CHAPTER 12

CAPACITY BUILDING FOR STAFF AT RESIDENTIAL CARE HOMES FOR THE ELDERLY

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Populations are ageing around the world. In line with escalating numbers of older people living in the community, admissions to Long-Term Care Institutions (LTCI) are increasing. Older people enter LTCI when they are no longer able to care for themselves. For most of these people, an LTCI will be their final "home". Increasing numbers of older people are now dying in LTCIs, rather than in their own homes. As a consequence, there is a growing awareness of the importance of providing high-quality care to residents of LTCIs during their last stage of life.

This chapter reviews international developments regarding end of life care (EoLC) in LTCIs, and particularly the need for promoting and developing EoLC services in residential care homes for the elderly (RCHE) in Hong Kong. It explores capacity building for staff in RCHEs. It outlines the Jockey Club End-of-Life Community Care (JCECC) Project capacity building programme in RCHEs, and presents the outcomes to date of the programme in enhancing the knowledge and skills of staff in RCHEs.

BACKGROUND

EoLC FOR OLDER PEOPLE IN LTCIs

More people around the world are living for longer, and consequently the median age of populations is increasing. This has been mirrored by a rising need for long-term residential care for older people who can no longer live independently because of age-related systems decline. Over the last 20 years in the Western world, there has been increasing concern regarding the quality of death and dying for older people living in LTCI as their "home". EoLC for people dying in aged care residential settings from age-related systems decline differs from conventional palliative care (PC) practices for people dying in hospitals from the ramification of disease.

There are recognised barriers to providing good EoLC in long-term residential care settings (Wowechuk, McClement & Bond, 2007). This includes knowledge, attitudes and beliefs regarding death and dying, and service gaps such as inadequate staffing levels, lack of supervision and inadequate knowledge of EoLC in supervisors and frontline workers (Wowechuk et al., 2007). Developing EoLC programmes in residential care settings requires time, a culture of learning, staff motivation, as well as management support (Watsons, Hockly & Dewar, 2006). With increasingly complex needs and frailty related dependency of older residents, staff may find it difficult to give sufficient time and energy to extend their practices. If an organisation lacks a learning culture, workers are less likely to be motivated to change, or develop (Watsons et al., 2006).

REVIEWING THE LITERATURE ON GOOD EoLC

This section reports on seminal international literature which presents definitions of EoLC, and/or aspirations for improving its quality, to raise awareness of the need for staff in RCHEs to support quality end of life (EoL) experiences.

As long ago as 1999, Age Concern in the UK proposed 12 principles of good death (Age Concern England, 1999, p. 42):

To know when death is coming, and to understand what can be expected

To be able to retain control of what happens

To be afforded dignity and privacy

To have control over pain relief and other symptom control

To have choice and control over where death occurs

To have access to information and expertise of whatever kind is necessary

To have access to any spiritual or emotional support required

To have access to hospice care in any location, not only in hospital

To have control over who is present and who shares the end

To be able to issue Advance Directives which ensures wishes are respected

To have time to say goodbye, and control over other aspects of timing

To be able to leave when it is time to go, and not to have life prolonged pointlessly

The UK National Health Service (NHS) commenced a National End of Life Care Programme in 2004, with its objectives of providing patients with greater choices about place of death, reducing unnecessary emergency admissions of patients who wish to die at home, reducing the number of patients transferred between care homes and hospitals in the last week of life, and improving skills of general staff in the provision of high-quality EoLC (Henry & Hayes, 2009). Support for the living is equally important as support for the dying. Froggatt (2004) identified three stages in the provision of EoLC in LTCIs: (1) concerning living and losses experienced in the LTC facility; (2) supporting patients during the actual dying process and death; and (3) bereavement care after a patient's death.

In 2006, the Australian Government published its Guidelines for palliative approach in residential aged care (Australian Government, 2006). With an aim to support continuous improvement in the quality of EoLC in LTC facilities, the guidelines "incorporate the best scientific evidence available regarding all facets of a palliative approach, including early identification and treatment of physical, cultural, psychological, social and spiritual needs" (Australian Government, 2006, p. 1).

In 2010, the General Medical Council of the UK defined patients "approaching the end of life" as those who are likely to die within the next 12 months, include those people whose death is imminent (expected within a few hours or days) and those with:

- Advanced, progressive incurable conditions;
- General frailty and co-existing conditions that mean they are expected to die within 12 months;
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition; and
- Life-threatening acute conditions caused by sudden catastrophic events (General Medical Council, 2010, p. 8).

In Australia in the same year, Parker, Hughes & Tuckett (2010) published a *Comprehensive evidence-based palliative approach in residential aged care,* which demonstrated that the use of an evidence-based palliative approach and the use of an EoLC pathway in RCHEs improved resident and family outcomes, as well as the quality of terminal care. Moreover, the following components were found to be crucial for the success of the approach:

- A comprehensive palliative approach education programme, with separate education resources tailored to the training needs of all levels of staff to improve staff confidence for providing a palliative approach for residents and families;
- Support from management;
- A systematic approach to Advance Care Planning (ACP) to respect the wishes of residents regarding care decisions including place of care;
- A PC case conference to facilitate the identification of the PC needs of residents and family, and provide a structure for multidisciplinary care planning, as well as to ensure that the care team, residents and family are "on the same page"; and
- Training for staff to convene PC case conferences and use the EoLC pathways (Parker et al., 2010).

In 2011, the World Health Organization (WHO) Regional Office for Europe published its report on *Palliative care for older people: Better practices* (WHO Regional Office for Europe, 2011), which called for member countries to focus attention on improving care for older people with terminal conditions. The report urged member countries to improve EoLC for older people in a range of care settings, including nursing and residential care homes (WHO Regional Office for Europe, 2011).

In the same year (2011), the European Association for Palliative Care (EAPC) Taskforce on Palliative Care in Long-term Care Settings for Older People, was formed to identify and map the various initiatives and strategies used in developing PC in LTCIs across 13 European countries (Reitinger et al., 2013). The results of the mapping exercise suggested that a significant proportion of older people die in LTCIs (e.g. 20% in UK). Residents in LTCIs often had complex trajectories of dying, as many lived with non-cancer comorbidities and there was a high prevalence of dementia. Thus, it was clear that EoLC required a different approach to that taken in conventional PC. This approach involved changes at multiple levels: individual level (resident, family, staff), group/team level, organisational level, regional/network level, and national level (Reitinger et al., 2013).

In any ageing society, there is no doubt of the need to review EoLC needs in LTCIs and prepare LTCIs to implement good quality EoLC. In particular, staff capacity building should be an integral part of any initiative in developing EoLC services in LTCIs, given that EoLC in LTCIs is different from conventional PC practices in hospitals.

THE NEED FOR QUALITY EoLC IN RCHES IN HONG KONG

Hong Kong has a rapidly rising ageing population. It is also the country with longest life expectancy in both men and women. It is expected that by 2030 at least 25% of the Hong Kong population will be older than 65 years (see **Table 12.1**). With a predominantly Chinese population, death and dying are often subjects about which discussion is avoided. Moreover, there is a heavy reliance on hospital care in Hong Kong. Most people will be admitted to hospital during their last few months of life and it is common for residents living in RCHEs in Hong Kong to die in hospital, rather than in their "home". With the high rate of institutionalisation of older people in Hong Kong (around 7% of elderly population) and with their expected high prevalence of chronic illnesses (compared with community-dwelling elderly), ensuring quality death and dying for residents of RCHEs is essential (see **Table 12.2**).

It is common practice that RCHEs in Hong Kong send residents to hospital in their final days of life (to die), rather than manage their death in-house (in the RCHE). This causes disruption to the continuity of care in RCHEs, as well as unnecessary distress to the older person and their family. According to statistics provided by the Hospital Authority (HA) in 2012, of all deaths in medical specialty wards in HA hospitals, the number of deaths of people aged over 60 years was 24,073. Of these, 45% were residents of RCHEs (10,800). This suggests an approximate 15% yearly death rate for aged care home residents (Leung, 2013).

In a study performed in the Kwun Tong District in Hong Kong in four private RCHEs over six months during 2013, 13.3% deaths occurred among residents (mortality rate approximately 26% per year) (Leung & Wong, 2013). The health conditions of those who died in this time period included advanced neurodegenerative conditions (53.8%), end-stage malignancy (21.5%) and end-stage heart and lung conditions (10.8%). It was also found that in the last three months of life, there was an average of three admissions to hospital per person, and the total admission days per person averaged 30. Lee et al. (2013) reported that many residents have frequent transitions between hospital and their RCHE because of unstable physical health and the medical ramifications of approaching death.

Improvements in EoLC practices in RCHE should improve the quality of life (QoL) and quality of death of residents. However, despite care providers trying, where possible, to meet the final wishes of the older person and their relatives, a network of supportive services that assists older people in having a quality EoL experience, may not be available in some RCHEs in Hong Kong. There may be a number of residential aged care settings in Hong Kong which cannot provide EoLC, or there may be a lack of confidence, or fear, when providing it (Luk et al., 2010).

Table 12.1 *Hong Kong Population Projections (2017–2066) (HKSAR Census and Statistics Department, 2017)*

YEAR	NUMBER OF PEOPLE AGE 65 AND OVER (MILLIONS)	TOTAL POPULATION (MILLIONS)	PERCENTAGE OF POPULATION AGE 65 AND OVER (%)
2017	1221.3	7389.5	16.53
2022	1524.5	7657.7	19.90
2027	1891.8	7869.6	24.07
2032	2202.2	8028.0	27.43
2037	2407.0	8163.5	29.48
2042	2541.3	8217.1	30.93
2047	2606.6	8197.1	31.80

Table 12.2 *Institutionalisation Rate of Older People in Hong Kong (Leung, 2013)*

YEAR	NUMBER OF PEOPLE AGE 65 AND OVER	RCHE PLACES	PERCENTAGE OF POPULATION AGE 65 AND OVER IN INSTITUTIONS (%)
01-02	747,052	56,231	7.5
02-03	777,100	60,821	7.8
03-04	795,400	62,941	7.9
04-05	819,000	64,243	7.8
05-06	834,700	66,371	7.9
06-07	852,790	69,044	8.0
07-08	972,200	71,721	8.2
08-09	882,700	72,827	8.2
09-10	893,400	73,663	8.2
10-11	912,100	75,325	8.2
11-12	941,400	75,228	8.0
12-13	977,900	75,416	7.7

To better understand the issues of EoLC practices in RCHEs in Hong Kong, the Hong Kong Association of Gerontology (HKAG) collaborated with the National Institute for the Care of the Elderly (NICE) of Canada between 2007–2009 to study EoLC needs in Hong Kong. Five focus groups were held with 30 participants from five RCHEs, and two roundtable discussions were held with elderly people, healthcare professionals and policymakers. This study found that older people and their family members were supportive of receiving EoLC in RCHEs, rather than being sent to die in hospitals. Policymakers and healthcare professionals were also positive about the development of a culture of providing EoLC in RCHEs. However, areas of concern were raised regarding the development of EoLC in RCHEs, including:

- Care home environment and its logistic arrangement for EoL
- Legal and policy issues
- Staff training
- Support

The most concern was raised regarding the lack of relevant training for RCHE staff. It transpired from this research that most of the care home staff were not familiar with EoLC. Moreover, relevant training and education, including ACP, grief and bereavement, and nursing care for dying patients, was not generally available. RCHE staff may feel uneasy about providing care for dying residents, and this stress may increase the staff turnover rate. Due to difficulty in diagnosis and determination of the nearness of EoL, it was perceived to be difficult for RCHE staff to ascertain if the resident's deteriorating conditions was reversible (or not), particularly if there is no resident doctor available to assist.

TRAINING AND SUPPORT NEEDS OF RCHEs STAFF ON EoLC

Considerable international research has shown that training is helpful for care workers, at all levels of management in RCHEs, to understand and support quality EoLC. However, training content should be designed based on the training needs of staff. A knowledge-transfer project in Hong Kong in 2013 investigated pre-post changes in staff behaviour and knowledge in RCHEs. Significant baseline knowledge gaps were identified in many areas of EoLC (Lee et al., 2013). These largely related to the impact of chronic diseases and symptom management at EoL. Moreover, staff expressed lack of confidence in managing the dying process, as well as in applying residents' ACPs in RCHEs. Communication difficulties between staff, residents and family appeared to result from lack of knowledge in assessing symptoms and providing appropriate comfort care for residents and their families at EoL (Lee et al., 2013). Following training, significant improvements were demonstrated quantitatively and qualitatively using questionnaires and interviews.

Literature also provides insights on a range of specific training needs, as well as required support for care staff to provide quality EoLC in LTCIs. For instance, training that will help staff engage sensitively, respectfully and creatively with dying residents is essential (Percival & Johnson, 2013). To deal with the emotional effects of delivering EoLC to residents who may be well-known to them, staff also need support from management and peers. For example, staffing levels must be sufficient to allow staff to spend unhurried time sitting with dying residents. Moreover, staff should be empowered to provide care in ways that resonate with the resident's personality, life history and wishes, together with the wishes of their relatives, to ensure a "civilised death" (Percival & Johnson, 2013). Having action plans and adopting a standardised approach to care for people in the last days of their life are also viewed as part of the strategies and quality markers for excellent EoLC (Gray, 2011). Having a mechanism in place to ensure that care for individuals is coordinated across organisational boundaries is thus essential for the provision of quality EoLC in RCHEs.

CAPACITY BUILDING FOR HONG KONG RCHE STAFF

This section reports on an innovative Hong Kong initiative to provide culturally appropriate training for staff in RCHEs. Between 2010 and 2016, the HKAG collaborated with The Salvation Army Hong Kong to launch a pilot project called "Palliative Care in Residential Care Homes for the Elderly in Hong Kong". This tested the feasibility of delivering PC in six RCHEs in Hong Kong, through development of care protocols, care guidelines, as well as training and education for staff. Subsequent to the successful pilot project, the HKAG received three years of funding (2016–2018) through the JCECC Project to implement EoLC in 36 RCHEs in Hong Kong. One of the core objectives of this project is to build capacity for staff in RCHEs to enable them to care for terminally ill residents in a better way than before, and to avoid unnecessary hospitalisation.

To assess the EoLC training needs of RCHE staff, HKAG conducted focus groups, interviews and a questionnaire survey in late 2017 to obtain information from staff working with elderly residents. For the questionnaire survey, 111 staff responded, with results showing that over 90% of them agreed that healthcare workers who serve older persons required EoLC training. From the interviews, respondents believed preparation on EoLC for the whole residential care industry was needed, especially for frontline staff who provide day-to-day services to residents and who require the competence to assist residents to have a quality death.

CAPACITY BUILDING CURRICULUM AND TRAINING COMPONENTS

Rationale behind designing the curriculum. The current training curricula in Hong Kong for both professional and non-professional caregivers on EoLC is limited. However, studies show that EoLC education is important to prepare healthcare workers to take care of terminally ill patients (Buss, Alexander, Switzer & Arnold, 2005; Steven, 2014). The needs of a person at EoL can be complicated and complex. Moreover, these people are often not in a situation to be able to express their needs adequately. EoLC education can enhance staff competencies in communication and empathy, and promote positive attitudes towards death and dying. Training can also increase self-efficacy, as well as improve knowledge and psychosocial skills (Adriaansen & van Achterberg, 2008; Duke, 2010; Mok, Wai & Wong, 2002; Mallory, 2003; Wong, Wai & Mok, 2001). Interactive educational programmes can heighten staff awareness, cultural sensitivities and understanding of the needs of older people who are approaching death (Fang, Sixsmith, Sinclair, & Horst, 2016).

DESIGN OF CURRICULA

Engaging all levels of staff in the RCHE. The delivery of EoLC cannot be achieved without the engagement of the whole RCHE. A structured training programme has therefore been designed to target all staff of RCHEs, with two streams of education tailored to professional (see Box 12.1) and non-professional staff (frontline staff) (see Box 12.2). This training programme was developed on the premise that healthcare workers (both professional and non-professional) can provide quality EoLC if education and on-site coaching is provided.

Core elements of the training programme for all staff include symptom control, ACP and Advance Directives (AD), legal and ethical concern in decision-making at EoL, psychosocial and spiritual care, grief and bereavement. Additional training is provided for professional staff to assess and manage symptoms. Training is delivered using multipronged approaches such as lectures, workshops, skill demonstrations and on-site coaching.

Box 12.1

Training programme elements for professional staff

The training content for professional staff of RCHEs includes:

- Ethics and legal issues of EoLC
- Symptom management for terminally ill patients
- Dying symptoms assessment and nursing processes
- Psychological, social and spiritual care of terminally ill patients
- ACP, psychological, social and spiritual care
- Bereavement counselling and handling

Box 12.2

Training programme elements for non-professional (frontline) staff

The training content for non-professional frontline care staff of RCHEs includes some of the professional staff training, sufficient for them to be able to support the professional staff when delivering care, as well as dealing appropriately with residents and their families:

- Ethics and legal issues of EoLC
- Symptom management for terminally ill patients
- ACP, psychological, social and spiritual care
- Communication skills with terminally ill patients and their family members

Emphasis on mindset and attitude change. Supportive attitudes and an empathic culture are essential for delivering quality EoLC, and therefore mindset-changing experiential workshops are provided to all staff in each RCHE before EoLC services are commenced. It has been regularly observed by staff in charge of the RCHEs that, after this workshop, participants have shown significantly positive attitude changes, as well as enhanced empathy, when taking care of residents who are dying.

Supporting the practice through on-site coaching. Ongoing on-site coaching is provided in the participating RCHEs throughout the EoLC service implementation period in order to support staff in putting what they have learnt into practice. This is actioned by a nurse and a social worker from the JCECC Project team designated to each care setting, who "walk along" with staff in their journey towards delivering quality EoLC.

OUTCOME EVALUATION

To understand the impact of the training programme on professional and frontline staff, outcome evaluations were conducted throughout the project. A quantitative approach was adopted using pre-post training measures.

Knowledge enhancement for trained staff on EoLC. To assess the effectiveness of the lectures in enhancing staff knowledge, staff were asked to complete questions on their knowledge regarding the training topics before and after the training session. Paired t-tests were used to assess knowledge gain, and findings showed that the knowledge on EoLC among professional and frontline staff had been significantly enhanced ($p<0.001$). The scores associated with each question are outlined in **Tables 12.3** and **12.4**. **Figure 12.1** provides an overview of the differences in total scores (pre-post training) for professional and frontline staff, and all staff. The score of all staff increased from 2.6 in the pre-test (SD=0.9) to 3.6 (SD=0.7) at post-test, with 4 as the maximum score.

Table 12.3 *Pre-Post Training Scores for Professional Staff*

PROFESSIONAL STAFF				
LECTURE TOPIC	N	PRE-TEST	POST-TEST	DIFFERENCE
Ethics and legal issues of end-of-life care	568	2.71	3.56	0.845***
Terminally-ill patients' discomfort symptoms' handling I	522	2.60	3.68	1.077***
Terminally-ill patients' discomfort symptoms' handling II	500	2.49	3.56	1.064***
Dying symptoms assessment and nursing processes	447	2.86	3.83	0.975***
Care of terminally-ill patients' psychological, social and spiritual needs	459	3.16	3.69	0.532***
Advance care planning and care of family members' psychological, social and spiritual needs	465	2.77	3.63	0.856***
Bereavement counselling and handling	459	3.35	3.79	0.483***

***p<0.001

Table 12.4 *Pre-Post Training Scores for Frontline Staff*

FRONTLINE STAFF				
LECTURE TOPIC	N	PRE-TEST	POST-TEST	DIFFERENCE
Ethics and legal issues of end-of-life care	806	2.52	3.43	0.904***
Terminally-ill patients' discomfort and dying symptoms handling	732	2.69	3.64	0.948***
Advance care planning and care of family members' psychological, social and spiritual needs	725	2.75	3.55	0.799***
Communication skills with terminally-ill patients and their family members	721	1.60	3.18	1.577***

***p<0.001

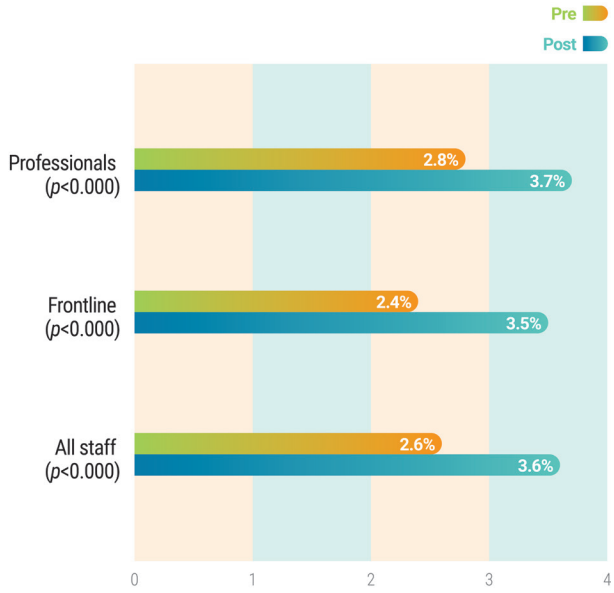

Figure 12.1 Overview of the Differences in Total Scores (Pre-Post Training) for professional and Frontline Staff, and All Staff

Promising results in trained staff's preparedness in EoLC delivery. To assess whether the project had achieved its objectives, staff readiness to deliver EoLC was measured by a 16-item validated questionnaire (Chan, Chun, Man & Leung, 2018). The questionnaire comprised three aspects of willingness, competence and resilience. Each staff member completed the questionnaire at the first activity of the project as a baseline measure, and also at one and two years after joining the project to provide longitudinal comparison. The comparison between baseline and after one year is outlined in **Figure 12.2**. The scores showed consistent improvement in readiness to deliver EoLC in terms of willingness, competence and resilience (**Figure 12.2**).

Figure 12.2 Improvements in Readiness to deliver EoLC One Year after the Initial Assessment (Baseline)

SUMMARY

There are a number of learnings and reflections from the RCHE capacity building curriculum:

- Participants appreciated the on-site training package, which they believed was appropriate in length and depth of content.
- Apart from the lectures and the experiential workshop, participants valued role play and discussion as learning modes.
- On-site clinical coaching, real case planning, demonstration, practice and discussion was helpful.
- Participants found the field visit to PC units in hospitals and nursing homes helpful because they could experience first-hand what the others were doing. Many of them noted that they found that EoLC was not as difficult as they had expected.
- No adjustment was made to the curriculum, although it will be reviewed after the completion of the project.

The strengths and limitations of the curricula are:

- The training is conducted by experienced nurses and social workers, which is important for credibility and case sharing with participants.
- On-site training is appreciated because all the workers in RCHE can join the training.
- The training curriculum is not adequate for leaders in RCHE and the professional workers who want to have more comprehensive training on EoLC. A structured and accredited course is therefore required to better address their needs.

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