PART IV:

CONCLUSION

CHAPTER 16

THE FUTURE OF COMMUNITY-BASED END-OF-LIFE CARE IN HONG KONG: SOME CONCLUDING THOUGHTS

Amy Y. M. Chow
Jockey Club Community End-of-Life Care Project, The University of Hong Kong
Department of Social Work and Social Administration, The University of Hong Kong

Iris K. N. Chan
Jockey Club Community End-of-Life Care Project, The University of Hong Kong

Cecilia L. W. Chan
Jockey Club Community End-of-Life Care Project, The University of Hong Kong
Department of Social Work and Social Administration, The University of Hong Kong

With the ageing population and expansion of inclusion criteria of service recipients, the growing demand for end-of-life care (EoLC) is an inconvenient truth around the world. The publication of the Strategic Service Framework for Palliative Care by the Hospital Authority (HA) (see chapter 4) indicates the readiness of the Hong Kong SAR Government in finding ways to react to this truth. This book outlines the possible response of community EoLC and describes the international and Hong Kong's local context of EoLC in the past three years. It documents the process of the experimentation of different models of community-based EoLC, delineates the parallel development of all-round competence improvement programmes and defines the evaluation mechanism. After the first draft of this book was prepared, The Lancet published a commission report on palliative care (PC) (Knaul et al., 2018). The National Coalition for Hospice and Palliative Care also revised their clinical practice guidelines and updated to a fourth edition (National Coalition for Hospice and Palliative Care, 2018). Chan (2018), who is one of the key pioneers in PC in Hong Kong, published the paper titled *Palliative care: The need of the modern era*, which sketches the future direction of PC in Hong Kong. Integrating these recent international publications with the previous chapters in this book, this concluding chapter reviews and reflects on the concepts and practices of community EoLC in Hong Kong, with a particular focus on the future.

REFLECTIONS IN THEORETICAL ASPECTS

NOMENCLATURE IN EoLC

As stated in Chapter 2, terminologies used in EoLC are not standardised internationally and locally. Chan (2018) echoes the lack of consensus in defining EoLC internationally. He considers "care at the EoL [end-of-life] is thus an integral part of palliative care" (Chan, 2018, p. 396). He accepts variations in defining the term by different users but urges for clear definition in its usage. Chow & Chan (see chapter 2) hold a different view: instead of appreciating the diversified use of terms, there is a need for standardisation.

Variation in terms confuses the audiences and is a barrier for public education and promotion of service. In particular, the terms of PC, hospice care and EoLC need to have a clear usage with consensus. From a different angle, PC uses the content of care to define its term: the palliation of symptoms of any kinds. EoLC uses the time of care: the final stage of life when someone is facing a serious illness with a limited prognosis, usually a 12-month time frame. As for PC, it can be offered to anyone with a serious illness, irrespective of its prognosis. Moreover, it can be carried out together with curative care. Conceptually, PC and EoLC are different, although there is a degree of overlapping.

The US National Institute on Aging offers a clear differentiation between PC and hospice care in their online materials (National Institute on Aging, 2017). Specifically, hospice care is eligible for those with serious illnesses that expect limited survival time (6 months in the US). Another key differentiation is that the hospice care recipient does not receive curative treatment concurrently, while the recipient of PC does. However, hospice care is part of EoLC. With these clear definitions and differentiates, is that helpful for care recipients? Does the definition facilitate the care providers in developing a clearer division of duties or better care for the patients? Rahman, Fields, Shirsat, Suastegui-Olivares & Enguidanos (2018) shared the challenges faced by professionals in introducing PC to patients and families. How the message of PC is introduced to potential consumers affects the decision of use of service. As reflected in the qualitative data eliciting consumer perspectives, users considered the linkage of PC with EoLC as "a huge mistake" because PC is offered at different stages as soon as the patient is diagnosed with an advance illness. The study also found that many consumers equate PC with hospice care, which causes unnecessary resistance to receiving PC services.

While there are movements in clarifying the English terms related to the care for those with serious illness, the Chinese terms are more confusing. Complicated by the geographical differences of Chinese-speaking places, Mainland China, Hong Kong and Taiwan use a different Chinese translation of PC (see chapter 2). In Hong Kong, HA uses the term 紓緩治療服務 for PC. Literally, this term is "palliative treatment service", which is associated with medical-related intervention rather than care. The need for standardisation of the term will be the first step in promoting the services.

EoLC FOR THE PREVENTION AND RELIEF OF SERIOUS HEALTH-RELATED SUFFERING

The Lancet Commission on Palliative Care coined a new concept: Serious health-related suffering (SHS). This is the suffering due to illness or injury to the level that requires medical intervention; and if not, physical, social or emotional functioning will be compromised. Although the Commission report focuses the discussion on a healthcare system that can alleviate physical and psychological suffering of patients and families, they acknowledge the significance of remediation of social and spiritual suffering. In particular, they highlight the potential impact on the delivery of PC services if patients and families have social or spiritual suffering (Knaul et al., 2018). Although quality of life has been commonly used as the outcome measure of EoLC (see chapter 5), should the new measure of the burden of SHS be included as a measurement? The objective of EoLC is the prevention and alleviation of suffering. It is sensible to adopt measures of SHS for assessment and evaluation in future work.

EoLC NEEDS EVERYONE'S EFFORT

The chapter authors of this book include administrators of funding organisations; academia in practice, policy and evaluation; researchers; hospital administrators; frontline health and social care professionals, and each party is involved in the provision of EoLC. As discussed in Chapter 3, Chung & Yeoh identified four levels of context that shape EoLC: the legal level; the organisation level; operational and socio-cultural level; and socio-cultural level. On top of the participation of health and social care professionals, legal experts, sociologists, educators and spiritual leaders all contribute to the development of EoLC. In the first three year of the project, over 1,900 professionals and frontline workers of 36 residential care homes for the elderlies received intensive training onsite. Over 5,300 medical and allied health care professionals in hospital and 2,100 health and social care professionals have been trained in these three years under the project. They reported significant improvement in their competence in and attitudes towards end-of-life care. In addition, 560 volunteers have been engaged to support end-of-life care services in the community. The face-to-face public education programme on end-of-life care also reached 22,500 general public members. The multi-media channels reached another 350,000 members in the community as well.

EoLC IS SCIENCES, ARTS AND HUMANITIES

Healthcare and medical care are a core part of EoLC, and is therefore considered as a scientific care. When facing life and death issues, the care also faces an ethical dilemma when there is a blurred area between right or wrong acts. Woo (see chapter 11) found that some healthcare professionals are reluctant to initiate communication with patients with serious illness due to the unfamiliarity of the topic. The time constraints and the challenges of accurate prognosis pose further obstacles in having serious illness conversations. In responding to the need, the project team developed a case book series to demonstrate the different possible angles of consideration in decision-making and treatment plan. Using real-life ethical cases, the book series explains the clinical ethical principles behind different decision-making processes to help educate healthcare professionals.

STRENGTH-BASED AND COMPETENCE APPROACH IN EoLC

Although health and social care professionals are offering support to patients with serious illnesses, the patients and families are not necessarily passive care recipients. Chow, Chau, Yu & Mak (see chapter 8) and Lui et al. (see chapter 9) adopted a strength-based approach in enhancing the competences of family members and patients, respectively, in offering care and self-care. Chan et al. in Chapter 7 appreciated the altruistic support of volunteers in the community. EoLC is not necessarily requiring external resources; providing a platform for supporting self-reliance is an alternative. For some patients, in particular Chinese, perception as a burden to others is demoralising. Being able to take care and take charge of oneself can be therapeutic. Likewise, some family members blamed themselves for not offering adequate support to the patients while they were alive. They became regretful and struggled in the bereavement process. While serving the patients and families, EoLC worker should adopt a strength-based perspective and let the patients and families excel.

REFLECTIONS IN PRACTICE ASPECTS

COMMUNITY-BASED EoLC

Chan, Chan, Chan & Fong (see chapter 1), and Chow & Chan (see chapter 2) portray the local and international scene that demands the development of community EoLC respectively. Community EoLC provide patients and their families with more choices in the setting of care. Leung et al. (see chapter 12) illustrated that the increased competence of staff at residential care homes for the elderly (RCHE) can better support older adults who choose RCHEs as the place of EoLC and the place of death. However, Chan et al. (see chapter 7), Chow et al. (see chapter 8) and Lui et al. (see chapter 9) each shared a successful case of receiving EoLC at the patient's homes.

The National Coalition for Hospice and Palliative Care (2018) recently published the fourth edition of the ***Clinical practice guidelines for quality palliative care***. One of the key revisions of the new edition is the increased emphasis on community-based resources and community-based providers, which is echoed by an international trend of expanding community-based EoLC.

PREVENTIVE EoLC

The findings of longer survival time of lung cancer patients who received early PC by Temel et al. (2010) caught the international attention of the benefits of early PC. Early PC can be started as soon as the diagnosis of a serious illness is made, irrespective of the prognosis. Early intervention is not limited to patients, but can also be applied to family members; and not only on physical care but also on social care. Chen et al. (see chapter 6) affirmed the value of Advance Care Planning (ACP) for patients and families. A five-step model of ACP was introduced. Chow et al. (see chapter 8), on the other hand, demonstrated that facilitating the communications of patients and family members when the former is healthy can reduce unfinished businesses, as well as preventing bereavement complication, even after the death of patients.

EVIDENCE-BASED EoLC

Evidence-based medicine emphasises the examination of clinical research instead of basing it only on intuition and clinical experience. It became popular in the 1990s and is gradually affecting psychosocial care. The UK Medical Research Council (MRC) (2006) published guidance of developing and evaluating the complex intervention, providing a clear framework for evaluation. Chan & Yu (see chapter 5) described the detailed process of planning and implementing the evaluation of the different projects of JCECC. The MRC published further guidance on process evaluation (Moore et al., 2015). Adding to the MRC's 2006 guidance, this updated guidance emphasised the importance of articulation of theory to explain the mechanism of intervention change required to achieve process evaluation. The context of the intervention being carried out, as well as the compliance and fidelity of the intervention, have to be taken into consideration. These are areas for future development.

REFLECTIVE EoLC AND INTEGRATED MODEL

The four non-governmental organisation (NGO) community EoLC models include the non-cancer patient capacity building model (see chapter 9), family capacity building model (see chapter 8), community capacity building model (see chapter 7) and enhanced community-based healthcare model (see chapter 6) were discussed in previous chapters of this book. They are complex interventions with several interacting care components offered by different levels of staff. They share a few common components, but they also have their unique elements, resulting in different levels of impact on the differentiated outcomes. The project has reached out to 3,800 patients and family members. Generally speaking, patients showed significant reduction in anxiety and depression. The physical symptoms of patients though expected to be deteriorating at the final stage, there were significant improvements as well. At the same time, family caregivers showed significant reduction in practical issues, family anxiety, caregiving strains and barriers in communication within family after receiving three months of services. The days of hospitalisation of the patients receiving the service were reduced in the third month of service when compare with pre-service stage. Subjective perception towards the services of the project was positive as reflected in the satisfaction survey of users and stakeholders.

The ultimate goal of the JCECC Project is to develop a comprehensive and holistic community-based EoLC model for Hong Kong: an "Integrated Community EoLC Support Teams" (ICEST) model. Through analysing and synthesising the available data of the evaluation of the four different models, a preliminary integrated model is created (see **Figure 16.1**). The model provides three core types of care – physical, psychosocial–spiritual and practical support – that have been found to be effective in the evaluation of the four NGO community models. A stepped-care model will be adopted such that interventions will be provided based on a risk-stratification tool. When the patients and their families have indicated needs in a certain care domain, as assessed by the risk-stratification tool, the model will suggest specific interventions and dosage to help guide the practice.

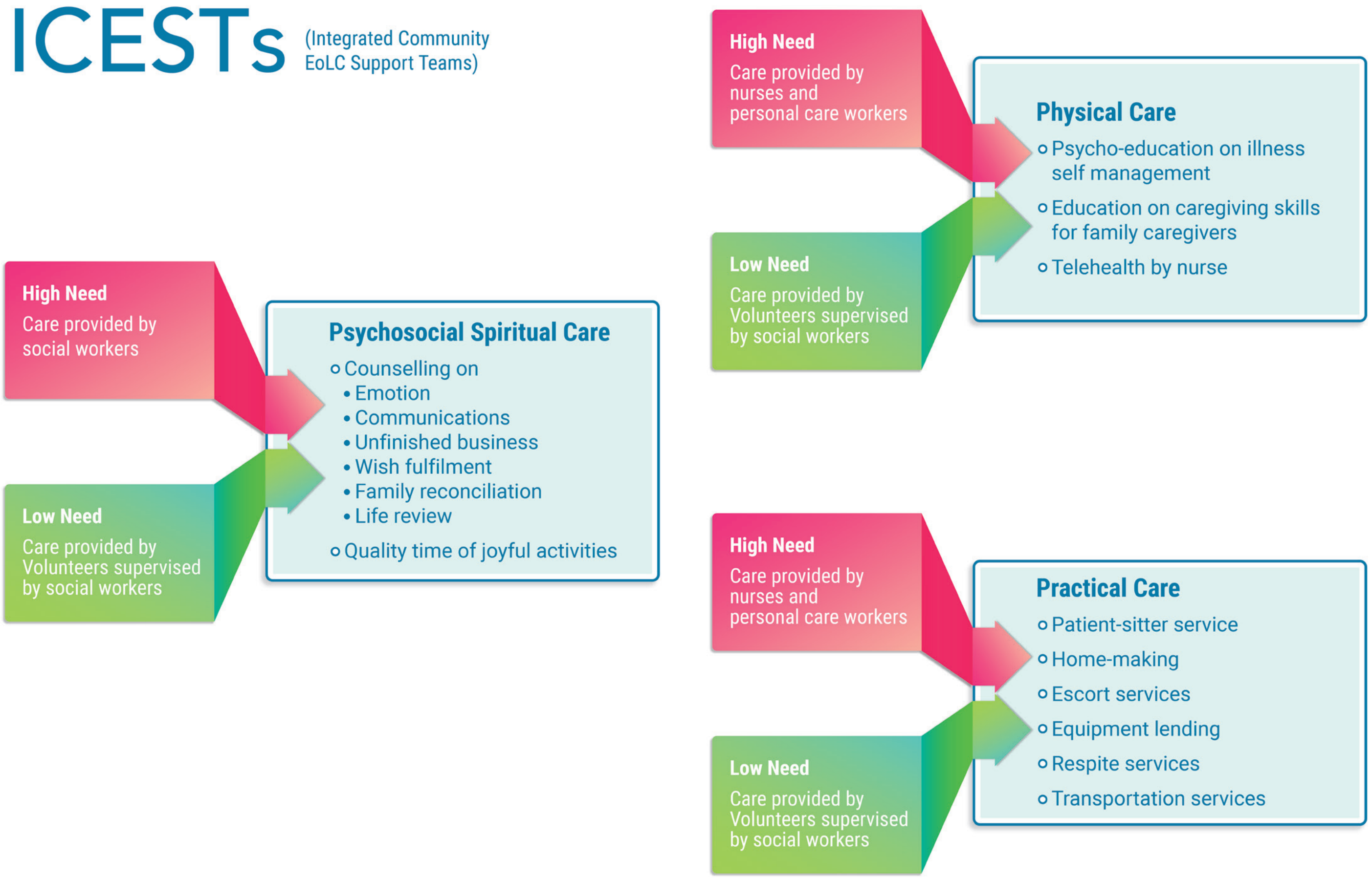

Figure 16.1 The Integrated Community EoLC Support Teams Model

As suggested by Brazil (2018), the integrated model might have a different meaning to different people. Our integrated model is not only integrating the four NGO models but it is also integration with other existing health and social care services. In line with the Strategic Service Framework for Palliative Care published by HA (HA, 2017), there is growing support of developing PC or EoLC in the community. HA is committed to enhancing medical–social collaboration to support PC in the community. Informal meetings with representatives of related bureaus and Government Departments had been carried out for exchanging ideas on the development of community-based end-of-life care in Hong Kong. Plans for collaboration with existing healthcare services provided by HA and social care services provided by the Social Welfare Department will be carried out.

CONCLUSION

The JCECC Project, which was initially a three-year project, is approaching the end of its first phase when this chapter was prepared and it has received funding from The Hong Kong Jockey Club Charities Trust for an extension of three more years until 2021. This book is like the eulogy, documenting the achievements, lessons learnt, reflections, as well as the impacts brought by the project. Hopefully the points raised in the book will offer some guidance for those who want to support people with serious illness in the community, just as legacies for the next generation and more achievements in the coming years would be recorded in the next eulogy.

REFERENCES

Brazil, K. (2018). A call for integrated and coordinated palliative care. *Journal of Palliative Medicine*, 21(S1), S27–S29.

Chan, K. S. (2018). Palliative care: The need of the modern era. *Hong Kong Medical Journal,* 24(4), 391–399.

Hospital Authority (HA) (2017). *Strategic service framework for palliative care.* Retrieved from www.ha.org.hk/haho/ho/ap/PCSSF_1.pdf

Knaul, F. M., Farmer, P. E., Krakauer, E. L., De Lima, L., Bhadelia, A., Jiang, X., ..., & Rajagopal, M. R. (2018). Alleviating the access abyss in palliative care and pain relief – an imperative of universal health coverage: The Lancet Commission report. *Lancet,* 391, 1391–1454.

Medical Research Council (2006). Developing and evaluating complex intervention. Retrieved from https://mrc.ukri.org/documents/pdf/complex-interventions-guidance/ Moore, G., Audrey, S., Barker, M., Bond, L., Bonnell, C., Hardeman, W., ..., & Baird, J. (2015). *Process evaluation of complex interventions: UK Medical Research Council (MRC) guidance.* Retrieved from https://mrc.ukri.org/documents/pdf/mrc-phsrn-process-evaluation-guidance-final/

National Coalition for Hospice and Palliative Care (2018). *Clinical practice guidelines for quality palliative care,* 4th ed. Richmond, VA: National Coalition for Hospice and Palliative Care.

National Institute on Aging (2017, May 17). *What are palliative care and hospice care?* Retrieved from https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care

Rahman, A., Fields, T., Shirsat, N., Suastegui-Olivares, D., & Enguidanos, S. (2018). Patient and caregiver perspectives on how to introduce community-based palliative care. *Journal of Palliative Medicine*, 21(11), 1544–1545.

Temel, J. S., Greer, J. A., Muzikansky, A., Gallagher, E. R., Admane, S., Jackson, V. A., ..., & Lynch T. J. (2010). Early palliative care for patients with metastatic non-small-cell lung cancer. *New England Journal of Medicine,* 363(8), 733–742.