in longer run, we suggest the Government to seriously consider establishing a central registry, standalone or by enhancing the current eHRSS system to be accessible by both public and private authorized personnel similar to the National Health Insurance Card (NHIC) in Taiwan. To address the possibility of time lags in uploading the latest AD in case of amend or revoke, practices and guidelines of simultaneously uploading the signed document by medical teams should be established.

8. Promoting Medical and Social Collaboration in ACP and soliciting AD
   8.1 To provide appropriate expertise and to relieve medical staff's burden, we recommend using a medical and social collaboration approach to facilitate the ACP process.
   8.2 We recommend the development of a medical-social collaboration framework of Holistic ACP in which the delineations of roles, communication strategies and collaboration among professionals are stated
   8.3 At the same time, capacity building programs to equip social care professionals in hospital and community settings in ACP facilitation are to be offered.

9. Making "Dying in Place" Possible
   9.1 We recommend the differentiation of the concepts of "Dying in Place" with "Death in Place". While respecting the choice of place of death of patients, it is equally, if not more, important to respect the choice of place of care in the final days.
   9.2 We support Dying in Place where the patient is surrounded by a familiar environment and familiar faces. Besides amending the current Coroners Ordinance and hardware upgrading, the most important is to provide adequate training and additional resources to equip both the managerial and frontline staff the caring attitudes, knowledge and skills to provide quality EoLC. The Hong Kong Association of Gerontology, a JCECC project partner, developed a district-based EoLC service model to support 36 RCHEs from 2016 – 2018, and expects to expand to 48 by 2021.
   9.3 In addition to assisting RCHEs residents, we strongly recommend the Government to develop community-based EoLC services to support community-dwelling patients with terminal illness and their family caregivers. It is estimated that in 2018, more than 21,000 deceased elderlies[1] were in need of EoLC and 55% of them resided in domestic homes[2]. The four JCECC partnered NGOs served over 770 families in 2016 to 2018, and expect to serve 460 families in 2019.

[1] An estimation according to the pain prevalence of various chronic disease published by World Health Organization in the "Global atlas of palliative care at the end-of-life" with the statistic on number of deaths in 2018. Death data was retrieved from website of the Centre for Health Protection, at https://www.chp.gov.hk/en/statistics/data/10/27/340.html

[2] A figure derived from the statistics presented by HA, and is cited in the "Innovation Impact – the foundation of community-based end-of-life care in Hong Kong" (p.20)

9.4 HA proposed strengthening collaboration between hospitals and community service providers in the care for patients with serious illness[3]. It is evident that community EoLC reduces the costs associated with hospital stays and emergency admissions, and the recent research done by JCECC on its EoL RCHEs and community programs shows encouraging results. To prepare for the foreseeable growing needs due to the rapidly ageing population in Hong Kong, we strongly recommend developing EoLC services for terminally ill patients living in RCHEs and at homes with a medical-social collaborative approach.

10. Public Education

10.1 Public awareness about palliative care and openness in talking about death and dying is crucial to the implementation of ACP/AD initiatives. According to the 2015 Quality of Death Index commissioned by the Economist Intelligence Unit, Hong Kong ranked low (38th) in community engagement.

10.2 In Hong Kong, death education is primarily done by NGOs, e.g. JCECC project partners. Due to limited resources, the public education is limited in its coverage and sustainability. We believe that the Government should create incentives and support systems to encourage community involvement, including funding and policy making to coordinate efforts from education, healthcare, social welfare and legal fronts. We propose adopting a public health tiered approach for life and death education. Recruiting EoLC volunteers is also an effective way of public education.

11. Special Groups

11.1 The current consultation paper addresses the EoLC for elderlies in general. However, some population may need special attention, including the Mentally Incapacitated Persons (MIPs) and persons with dementia. In essence, persons with limited intellectual abilities should not be deprived of their rights to make EoL decisions. They should be facilitated to express their preferences and wishes, with family members involved. For patients with dementia, it is encouraged that ACP be done and proxies be appointed as early as possible.

11.2 Regarding the suggestion on amending the Coroners Ordinance to make Dying in Place possible, besides RCHEs, other residential services for the physically and mentally handicapped should be included.

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[3] Hospital Authority (2017). Strategic service framework for palliative care. Retrieved from http://www.ha.org.hk/haho/ho/ap/PCSSF_1.pdf