CHAPTER

HEALTHCARE PROFESSIONAL CAPACITY BUILDING WITHIN HOSPITALS

Jean Woo

Department of Medicine & Therapeutics, The Chinese University of Hong Kong

professional capacity building of staff working with older patients in hospitals. The approach taken to raise capacity in end-oflife care (EoLC) was structured using the quality improvement Plan, Do, Study, Act (PDSA) cycle, where quality improvement

This chapter presents an overview of is achieved incrementally through iterative PDSA cycles. This chapter details the first cycle and the beginning of the second cycle. These cycles occurred during the first twoand-a-half years of the Jockey Club End-of-Life Community Care (JCECC) Project.

BACKGROUND

OVERVIEW OF TRAINING NEEDS IN AGEING POPULATIONS

Palliative care (PC) services in Hong Kong were first developed for patients with cancer about 30 years ago, following the UK model. PC services in Hong Kong were led by the Society for the Promotion of Hospice Care and supported by the Hospital Authority (HA). The HA subsequently established a small number of hospice beds in hospitals all over Hong Kong. Formal PC training of physicians began with the establishment of the subspecialty of Palliative Medicine shortly after 1997, with the formation of the Hong Kong Academy of Medicine and constituent Colleges. A self-financed postgraduate diploma course in End of Life Care was also offered by the Chinese University of Hong Kong (CUHK) for health and social care professionals from 2007.

A few years later, in line with population ageing and the changing profile of patients in hospitals, it became apparent to geriatricians working in HA that EoLC was also a core component of quality care for non-cancer patients dying from chronic diseases. A continuous quality improvement initiative (CQI) following the PDSA cycle was initiated in Shatin Hospital (a non-acute hospital where geriatric services for the New Territories East [NTE] Region were based and developed). This promoted the perspective that all professionals should be competent in applying PC principles to those at their end of life (EoL). The first PDSA phase documented that the needs and symptoms of non-cancer patients were comparable to those with cancer (Woo, Lo, Cheng, Wong & Mak, 2011). This was followed by the development of training materials for staff; pamphlets for patients and families that were placed in each ward; weekly meetings of multidisciplinary teams to identify those at EoL; and communication skills training through role play (Woo et al., 2009). The evaluation phase showed that there was better symptom control, reduced investigations and reduced length of hospital stay for non-cancer patients at EoL (Woo, Cheng et al., 2011).

A service pathway was subsequently developed to facilitate direct admission of older people into residential care homes for the elderly (RCHEs), supported as much as possible by the Hospital Authority (HA) Community Geriatric Assessment Team (CGAT) in the Shatin Hospital. Under a collaborative model between CGAT, the hospital and the Accident & Emergency (A&E) Department, it was found that 40% patients at EoL could be managed in an extended care facility without compromising their quality of care or survival (Hui et al., 2014). Advance Care Planning (ACP) was subsequently initiated in both the hospital and RCHEs, with the pathway resulting in an average of only four days of acute hospital stay, 1.4 A&E attendances for the last 90 days, and improved self-efficacy and satisfaction of family members. The quality of care was rated at 70% or more for support for patients before death; support of psychosocial well-being of relatives; autonomy and empowerment; and aftercare (HA Convention May 2018 winners of Outstanding Team Award). This model is currently being promulgated to all HA clusters. Regular accreditation visits to all hospitals now have EoL care as an item for regular review. Advance Directives (AD) have been incorporated into computerised electronic health records, and ACPs are being developed in several pilot hospitals in Hong Kong. These have been adopted recently by RCHEs in the New Territories West (NTW) cluster, with the aim of adopting the model throughout the other clusters.

However, the development of EoLC pathways and guidelines have not been accompanied by the skills required to deliver quality care in EoLC by professional staff. This is partly a result of high staff turnover, such that many of those who participated in the original CQI have left the hospital. Thus, the usual view that such care should be the responsibility of trained PC teams prevailed, and the key philosophy that motivated the CQI has been lost. This view has unfortunately been endorsed by the currently prevailing specialist medical organ-based approach to healthcare, which has resulted from subspecialty medical training, and media reinforcement of advances in new disease-focused technologies. Among both professionals and members of the public, there is an over-emphasis on curative treatment and life prolongation, rather than accepting life limitation and optimising quality of the remaining duration of life. This quality gap is apparent at all levels in the hierarchy of hospital services.

The JCECC Project provided an opportunity to close this quality gap. This project involves multiple partners in community, residential care and hospital settings, and it reflects the recent promulgation of compassionate communities as part of the public health approach to EoLC (Abel, 2018). Central to the ever-widening circles of care is the person with illness, whose first contact is most likely to be with hospital staff managing the illness. How this contact is managed will affect the subsequent widening of care circles, and quality improvement is therefore crucial in determining whether subsequent support networks are able to provide the required support. Currently, a large quality care gap exists in hospitals, with respect to estimating and managing the PC needs of frail older patients. For example, it has been estimated that the future principal drivers of need for PC will probably be dementia, rather than cancer, in the UK (Millington-Sanders, 2018). In Hong Kong, the average life expectancy for is between 80-90 years. Approximately 70% patients in general medical wards in Hong Kong hospitals are aged 80 years or older, with 50% classified as frail. Furthermore, between 30-50% reside in RCHEs, and approximately 33% of these have dementia. It is known that the use of hospital services escalates in the last year(s) of people's lives. In this scenario, it may be expected that a substantial number of people admitted to hospital will be at the endstage of life, and that initiation of EoLC conversations are appropriate. EoLC conversations allow discussion with family members regarding the patient's wishes, the intensity of care or life-sustaining treatments, as well as the importance of providing time for preparation and focusing on the most important things to the patient at their end of life.

A recent document, published in the UK, outlines a national framework for local action (2015–2020) (National Palliative and End of Life Care Partnership, 2015). This document promotes the uniqueness of each person, and suggests that this should be recognised by honest and timely conversations, which consider a patient's preferences and provide information for patients and their families to support them in making informed EoL choices. To facilitate this, developing good communication skills should be a key component of doctors' and medical students' training (British Medical Association, 2016). Such training programmes have also been advocated in the US Institute of Medicine report, Dying in America (Institute of Medicine, 2015). An example of such a programme is the Serious Illness Care Programme, which teaches early initiation of serious illness conversations in communication skills workshops (Bernacki et al., 2015).

In acute hospital settings, EoLC "should be everybody's business" (Cox, Brighton & Russell, 2018). Education and training in EoLC should improve the quality of care and the experiences of patients and their families. Due to the increasing number of frail older people in hospitals, EoLC should not be seen as the responsibility of specialists in palliative medicine, but rather viewed as the responsibility of all health professionals. To achieve this, however, challenges to EoLC education have to be addressed. Staff competency should be improved because training should ensure an effective change in mindset and behaviour, particularly in providing holistic care that reflects a patient's and family's viewpoints. Organisational support, continuous training on-the-job, role modelling, roleplay, and audit and evaluation of effectiveness are all important ingredients of a knowledge-based core curriculum. For instance, a key area of competence that requires attention is how to engage in conversations about EoLC, a skill that many doctors and medical students lack (Royal College of Physicians, 2017).

STRATEGIES TO RAISE CAPACITY: THE PDSA QUALITY IMPROVEMENT CYCLE

PLAN

The standard type of educational approach using a stand-alone pre-designed curriculum may not be effective or appropriate in a busy hospital setting, although it may well be relevant in undergraduate training settings. Whichever way education is provided, it needs to be delivered on an ongoing basis, as part of quality assurance to improve quality care. For example, there are currently regular workshops in PC, as well as structured postgraduate programmes, that provide knowledge and skills to those who are already oriented to this area, but not to the majority of hospital staff. Since hospitals place a strong emphasis on quality of care, conduct regular audits in all work units and undergo regular visits from accrediting agencies, EoLC competence would be best anchored as part of a quality improvement framework and reviewed on a regular basis. Since there are hospital-by-hospital variations in staff complements, organisational culture, and patient and family characteristics, capacity building programmes need to be individually tailored to hospitals. In this way, hospitalspecific requirements can be built into training and site-specific incremental improvements can be achieved, using the PDSA CQI cycle. This initiative requires support from the highest administrative levels, such that organisational mindset change may be achieved from top to bottom. At the same time, patients, family members and the general public should also be educated in EoLC to enable EoLC conversations between healthcare professionals and patients. The HA has already created AD forms and has commenced pilot projects in ACP. However, these forms are not often used and there are also many barriers to using AD forms and to ACP, for instance competition for funding by different medical specialties and territorialism, coupled with an emphasis on legal issues resulting in default defensive practice in response to complaints of medical error and/or ageism from relatives when patients die. This culture does not place the patient at the centre of care, neither does it promote the concept of individualisation at EoL.

Raising competency in EoL care among health and social care professionals: the current status in Hong Kong Hospitals. Services for end-stage non-cancer patients are poorly developed in Hong Kong compared with palliative services for cancer patients. This is despite non-cancer patients experiencing many of the same symptoms as cancer patients. Adequate staff training and experience have been identified as key features of quality EoLC, although the predominant curative focus in medical care is a barrier to providing this (Threapleton et al., 2017). A case-note audit was conducted of 61 patients (mean age 84 years) characterised by multi-morbidities and disabilities, who had died in an acute general hospital during the previous 180 days. Over half of these patients had been residents of long-term care homes. The audit found that EoLC conversations occurred for only 21% patients, with no patients having an ACP or AD, although 79% had a "do not attempt cardiopulmonary resuscitation" (DNACPR) order (Au et al., 2017).

There are few measures of competence in caring for patients who are at EoL. As a first step, we sought to obtain an indication of the degree in competence required in death work, using a locally derived and validated death competence scale (Chan, Tin & Wong, 2015). Eight hundred and fifty-five health and social care workers in the eight institutions in the NTE region, who had attended initial talks at a number of hospitals, were invited to complete this death competence survey between January and October 2016. The findings showed that competence related to organisational goals and training varied between institutions. Competence increased with age and personal bereavement experience, and thus, not surprisingly, competence was highest in Bradbury Hospice, which has 25 beds dedicated to the care of the terminally ill. In general, there was no difference in competences comparing nursing staff and personal care assistants. The number of doctors surveyed was too small for analysis. The survey identified important factors contributing to competence, namely personal resources, existential challenges and coping, emotional challenges and coping, and need for improvement in self-competence. The survey showed that there was room for improvement in self-competence in death work among health and social care workers, especially those in younger age groups, nurses and those working in acute hospitals.

The EoL Capacity Building Programme in NTE Pilot under CUHK Jockey Club Institute of Ageing. In the initial programme planning phase, a series of topics were to be covered in workshops or lectures/seminars. These would be delivered in hospitals in the NTE region as a pilot to examine feasibility, uptake and effectiveness, and would also deal with a range of current obstacles to quality EoL care, including:

- » Avoidance and lack of knowledge among hospital staff about how to talk to patients and relatives about death, resulting in default option of drugs, machines, and artificial hydration and nutrition;
- » Lack of knowledge about AD, enduring powers of attorney and other matters in situations where patients are mentally incapacitated; and
- » Lack of knowledge of patient and family regarding EoL choices; the balance between prolonging death with suffering (i.e. poor quality of dying) versus expectation of recovery and cure; and what care is available in hospital settings. This can result in conflict between hospital staff and family members.

The key points of the capacity building and education programme in the NTE region and the community at large included:

- » Identifying patients at their EoL;
- » Promoting ACP through initiating exploratory conversations with patient and family regarding their wishes and preferences;
- » Achieving mindset change among the healthcare community, patients and their relatives and/or caregivers regarding EoLC issues through discussion sessions, forums and workshops based on the principles of medical ethics (Woo et al., 2015); and
- » Partnering with HA in strengthening the quality EoLC model and practices in hospitals, and achieving sustainability through documentation of such practices in the audit and accreditation process.

The capacity building program has four components:

- 1. Conducting sessions for hospital staff (doctors, nurses, social workers, etc.) on the principles of EoLC in the hospital setting, and how to initiate conversations with patient and family members, with an emphasis on ethical principles such as autonomy, benefit and harm with respect to quality of life (QoL), rather than life extension as the goal of treatment. Real cases are discussed; either current ongoing problems or past cases, especially those that resulted in conflict either between family members, between patient and family, or between hospital staff and family. Simulation workshops will also be held for staff to train in communication skills.
- 2. Conducting sessions for family members and patients, who are in and out of the hospital system during the EoL period, to discuss curative versus palliative treatment regimens and how choices can be made by patients and families specific to their clinical conditions, e.g. AD, end-stage dementia, end-stage organ failure, disseminated cancer, etc. This can be achieved in the nature of a support group, where attendees are encouraged to express their points of view.
- Conducting sessions in the community so that older people and their families can prepare for these scenarios both psychologically and materially (making enduing power of attorney and other financial arrangements; nominating family decision-makers; making AD and wills, etc.); and
- 4. Conducting sessions for RCHE staff, where the format and content is adapted to fit the RCHE setting.

The contents of the EoL capacity building programmes vary according to the target audience. The training is delivered via talks using case presentations; group discussions of individual experiences; role play, especially for training of communication skills; and using artistic media, e.g. art, drama.

FOR THE LAY PUBLIC, PATIENTS AND RELATIVES

The topics covered for patients, families and the general public include:

- » What is an AD and how to make it;
- » Understanding the three components of the current AD resulting from the Law Reform Commission recommendations and action by the HA: do not resuscitate; withholding and withdrawing artificial nutrition and hydration; use of mechanical ventilators;
- » Understanding current EoLC service provisions in Hong Kong (both public and private sectors);
- » What happens to the body: practical guide from hospital to cremation/burial;
- » What is power of attorney and how to enact it;
- » Putting financial affairs in order and making wills; and
- » How to initiate discussions regarding impending death: patient and family members; patient and healthcare professionals; family members and healthcare professionals.

FOR HEALTH AND SOCIAL CARE PROFESSIONALS, ADMINISTRATORS AND POLICYMAKERS

The topics covered for healthcare professionals include:

- » How to identify people who are at the EoL;
- » Understanding their physical, psychological and spiritual needs, and plan management according to QoL rather than standard disease management approach; common symptoms encountered; pharmacological and non-pharmacological management of symptoms; existential distress; dealing with unfinished business; anxiety/depression/ denial/anger;
- » Use of AD: when and how;
- » What is power of attorney and how to enact it;
- » Understanding current EoLC service provisions in Hong Kong (both public and private sectors);
- » How to initiate discussions towards the EoL with patients and family members; and
- » Identifying and designing initiatives to overcome barriers to improving the quality of dying.

DO

From January 2016 to February 2018, a total of 201 talks, workshops and seminars were delivered to staff working in HA. The total number attending was 5,939, of which 57 were doctors and final year medical students; 32 were nurses; 52 were doctors, nurses and allied health professionals; and 5 were support staff. In addition, 13 public meetings were held (with 690 people attending) and 31 information sessions held where patients and their family members attended the participating hospitals. Commonly encountered cases were used as illustrations as much as possible.

A case book series based on real-life situations has been developed, emphasising management according to clinical ethics principles. This has involved input from the CUHK Centre for Bioethics and the Ethics Committee of the Hospital Authority, and can be found on the CUHK Jockey Club Institute of Ageing website (www.ioa.cuhk.edu.hk/en-gb/casebook/introduction). This provides open access online resources for all healthcare professionals who face ethical issues when caring for older adults at the EoL.

STUDY

A project team member made observations from audience responses and comments at these events, which serve as an indicator of current perspectives on EoLC. Members of the public welcomed the idea of expressing their wishes early in terms of AD and/or ACP while they were of sound mind, and not in physical or psychological distress, and also while they had the opportunity to discuss matters with their family members. However, many reported that doctors were reluctant to discuss these issues with them and to sign ADs. Nurses were more receptive but expressed difficulties in participating in EoLC plans when the doctors do not initiate EoL conversations. Many doctors equated EoLC with terminal care, and felt that documenting a DNACPR was sufficient. There was little knowledge about the definition of EoL, symptoms and management choices, prescription of drugs, when to initiate EoL conversations with patients and family, ADs and ACPs. At the same time, there was a reluctance to engage in this area, with commonly cited reasons including no time to talk to patients; difficult to make prognosis on life expectancy; and the usual default management position of prolonging life without engaging the patient's or family members' wishes or considerations regarding QoL. Avoidance of EoL issues was also common among final year medical students, who were concerned about the legal consequences of signing ADs. For more details of observations about this first phase, together with examples, see Woo (2017).

ACT

Based on these observations, and with the aim of changing practices and behaviours through mindset change, we formulated additional strategies to engage doctors and medical students. Since EoL care is considered as being largely provided by physicians, we sought to engage physicians by their medical specialties, through different health services projects. For example, many patients dying with chronic obstructive pulmonary disease and heart failure are admitted repeatedly to hospital in the last year of life. Another category is patients who have end-stage dementia being cared for in RCHEs or in infirmaries. The EoL team worked with individual medical specialties in joint projects. As an example, views were elicited through focus groups of patients who had received non-invasive ventilator

support. Common findings were that the treatment was an ordeal, that doctors never gave them a choice to refuse and that patients valued QoL in their remaining time. These views were likely to motivate respiratory physicians engaged in their care to initiate serious illness conversations. Consequently, communications training workshops regarding serious illness were initiated for physicians, physician trainees and final year medical students.

To facilitate serious illness communications, videos were made to describe the course of the disease and treatment options (from life prolongation to comfort care) using realistic scenarios based on current treatment options in hospitals. To date, videos have been made for chronic obstructive pulmonary disease, chronic heart failure and end-stage dementia.

RESULTS OF TRAINING

"In the third year of the project, the same questionnaire with the death competence scale (Chan, Tin & Wong, 2015) was used to understand the change of self-competence of health and social care workers in death work. In 614 questionnaires completed by health and social care workers in RCHEs and seven hospitals in the NTE cluster from February 2018 to June 2018, it was found that participants who had attended more training sessions offered by the Institute perceived higher self-competence in death work as evidenced by a higher mean score on the death competence scale when compared to those who had attended fewer training sessions or none (mean = 63.72 for three and more training sessions; mean = 60.38 for one to two training sessions; mean = 59.68 for no training). The largest benefit observed in training was symptom control (difference between means = 3.19), possibly because it helped participants recognise their contribution to relieving patients' suffering and thus find meaning in their work.

For doctors' communication skills training, twenty post-training questionnaires were collected from doctors in four hospitals right after the training. Percentage increases in their self-perceived preparedness in communication skills ranged from 24.6% to 40.3% (mean = 33.1%) after training when compared to before training. The largest improvement was found in the preparedness to explore goals of care with seriously ill patients or their families. Participants rated the importance of the training to the development of their clinical skills at a mean of 4.35, on a scale from 1 (not at all important) to 5 (very important). The majority (94.7%) would recommend the training to other physicians in their specialty and 89.5% agreed that all higher physician trainees in their specialty should be required to attend the training.

From February 2018 to March 2018, 66 staff (more than half were nurses or social workers) in RCHEs who had attended the training sessions had completed the post-training questionnaires. It was found that respondents participating in more training sessions organized by the Institute had better knowledge of EoL care as manifested by a higher mean score on a 10-item test (mean = 8.77 for three and more sessions; mean = 8.65 for two sessions; mean = 7.86 for one session)."

THE NEXT PDSA CYCLE

PLAN AND DO

Future plans include working closely with hospital management to position this topic as an integral part of quality care in hospitals, utilising the currently existing processes in place (hospital accreditation, ADs, ACPs), specifically:

- » Institute regular audit meetings in hospitals for EoLC as part of mortality and morbidity meetings; document conversations as well as patients' and families; wishes;
- » Conduct regular serious illness communication workshops with the participation of all levels of professional staff, and of different specialties;
- » Use videos as decision aids in such sessions;
- » Continue patient, family and public education regarding choices, and how to carry out serious illness conversations with healthcare professionals;
- » Continue partnerships with bioethics input to highlight the importance of using a bioethics framework;
- » Consider aspects of EoLC required to change culture, and as a basis to resolve conflict; and
- » Include this training as a core element of the final-year undergraduate medical student curriculum.

STUDY

Outcome evaluation plans. The effectiveness of EoLC education may be assessed using the conventional four levels of learning evaluation (Kirkpatrick, 1967):

- 1. Reaction to the learning experience (pre-post questionnaires);
- 2. Changes in confidence, knowledge and/or attitudes (pre-post questionnaires)
- 3. Changes in behaviours (documentation, ADs, ACPs), performance in real or simulated scenarios; and
- 4. Changes in patients' and family members' experience or outcomes.

The EoL case book series with ethical comments in the teaching of healthcare professionals should also be used. It is possible that adding bioethical perspectives may draw more attention to EoL care, resulting in a change of mindset and culture. The adoption rate by various organisations for teaching should also be documented.

SUMMARY

Creation of a compassionate community for EoLC has, at its origin, compassionate care when transitioning from curative care and life prolongation to EoLC. It is at this point that healthcare professionals in hospitals should be fully engaged. This should be woven into the fabric of existing quality care frameworks with regular audits, accompanied by improved training in serious illness conversations for doctors and medical students. Patients and families should be engaged in this process and their perspectives should be the central driver to improving the quality of EoLC.

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