

## Reflections on End-of-Life Care and Perspective of Nursing Education for Aging Societies in Asia

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**Abstract** Access to high-quality care at the end-of-life is a fundamental human right; therefore, it is necessary to examine how end-of-life care should be taught in nursing education to prepare for a super-aging society. Japan and Hong Kong are both in the East Asian region and are facing similar super-aging challenges, such as increased mortality and declining birth rates. This paper explores the literature on this topic and discusses how end-of-life care is taught in undergraduate nursing education in both Japan and Hong Kong. A comprehensive literature search was performed using end-of-life care keywords. Subsequently, the authors engaged in a discourse on expert perspectives, insights, and results from the literature. It is necessary to bridge the gap between the desired manner of spending one's final days and the practical reality of considering patients' best interests by referring to the existing policies, laws, guidelines, and frameworks of healthcare systems. This study suggests the importance of understanding patients' views on life, death, values, and cultural backgrounds and educating healthcare personnel to apply these principles flexibly in their practice.

*Key words:* international collaborative research, Hong Kong, Japan, end-of-life care, nursing education

### Introduction

Higher mortality rate due to rapid aging is one of the most urgent social issues worldwide.<sup>1</sup> The global population of individuals aged 65 and above is projected to increase from 9.3% in 2020 to 17.8% by 2060. It is anticipated that by 2060, approximately one out of every ten individuals globally will be an Asian senior citizen.<sup>2,3</sup> Older individuals commonly encounter persistent ailments such as dementia and cerebrovascular conditions and experience a gradual decrease in their life

functions as they approach the final stage of life. Nursing care is difficult to predict owing to the different aging reserve capacity and perception of symptoms among individuals. Moreover, end-of-life care (EOLC) is a critical aspect of emergency care, as sudden incidents can result in the final stage of life.<sup>4</sup> When discussing EOLC, it is essential to consider the prognosis and course prediction based on the trajectory of the disease. For many individuals, the final phase of life is characterized by sudden death, terminal illness, multiple organ failure, or frailty, each with varying

durations and degrees of deterioration. These factors contribute to assessing a patient's condition in the later stages of life.<sup>5</sup>

The World Health Organization (WHO, 2020)<sup>6</sup> defines palliative care as improving patients' quality of life (both adults and children). Unlike other circumstances and life experiences, which pertain to a limited portion of the global population, end-of-life is an inevitable phase that every individual, especially older individuals, will encounter at some point.<sup>7</sup> Healthcare providers must offer exceptional EOLC aiming for a "good death" in the best interests of patients and their loved ones rather than solely focusing on whether life can be extended.<sup>8</sup> Nurses are a vital part of the EOLC team and experience several obstacles in providing quality EOLC for patients and families mainly due to a lack of education and training.<sup>9</sup>

Owing to the increasing globalization and migration of populations, nurses have more opportunities to provide care to patients and their families from diverse cultural backgrounds. Additionally, they can collaborate with nursing professionals from various cultural contexts. Every individual is entitled to EOLC. Considering the impending high death rate associated with non-communicable diseases, it is crucial to explore appropriate methods for teaching EOLC in nursing education. Japan and Hong Kong Special Administrative Region (Hong Kong), both located in the East Asian region, face similar super-aging challenges, including increased mortality rates and declining birth rates.<sup>10</sup> This study will explore and discuss expectations for nursing education regarding how EOLC is taught in undergraduate nursing education.

## 1. Backgrounds

Nursing professionals who work with human life require specialized knowledge, skills, and a high level of ethics fostered by the nursing education system. Cultural diversity should also be considered in nursing education. For example, patients, families, and nurses in countries where euthanasia is legally recognized may have different values and views on care compared to those in countries

where euthanasia is illegal. Owing to the differences between Asian and Western conceptions of family and individual autonomy, the Western perspective on EOLC approaches may not be applicable in Asian countries.<sup>11</sup> Death is often considered a taboo subject in many Asian cultures, which can make it challenging to address the topic openly.<sup>12</sup> In traditional Chinese culture, for instance, it is customary to avoid mentioning death altogether, as it is considered a sensitive issue.<sup>13</sup>

Although Hong Kong and Japan have different population sizes, both have low birthrates and a highly aging population.<sup>10</sup> A comparison of the two areas is legitimate because they share a common status, characterized by high-income economies and advanced societies. Low birthrates and a highly aging population are common challenges in other Asian countries too.

The leading causes of mortality in Japan are cancer (24.6%), cardiovascular disease (14.8%), and senility (11.4%), which account for approximately 50% of all deaths.<sup>14</sup> The healthcare system in Japan is structured around a universal health insurance model.<sup>15</sup> Cancer has been the foremost cause of fatality since 1981, and the cancer incidence rate (2019) stands at 65.5% for men and 51.5% for women, representing a striking statistic wherein one in every two individuals are affected.<sup>14</sup> The government has been actively engaged in cancer control since 1984, and in 2006, the Basic Act on Cancer Control was enacted to promote comprehensive cancer control measures.<sup>16</sup> In Japan, care for patients with non-cancer diseases has lagged, as palliative care has mainly been developed for cancer patients from a reimbursement perspective.<sup>17</sup> However, there has been a growing interest in providing EOLC for advanced-stage non-cancer diseases.<sup>18</sup>

Japan has established a community-based comprehensive care system that aims to provide various services such as medical care, nursing care, prevention, housing, and lifestyle support within a familiar community, including fulfilling an individual's wish to spend the last days of their life in their own home. In 2020, the proportion of deaths at home in Japan was only 15.7%, which is not particularly high. Most deaths took place in

hospitals, accounting for 68.3% of the total, and the remaining deaths occurred in nursing homes, long-term care hospitals, and others.<sup>19</sup> A senior citizen whose health worsens is not typically admitted to the same hospital; instead, they are sent to a facility with the necessary medical capabilities only for the duration of their need for intensive care, based on their condition at that particular moment. Meanwhile, an individual's place of care may change frequently, shifting from home to hospital, hospital to nursing home, or nursing home to another hospital, as needed. It is crucial to ensure that ongoing care is provided according to the patient's or user's desires and preferences, considering their expressed wishes and goals regarding how they wish to live.

In Hong Kong, the top three causes of death are cancer (29.3%), pneumonia (18%), and heart disease (13%).<sup>20</sup> Hong Kong's healthcare system is divided into the public and private sectors. Public healthcare is governed by the Hospital Authority Ordinance,<sup>21</sup> ensuring equitable access to affordable healthcare services that the government highly subsidizes. The Voluntary Health Insurance Scheme (VHIS) is a private health insurance scheme introduced by the Hong Kong government in 2019. It consists of two types of plans: the Standard Plan offered by all insurance companies with the same coverage and the Flexible Plan. VHIS is accessible in public and private healthcare institutions and includes hospitalization, surgical procedures, cancer therapy, and psychiatric care. People in Hong Kong can seek private healthcare services on their own, with or without insurance coverage.

Compact housing and high population density in Hong Kong make it difficult for individuals to die in their own homes or at their place of residence. Approximately 80% of people who died outside of their homes did not want to trouble their family.<sup>22</sup> Furthermore, care homes are not legally accepted as a place of death.<sup>23</sup> Residents will be referred to hospitals for medical treatment when their health status worsens. The reasons behind this are primarily the potential for legal action and the absence of medical professionals and resources in residential care environments.<sup>23</sup>

Some studies revealed that over 30% of individuals from Hong Kong expressed a preference for passing away at home,<sup>24</sup> while 16.2%-34.7% preferred care homes.<sup>22</sup> A study surveyed residents living in nursing homes about their preferred places to receive EOLC and found that 41.6% of the respondents indicated nursing homes were the most preferred place.<sup>25</sup> Additionally, approximately 70% of those who chose a place of death other than their home were concerned about the lack of professional and technological support at home.<sup>22</sup> Therefore, most fatalities transpired in public hospitals, which accounted for over 90% of the total number of deaths.<sup>26</sup> Furthermore, previous research has indicated that approximately 30% of individuals prefer to pass away in the comfort of their own homes. This disparity between individuals' desires and their current situation highlights the practical necessity of implementing home-based EOLC practices in Hong Kong.<sup>22</sup>

## 2. Methods

This study compares Hong Kong and Japan to examine the necessary steps for acquiring professional nursing education within an international context characterized by an aging population and high mortality rates.

A comprehensive literature search was conducted using EOLC keywords. The authors engaged in a discourse on experts' perspectives, insights, and results from the literature. The reflective writing process was performed through the collective deliberations of the authoring team.

## 3. Findings

In a report on the quality of death published by the Economist Intelligence Unit in 2015, Japan ranked 14th and Hong Kong 22nd out of 80 countries and regions. Additionally, in the 2022 EOLC ranking by Finkelstein et al., six countries, namely the United Kingdom, Ireland, Taiwan, Australia, South Korea, and Costa Rica, achieved an A rank, whereas Hong Kong and Japan were ranked B.<sup>27</sup>

### 1) Current Status of EOLC and Nursing Education in Japan

The government has emphasized the importance of EOLC and terminal home care over the past decade.<sup>28</sup> Open discussion on death and severe illness is uncommon in Japan. Although it has recently become common for physicians to diagnose cancer and other life-threatening diseases, in some cases (for example, when the patient is older), they still ask the family first and then decide whether or not to inform them.<sup>29</sup> The “Guidelines for the Decision-Making Process of End-of-Life Care” was established in 2007, which included the following provisions regarding medical care in the final stage of life: patients should be provided with appropriate information and explanations by physicians and other healthcare providers. Patients should also discuss with healthcare providers and make their own decisions. In 2015, this guideline was renamed the “Guidelines for the Decision-Making Process in the Final Stage of Life.” Then, in 2018, the guideline was renamed again the “Guideline for the Decision-Making Process for Medical and Nursing Care at the

Final Stage of Life” and revised based on the development of community-based comprehensive care in the context of an aging and aging society with high mortality rates, including the spread of research and initiatives based on the concept of Advance Care Planning (ACP), particularly taking reference from the United Kingdom and the United States.<sup>30</sup>

The number of universities providing nursing education in Japan has recently increased from 218 institutions in 2013 to 299 in 2023.<sup>31</sup> The Ministry of Education, Culture, Sports, Science and Technology (MEXT) has developed a model core curriculum for undergraduate nursing programs to guarantee that the content of nursing education is appropriate.<sup>32</sup> Table 1 contains the model core curriculum for nursing practice for people in the last stage of life. This table encompasses the cognitive processes of nursing professionals, essential nursing skills, and the roles that nursing professionals play within the organizational framework.<sup>32</sup> Assessing nursing students’ proficiency in applying these

Table 1 The model core curriculum in Japan: Nursing practice for the people in final stage of life

<p>D-4-5 Nursing practice for the people in final stage of life*</p> <p>Goal: Learn nursing practice for the person in final stage of life to live a life with dignity depending on individual characteristics. Also, learn the nursing practice for the family of the person in the final stage of life.</p> <p>Learning objectives:</p> <ol style="list-style-type: none"> <li>Explain physical changes of the person in the final stage of life.</li> <li>Draw out the value, outlook on life, and view of life and death of the person in the final stage of life, and explain how to build the supporting relationship to think of the way to spend the terminal period.</li> <li>Understand the importance to tie up related organizations/professions for the person in the final stage of life to live their own life.</li> <li>Understand the methods to assess and control the pain of the person in the final stage of life, and explain the total care of pain relief.</li> <li>Explain the process of accepting death and mental care for the objects and their families.</li> <li>Explain the characteristics of decision-making process of the person in the final stage of life and the method to support.</li> <li>Explain family care (grief care) after death.</li> <li>Explain the significance of care after the death with dignity.</li> </ol>
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Committee for Fostering Human Resources in Nursing Education, MEXT, Japan :

Model Core Curriculum for Nursing Education in Japan : Learning objectives aiming for acquiring “core abilities of nursing practice in bachelor’s degree program” 47, 2017<sup>44</sup> Excerpt in part from p.47

\*The meaning of “final stage of life” is much the same as “end-of-life”, with the exception of unpredictable deaths such as sudden death.

skills to practical nursing scenarios will pose a significant challenge in the future.

The Japanese society for palliative medicine supported an educational program for nurses and nursing faculty called the End-of-Life Nursing Education Consortium in Japan (ELNEC-J), which consists of 10 modules, based on the ELNEC in the U.S.<sup>33</sup> The ELNEC, established by the American Association of Colleges of Nursing (AACN) and the City of Hope National Medical Center and funded by the Robert Wood Johnson Foundation and the National Cancer Institute, offers an educational program divided into nine modules to provide nurses involved in EOLC with the necessary knowledge.<sup>34</sup>

Since 2009, the ELNEC-J Working Group of the Education and Training Committee has been holding the ELNEC-J Core Curriculum Instructor Training Program as part of the Society's projects and has been trained to practice ELNEC-J.<sup>33</sup> This group aim to deliver quality EOLC to all people and to improve the quality of nursing care. Meanwhile, the ELNEC-J educational program for nursing professionals and faculty shares similarities with the core curriculum shown in Table 2, with some content areas converging. Focusing on undergraduate education for the provision of quality nursing, the authors contrasted the educational content of the ELNEC-J with the learning objectives

of the core curriculum of nursing universities. First, the content of ELNEC-J in the book was carefully read and the parts that corresponded to the core curriculum were extracted to create Table 2. Furthermore, the authors asked the nursing professionals who participated in the educational seminars about the latest content and checked for any discrepancies with the content in Table 2. The disparity in competency levels between nursing professionals and students in the context of EOLC can be attributed to the complexity of competencies rather than their presence or absence. Providing EOLC education in Japan is expected to enhance care.

## 2) Current Status of EOLC and Nursing Education in Hong Kong

Recent developments involve engaging the social service sector to provide non-medical interventions to achieve a holistic EOLC.<sup>26</sup> The concept of "good death" has emerged in Hong Kong over the past decade. Luk et al. defined a "good death" as people having choice and control over the location of their death and the presence of specific individuals during their final moments.<sup>35</sup> The availability of choices between dying at a familiar location or in a place of one's choice and being accompanied by family members or significant others are crucial factors. The term "End-of-Life Care" in the Hong Kong context, indicates

Table 2 ELNEC-J and the model core curriculum in Japan

ELNEC-J*	Model core curriculum items of particular relevance to ELNEC-J (for under graduate students)
Module 1: Palliative nursing care	b · c
Module 2: Pain management	a · d · e
Module 3: Symptom management	a
Module 4: Ethical issues in palliative care nursing	b · f
Module 5: Cultural considerations in end-of-life care	f, · h
Module 6: Communication	b · f
Module 7: Loss, grief, and bereavement	e · g
Module 8: Preparation for and care at the time of death	a · c · d
Module 9: End-of-life care for the elderly	—
Module 10: Achieving quality palliative care	—

\*The designation of Modules is quoted exactly from the original text of reference No.33 by Takenouchi et al.

a distinct departure from more medicalized forms of palliative care towards more socially oriented care at the community level.<sup>36</sup>

Nursing education in Hong Kong requires a minimum of 16 hours of study in “oncology nursing and palliative care” as the standard for accreditation of nursing education programs.<sup>37</sup> Additionally, in Hong Kong, principles of oncology nursing, principles of palliative care, and care of clients with cancer and their families are listed in the Cancer Nursing and Palliative Care section (Table 3),<sup>38,39</sup> but the contents are not clearly described. A growing number of graduate schools now offer programs specializing in EOLC, requiring 30 credits for completion: novel approaches in Extensive EOLC, social innovation and entrepreneurship, clinical entrepreneurship, discourse on life, therapeutic communication in extensive EOLC, and mindfulness.<sup>40</sup> Moreover, postgraduate education incorporates the topics of Integrative Symptom Management, Discourse on Life, and Therapeutic Communication and teaches how to address a person’s life circumstances and manage symptoms to enhance EOLC. These endeavors may pave the way for the evolution of EOLC in the future, going beyond oncology and non-cancer areas.<sup>38,39</sup>

#### 4. Discussion

##### 1) Differences in EOLC systems between Japan and Hong Kong

Recently, the concept of comprehensive community care has led to an increased preference for EOLC in the home environment in Japan. Moreover, it is now feasible for older adults, including those living alone, to remain in their homes and receive EOLC

until their final days through technological advancements.<sup>41</sup> Healthcare, social systems, and nursing education must be regularly reviewed and improved in the social context, especially when considering EOLC. This necessitates effective coordination among the nursing professionals. Regardless of the location of a person’s passage, it is vital to alleviate any discomfort, preserve their dignity, and provide support that enables them to live as desired until their final moments.

In Hong Kong, end-of-life medical services in communities are challenging. Despite increasing awareness of palliative and EOLC in Hong Kong, policy, economic, sociocultural, environmental, and legal factors hinder the development of these services.<sup>42</sup> Palliative and EOLC education is necessary to examine the impact of continuous training on professionals’ actual practice.<sup>43</sup>

Considering the aforementioned information, it is essential to note that despite the contrasting cultural backgrounds and healthcare systems of Japan and Hong Kong, efforts to bridge the gap between the desired manner of spending one’s final days and practical reality must be made in both contexts. While the applicability of this approach to Hong Kong may be subject to certain constraints, it is crucial to consider patients’ best interests by referring to the existing policies, laws, guidelines, and frameworks of the healthcare system.

##### 2) Promoting EOLC in Nursing Education

As both Japan and Hong Kong are aging societies, promoting EOLC among older adults is an urgent issue. Cancer and non-cancer diseases affect physical function differently,<sup>5</sup> and it is essential to comprehend

Table 3 A Reference Guide to the Syllabus of Subjects and Requirements for the Preparation of Registered Nurse (General) in the Hong Kong Special Administrative Region<sup>37</sup>

Topics	Minimum Hours
Oncology Nursing and Palliative Care · Principles of oncology nursing · Principles of palliative care · Care of clients with cancer and their families · Legal and ethical issues related to oncology nursing and hospice care	16

Excerpted in part from p. 27

and address the specific trajectory of illness resulting from each disease. Particularly in organ failure and frailty states, it is difficult to determine when EOLC begins, and the subject may not be prepared for a good death. Furthermore, it can be challenging for healthcare providers to decide when to shift their approach to care, as the disease trajectory is often long-term. Therefore, it is crucial to incorporate formal EOLC training into the nursing curriculum to understand the unique care requirements for different types of diseases.

The ELNEC-J program aligns with several components of the model's core curriculum. The essential educational content of the EOLC is imparted at the undergraduate level and is progressively enhanced at subsequent levels. The Model Core Curriculum's objective is to "draw out the value, outlook on, and view of life and death of a person in the final stage of life and explain how to build the supporting relationship to think of the way to spend the terminal period (Learning objectives b on Table 1)"<sup>44</sup> in nursing practice to provide patients with quality care. The fundamental principles that define a good death include preferences for the dying process, a pain-free state, and emotional well-being, which account for 94%, 81%, and 64% of reports, respectively among patients, families, and health care providers.<sup>45</sup> It is imperative to provide education to respect these preferences and to cultivate one's understanding of these concepts to grasp an individual's perspective on the value of life and their views on life and death. An educational environment that emphasizes these aspects is necessary to foster the development of personal values and views of life and death. Patient decision support and pain management must be incorporated into undergraduate nursing education.

The nascent stage of palliative care and EOLC services in Hong Kong includes a medicalized approach to care for the dying, which emphasizes specialist-led services, hospital-based care, and a greater focus on cancer patients. Standard care for terminally ill individuals in Hong Kong reflects this medicalized palliative care approach.<sup>35</sup> The following factors contribute to the challenges faced in implementing EOLC in Hong Kong:

- 1) a widespread aversion and trepidation towards death and dying;
- 2) cultural interpretations of filial piety that may prolong the discomfort of patients nearing death;
- 3) the absence of comprehensive EOLC policies;
- 4) the uncertainty surrounding the legal basis for mental incompetence;
- 5) obstacles impeding the registration of advance directives; and
- 6) inadequate medical knowledge, skills, and resources.<sup>43</sup>

Regardless, EOLC is being deliberately and systematically integrated into nursing education. As its significance in Hong Kong continues to grow, it is becoming increasingly crucial to be taught methodically in professional nursing education.

We hope that the quality of nursing care in EOLC situations will be improved by integrating the ELNEC as a core component of the undergraduate nursing curricula.

### 3) Culture

In Japan, the extensive utilization of ACP has resulted in increased acceptance of mortality. Conversely, in Hong Kong, a prevalent conviction that broaching the topic of death elicits sensations of unease, dread, and culpability remains.<sup>46</sup>

Jankelevitch<sup>47</sup> described the "personhood of death." Future societies characterized by multiple deaths are easily comprehended in a detached manner when considering third-person deaths. Thus, they encounter challenges when addressing second-person deaths involving family members and acquaintances, including one's own first-person death. To tackle these first- and second-person death-related issues, it is crucial that education about death be incorporated into school curricula. Moreover, as nursing education is grounded in confronting people's health, nursing students must understand and contemplate various aspects of death, including its physical, mental, spiritual, and sociocultural dimensions.

This report analyzes the role of nursing education in the context of an aging society with high mortality rates in Hong Kong and Japan. These two countries share similar demographics but have different policies, systems, education, and cultural backgrounds. Nurses must receive education on the sensitive subject of death in the internationally aging society. They must also establish supportive

relationships with individuals in their final stages of life, collaborate with them to decide how to spend this time, and offer support until the end of life, which is unique to each person.

## Conclusion

This paper aimed to assess the current state of nursing education in an increasingly aging society by comparing the approaches used in Hong Kong and Japan. Researchers from both countries collaborated to discuss EOLC concerning Japan's core curriculum for nursing education, Hong Kong's Guide to the Syllabus of Subjects and Requirements for the Preparation of Registered Nurses, and relevant literature. The study found that while healthcare policies differ between Hong Kong and Japan, nursing education regarding EOLC in both is crucial, encompassing physical management such as pain relief. These allow patients to live their final period according to their own desires. Moreover, this study emphasizes the importance of understanding patients' views on life and death, values, and cultural backgrounds and educating healthcare personnel to apply these principles in their practice flexibly.

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## Conflict of Interest

The authors declare no conflict of interest.

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