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Population Ageing and Quality of Life at the End of Life

Hong Kong is facing a rapidly ageing population. Due to increasing life expectancy and declining fertility rate, the *number of persons aged 65 and above has surged nearly 40% in the past two decades, and is expected to reach 2.58 million by 2041 to account for 30% of the total population.*[1] One of main contributors to this phenomenon is the constant rise in life expectancy, unfortunately, increased longevity does not translate to increased well-being at old age. Owning to greater prevalence of chronic terminal illnesses with extended dying trajectories, Hong Kong's elderly dependency ratio will more than double within the next thirty years, and demand for long-term-care services is also projected to rise considerably in the foreseeable future.[2]

The Interfacing of Long-Term Care (LTC) and End-of-Life Care (EoL)

Under the context of population ageing, the most confounding challenges among health care providers is to optimize quality of life and promote death with dignity for older people suffering from terminal illnesses. While palliative care are traditionally rendered through hospitals and stand-alone hospices, a major shift has been observed in recent years where it is now increasingly common for elders to receive end-of-life (EoL) care in long-term-care settings. In fact, the provision of EoL care in nursing homes is gradually becoming standard practice in many Western countries with strong evidences supporting its effectiveness in enhancing dying residents' quality of life though the introduction of advance care planning, pain and symptoms control, psycho-socio-spiritual support, as well as inter-agency care coordination. This comes as no surprise given the growing number of institutionalized elders around the globe, but what is disconcerting is that Hong Kong, with one the highest institutionalization rates in the world at nearly 8%, has done relatively little to remedy the situation.

The Surging EoL Needs of Hong Kong LTC Residents

According to a recent large-scale study with 1,600 elderly residents from 140 nursing homes (NH) across Hong Kong, 94% of respondents preferred to be informed of the diagnosis if they had terminal illness, 88% were in favor of having an advance directive; 59% wished to receive palliative end-of-life care in nursing home settings, and 35% desired to die in their present nursing home.[3] However, less that 1% of older terminally-ill patients actually die at a place of their choosing as the majority of deaths occurs in hospitals. Evidently, dying in NHs is not commonly expected because EoL care is

[1] Census and Statistic Department, Hong Kong SAR Government. (2014, May). *Hong Kong Monthly Digest of Statistics.* Hong Kong: Hong Kong SAR Government.
[2] Social Work Department. (2013). Overview of Residential Care Services for Elders. [Online] Available from: http://www.swd.gov.hk/en/index/site_pubsvc/page_elderly/sub_residentia/id_overviewon/. [Accessed 15th May 2014]
[3] Chu, L. W., Luk, J. K. H., Hui, E., Chiu, P. K. C., Chan, C. S. Y., Kwan, F. et al. (2011). Advance directives and end-of-life care preferences among Chinese nursing home residents in Hong Kong. *Journal of American Medical Directors Association*, 12: 143-152.

not a standardized provision of long-term-care services. As a matter of fact, NHs in Hong Kong are only required to provide basic medical and nursing care, and most of them lack the expertise and personnel to render adequate palliation and psycho-socio-spiritual support to those nearing the end-of-life. As a result, NH residents with terminal illnesses are often unable to engage in advance care planning and make informed decisions that best reflect their needs and wishes. Instead, they are traumatized through the 'Revolving Door Syndrome' characterized by repeated hospitalizations when their conditions deteriorate, and disempowered to maintain autonomy and achieve dignity – a basic human right – in the face of mortality.

The Accumulating Evidence of the Feasibility and Efficacy of Integrated LTC with EoL Care

Conceivably, the call for establishing EoL care provisions in NHs and long-term-care settings has been echoed widely among researchers and clinicians. And repeated research has encouragingly shown that nursing home staffs seem to welcome and are ready to adopt a palliative care approach in caring of their older terminally-ill residents with collaborated support from hospital medical practitioners.[4] Moreover, results from numerous pilot studies of implementing EoL care in subvented NHs is not only feasibility but are admirably effective in improving the quality of life and promoting death with dignity among terminally-ill residents and their families (Figure 1).[5] All of these evidence clearly indicate that the seeds for EoL care have been planted in LTC settings and are now germinating healthily across Hong Kong; but without a government led policy that solidify the integration of EoL care and Long-Term-Care, these commendable initiatives will not be sustainable and the tireless efforts of all healthcare professionals involved will be despondently wasted. Thus, in order to continue this paramount social movement, collaborative policy-making that include interdisciplinary teamwork across professions (physicians, nurses, social workers, nursing home staffs); well-planned care management across agencies (i.e. hospitals, nursing homes, elderly care facilities); adequate resources allocation with enhanced funding, manpower, alignment of services; as well as culture building through professional trainings, public educations and on mortality and end-of-life care, are imminently needed (Figure 2).[6]

A Critical Paradigm Shift that starts with Regulatory Empowerment via Public Policy

Under the rubric of population ageing, the success of care for those facing mortality no longer rests on a small group of specialists or even the medical profession alone, but the concerted efforts and vested interest in living and dying with dignity of every individuals, groups, communities and government bodies of our global community. And the fundamental driving force of this critical paradigm shift starts with a public policy-driven initiative that both regulates and empowers the integration of End of Life Care with Long Term Care in all health and social care systems in our very own society.

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[4] Lo, R. S. K., Kwan, B. H. F., Lau, K. P. K., Kwan, C. W. M., Lam, L. M., & Woo, J. (2012). The needs, current knowledge, and attitudes of care staff toward the implementation of palliative care in old age homes. *Am Journal of Hospice & Palliative Medicine*, 27(4): 266-271.

[5] Ho, A.H.Y., Luk, J.K.H., Chan, F.H.W., Ng, W.C., Kowk, C.K.K., Yuen, J.H.L., Tam, M.Y.J., Kan, W.S., & Chan, C.L.W. (Under Review). Dignified palliative care in long-term care settings: an interpretive-systemic framework for end-of-life integrated care pathway (EoL-ICP) in Hong Kong. Age and Ageing.

[6] Ho, A.H.Y., Lou, V.W.Q., Dai, A.A.N., Lam, S.H., Wong, S.W.P., Tsui, A.L.M. & Tang, J.C.S. (Under Review). Development and Pilot evaluation of a novel dignity-conserving end-of-life (EoL) care model for nursing homes in Hong Kong. Journal of American Medical Director Association.

Figure 1. A Dignity-Conserving EoL Care Model for Nursing Homes in Hong Kong

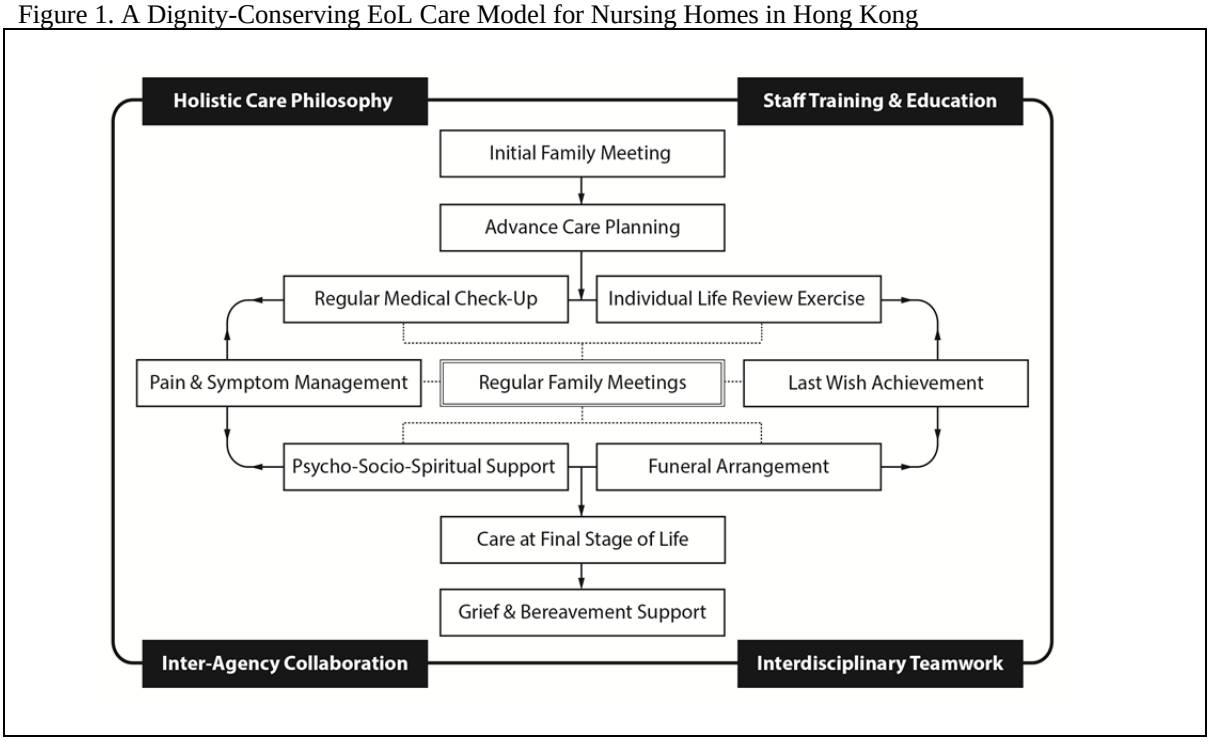

Figure 2. A Systemic Framework for Integrated LTC and EoL Care in Hong Kong