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## **Palliative care education and its effectiveness: A systematic review**

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## **Palliative care education and its effectiveness: A systematic review**

### **Abstract**

**Background:** Palliative care education (PCE) is an important public health approach to palliative care and is crucial to improving its utilisation. The current study aims to develop a comprehensive understanding of PCE and its effectiveness.

**Method:** A systematic review approach, including narrative synthesis, was employed to review qualitative and quantitative studies published in the English language between January 1969 and January 2019, focusing on PCE programs.

**Results:** Thirty-nine research studies were included in the systematic review. The target audience of the included studies were mostly healthcare professionals, followed by family caregivers. Definitions of death and palliative care, symptom management, and communication were leading themes in the reviewed PCE programs. The educational resources used in PCE programs were mainly self-developed teaching materials, with some programs utilising eLearning resources. The included PCE programs were effective in improving knowledge, attitude, and confidence in palliative care, and the satisfaction of participant learning experience.

**Conclusion:** PCE is a useful tool to improve knowledge of, confidence in, and attitudes towards palliative care amongst healthcare professionals and carers. To make palliative care a public health issue, PCE should be expanded to the public and policymakers.

**Key words:** Palliative care knowledge; end of life; death; symptom management; effectiveness

## **Introduction**

Palliative care is an approach to improving the quality of life of patients with life-threatening illnesses and their families. This is achieved by preventing and relieving suffering through early identification, impeccable assessment, treatment of pain, and related physical, psychosocial, and spiritual issues [1]. The World Health Organisation (WHO) [1] pioneered a public health approach to integrating palliative care into a country's healthcare system [2]. Initially, this approach focused on cancer pain relief with public health values by establishing three foundational measures: Education for the public and professionals; drug availability by changing legislation and prescribing practices; and governmental policy to support the other two measures [3]. In previous decades, palliative services have prioritised community engagement by embracing the public health approach to palliative care. The approach improves social responses to, enhances support in, and addresses anxiety about, end of life care for families and communities [4]. Such public health initiatives include the integration of health promotion, community development, and death education into palliative care that was previously focused primarily on clinical care [5].

Even though palliative care enhances quality of life for patients and their families, it remains underutilised [6]. Research has identified numerous barriers to accessing palliative care services, including patient and family reluctance, fear, misconception, ignorance, and under awareness of resources [7]. Knowledge of palliative care could help overcome such fear and misunderstandings of palliative care services and thus improve the utilisation of the services because of the better understanding of the benefits of the services [7]. This is evident in Kozlov et al.'s [6] study reporting that knowledge of palliative care was positively correlated to improved utilisation of palliative care services. To increase the public knowledge and overall awareness of palliative care, PCE is crucial [8], which reflects the WHO Public

Health Model of palliative care that emphasises the education of policymakers, healthcare workers, and the public [1].

Substantial research across numerous countries also supports the notion that PCE is essential to facilitate greater utilisation of palliative care [9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19].

However, there is no comprehensive review of the state of existing knowledge in PCE that can be used as a reliable source of evidence in guideline development in this field. The authors search in Cochrane and PROSPERO indicated that there were no systematic reviews on this topic. To address this research gap and deliver a thorough summary of all the available primary research in PCE, a systematic review of PCE programs is conducted.

Palliative care knowledge is at the core of PCE because the attitude and behavioural changes often begin with experience and knowledge [20]. Targeting the improvement of knowledge delivery, four research questions are proposed:

1. Who were the target audiences of the PCE programs?
2. What was the content covered in PCE programs?
3. Which educational resources were used in PCE programs?
4. Were the PCE programs effective in improving the knowledge, attitudes, confidence of palliative care and the satisfaction in the learning experience?

## **Method**

### *Inclusion and exclusion criteria*

This systematic review was registered in PROSPERO (Reg: CRD42020151415). Inclusion criteria included qualitative and quantitative studies specifically focusing on the PCE programs and published in peer-reviewed journals. Initial exclusion criteria were studies

published in languages other than English and did not have the search keywords in the title or abstract. The sequential exclusion criteria were articles without full-text and studies using data from shared databases (e.g., systematic reviews) to prevent data duplication. A total of six studies did not have the full text, authors of which were contacted. Only after no response was received from the authors, the six articles were excluded from the review.

### *Search strategy*

The data search was conducted in the period between 10 September and 20 October 2019. Seven electronic databases (MEDLINE, PubMed, SCOPUS, CINAHL, PsychInfo, ProQuest, and Google Scholar) were searched for articles published between January 1969 and January 2019. Medical Subject Headings (MeSH) terms of palliative care, end of life, care, care education, grief, terminal illness, cancer care, pain management, dying, death, life-limiting diseases, chronic progressive diseases, life prolonging treatment, hospice, and bereavement were used. The following strategy was used to search the databases: (“palliative care” OR “end of life care” OR “cancer care” OR “terminal illness care” OR ageing OR aging OR dying\* OR death\* OR “dying with dignity” OR “life-limiting diseases” OR “chronic progressive life diseases” OR “life prolonging treatment” OR dementia\* OR “pain management” OR compassion\* OR compassionate\*) AND (family\* OR “family caregiver” OR “family carer” OR “cultural beliefs” OR community\* OR hospice\* OR grief\* OR bereavement\* OR empathy\* OR sympathy\*) AND (“palliative care education” OR education\* OR induction\* OR “educational programs” OR programs\* OR seminars\* OR classes\* OR teaching\* OR teach).

### *Study Selection*

The authors independently assessed the retrieved articles using codes of ‘yes’, ‘no’, or ‘maybe’ to determine eligibility based on whether the studies specifically focused on PCE.

The studies coded unanimously as ‘yes’ were eligible for further quality assessment, whereas the studies assessed with unanimous ‘no’ were removed. The studies coded as ‘maybe’ or with disagreement were discussed until an agreement achieved for either inclusion or exclusion.

The full texts of the eligible studies were assessed for methodological quality using the modified Mixed Methods Appraisal Tool (MMAT) Version 2018 [21]. An agreement index for each study was calculated: “the number of reviewers rating ‘yes’ divided by the total number of reviewers”. A study with an overall agreement index lower than 0.80 was considered as low methodological quality [21]. As suggested by the manual of MMAT 2018, studies with low methodological quality were not automatically removed, they instead were discussed and re-evaluated. Three articles were removed after the re-evaluation due to the lack of information related to the RQs of the current study.

### *Data Extraction*

A standard form was created to extract data, including items of the reference details (including first author, publishing year, country of the study, sample size, analytic methods, content of the program, target audience/participants, educational resources, and effectiveness assessment). The authors assessed the extracted findings by coding the evidence for claims made in the article as ‘unequivocal’, ‘credible’, or ‘unsupported’ [22]. An agreement index for each article was calculated: “the number of reviewers rating ‘unequivocal’ and ‘credible’ divided by the total number of reviewers”. All articles achieved agreement indexes higher than 0.80 without post-discussion.

### *Data synthesis*

A narrative synthesis was used to analyse the data, through which the similarities and differences between the findings of different studies were explored and patterns in the data were identified [23]. A narrative synthesis allows the current study to focus on a wide range of questions, not only the effectiveness of PCE intervention. The following steps were employed to conduct the synthesis: Developing a theory of how PCE works, why and for whom; developing a preliminary synthesis of findings of included studies; exploring relationships in the data; and assessing the robustness of the synthesis [24].

## **Results**

Figure 1 presents a PRISMA flow diagram of articles included and excluded in this review. The literature search identified 2,092 titles after duplicates were removed, 2,027 of which were excluded after title and abstract screening. The full-text methodological quality assessment resulted in 65 articles being eligible for data extraction, 26 of which were further excluded. Thirty-nine studies were included in the narrative synthesis.

INSERT FIGURE 1 HERE

Of the 39 included studies, 23 were conducted in the USA, followed by four in the UK, and three in Canada. Apart from one international study with participants from 14 countries, the remaining studies were conducted in Japan (n=2), Hong Kong (n=2), Australia (n=1), Singapore (n=1), Israel (n=1), and Taiwan (n=1). The sample size of the individual studies varied considerably (n= 2-1,324), with the total number of participants being 5,879. The overview of the studies is presented in Table 1.

INSERT TABLE 1 HERE

### ***The target audience of the PCE programs***



Of 5,879 participants, 4,622 (78.6%) were healthcare professionals (nurses, medical doctors, medical students, and allied healthcare workers). There were 1,030 (17.5%) family caregivers, 121 (2.1%) indigenous community carers (Canadian First Nations elders/knowledge carriers and external health care providers, and African American community carers), 89 (1.5%) patients and 17 (0.3%) volunteers.

### ***The content covered in the PCE programs***

A total of 14 key themes were identified in the included studies. Most of the themes were overlapping across the audience groups with 12 themes common to target audiences and two themes specific to healthcare professionals.

#### *Themes common to target audiences*

Introduction to death, palliative care, and hospice. Eighteen studies (13 studies for health professionals, two for family caregivers, two for volunteers, and one for indigenous community carers) covered the following aspects: definitions of palliative care, hospice, and death in medical and legal terms [25,26,27,28,29,30,31,32,33,34,35,36]; core hospice concepts such as supporting not only the patient but also caregivers and interdisciplinary practices [37]; the theory of ‘circle of care’, philosophies, and principles of palliative care [38,39,40]; death as a developmental story [41]; and trajectories of various end-stage diseases [42]. While the content of this theme largely followed the medical and legal terms of death, the PCE for Northern Plains American Indians (NPAIs) delivered the program by consulting with the targeted indigenous community and employed indigenous language to introduce the concept of death. For example, the information of ‘Wakunza’, a Lakota word for speaking of the concept such as death, was added to the program [29].

Symptom management and medical care. Eighteen studies (16 for health professionals, one for volunteers and one for patients) covered the following areas: pain assessment and management [25,28,30,31,33,34,35,38,40,41,42,43,44,45]; fluids, hydration and nutrition [25,28,38]; seizures [25]; eating and drinking problems and tube feeding [45,46,47]; dyspnoea [28,34,45]; respiratory symptoms [25,42]; fatigue/weakness/immobility [28,34]; delirium/agitation/terminal restlessness [28,45]; cardiac arrest [34,48]; bowel and bladder [25]; neurological symptoms [33]; and depression [45,49]. Pain management was the focus of symptom management. The areas of pain management included pain assessment, impact of pain on quality of life for the patient and family caregivers, barriers to pain management, pharmacologic management of pain, and alternative therapies/non-pharmacologic management of pain [25,28,30,31,33,34,35,38,40,41,42,43, 44,45]. The PCE programs targeted towards volunteers took a holistic approach to pain management, covering not only topics on pain symptomatology but also emotional and mental pain experienced by patients and caregivers during palliative care [38].

Communication. Thirteen studies focused on improving healthcare professionals' communication skills to understand patients' stories, successfully conduct family meetings, and strengthen family relationships [28, 30, 31, 32, 33, 38, 43, 44, 45, 48, 49, 50, 51]. One study focused on improving volunteers' communication skills with patients and their families [52]. The studies emphasised the strategies, skills, and importance of effective verbal and non-verbal communication.

Cultural beliefs of death and palliative care. Fourteen studies (13 for healthcare professionals and one for indigenous community carers) covered the following topics: caring for and communicating with patients and families from varying ethnic and cultural backgrounds [25,30,31,44,52,53]; cultural differences and issues concerning end of life [33,41,54];

Chinese views on dying at home, spiritual beliefs, and the use of Eastern treatment remedies [55]; cultural beliefs, values, and traditions of indigenous people related to end-of-life care [56,57]; and cultural proficiency and competency in end of life care [58,59].

*Ethics, law, and organ donation.* Thirteen studies (12 for health professionals and one for indigenous community carers) discussed the topics of ethical and legal standards of substitute decision making [52]; ethical dilemmas [53]; moral distress in ethical decision making [32]; death certificate and coronation [33]; ethical and legal issues related to medication and euthanasia [33,34]; conflicts between the patients' wishes and those of family members [45]; laws regarding organ and tissue donation [52,59]; and ethical issues associated with breaking bad news, and clinical decision making such as discharge planning, sedation for refractory symptoms, and artificial hydration and nutrition [39,45]. Through the themes, participants learnt who was the substitute decision-maker for an incapable patient, the role of medical staff in ethical decision making, and the importance of information and discussion in the decision-making process around organ donation. There were five articles where ethical and legal issues were discussed in the program but did not provide details [29,31,44,51,54].

*Grief and bereavement.* Grief and bereavement were addressed in 13 articles (12 for healthcare professionals and one for family caregivers), including topics of the expression of grief and the grieving process [60,31,33,38,51,58,59]; bereavement support services [32,43,49]; theories of grief and bereavement [53]; and grief, loss, and bereavement of bereaved parents [30,41]. Participants learned of the five stages of grief; how to address loss, grief, bereavement issues for patients, their families, and the associated healthcare workers; and how to support grieved and bereaved family caregivers.

*Care for the family.* The areas discussed in 12 studies (11 for healthcare professionals and one for volunteers) included: giving the bad news to the family [25]; engaging and interacting

with the family and caregivers [25,33,46,61]; family involvement in decision making [43]; family-centred care [44]; interacting with Latino caregivers [37]; care for the family, family caregivers, and volunteers [38,48,54]; family assessment [61]; and family perspectives on giving and receiving care [59].

Care for the dying. The discussion in 10 studies (eight for healthcare professionals, one for family caregivers and one for community carers) included: caregiving and management in the last days/at the time of death [29,30,31,32,54,58]; patients' preferences in the end of life [46,61]; common symptoms of dying people [60]; and preparing for death at home for home-care agencies [28]. The program for family caregivers discussed common symptoms experienced by the dying person and ways a caregiver can make the dying person more comfortable. The study for community carers discussed caregiving and management of the dying person in their last days which included topics such as medication use and nutrition.

Advanced planning and advanced directives. Six studies (three studies for healthcare professionals and three for family caregivers) addressed this topic in the following areas: advance care planning [60,49,58]; advance healthcare plan [33]; and substitute decision making [52,62]. Apart from learning about advance care planning, the healthcare professionals also learnt how to manage conflict between family members of the patient. The studies oriented towards family caregivers discussed advanced planning and advanced directive, which included information such as the legal processes when the dying will be unable to make decisions themselves.

Spiritual beliefs. Six studies (five for healthcare professionals and one for indigenous community carers) included the topics of patients' spiritual and religious needs [31,33]; spiritual beliefs of death in the Chinese culture [55]; understanding the dying person's

experience from a spiritual perspective [38]; the spirituality of African people [56]; and beliefs and practices around death and dying in different religions [48].

Community resources. Five studies (three for healthcare professional, one for family caregivers and one for volunteers) covered the following information: community services for the bereaved [60]; home support workers [38]; funeral and memorial services [58]; community resources and social support for the patient and his/her family [33,49].

Impact of death on healthcare professionals and volunteers. Four programs (three for healthcare professionals and one for volunteers) included the discussion of volunteer/home support worker grief and coping with stress [38]; support for nurses [32]; and training volunteers [35]. One article did not provide details of the topic discussed in the program [25].

#### *Themes specific to healthcare Professionals*

Healthcare system, institutional issues, and community-based care. Eight studies explored the following topics: lessons from the system failure in end-of-life care [61]; community clinical end-of-life care [55]; healthcare models of excellence in end-of-life care [52]; organisations of palliative care and services provision [33,51]; politics, healthcare system, and palliative care [54,59].

Alternative and complementary remedies. Three studies discussed use of Chinese treatment remedies such as the use of Mugwort (a herb) to facilitate healing and release of toxins from the body [55], and music therapy, which is personalised for the patient and varies from live to televised music [35,54].

#### *Educational resources used in PCE programs*

A total of 26 studies utilised palliative care materials to develop a PCE program for healthcare professionals, 22 of which used self-developed palliative care materials [28,31,32,33,34,36,37,39,40,42,43,44,46,47,48,49,51,53,56,57,58,59] and four of which employed existing online resources [36,46,55,63]. There were three studies that utilised the self-developed palliative care materials to develop PCE programs for family caregivers. Three studies developed PCE programs using self-palliative care materials for indigenous community carers [29], volunteers [38], and patients themselves [42]. Six studies did not provide information on what educational resources were used [25,35,45,54,61,62]. Detailed information of the materials is presented in table 1.

### ***The effectiveness of the PCE programs***

Thirty-one studies conducted either qualitative or quantitative evaluation on the effectiveness of the PCE programs. Among these, 23 studies were quantitative and used self-developed questionnaires to evaluate the effectiveness of the programs using the pretest-posttest design [25, 26, 28, 29, 30, 31, 32, 33, 38, 39, 40, 41, 42, 44, 47, 49, 50, 52, 54, 58, 59, 60, 62]. The areas evaluated included: changes in attitude, knowledge, and confidence in palliative care [26, 28, 29, 30, 32, 39, 40, 41, 44, 47, 49, 50, 52, 58, 59, 62]; participant comfort such as in the discussion of end-of-life care and symptom management [25]; familiarity with hospice and advanced care plan [60]; and fear of and coping with death [38]. The evaluations indicated that all programs demonstrated significant improvements in the evaluated areas, except one study [38], which showed no significant differences in mean death anxiety scores between participant pre- and post-training. However, the same study showed significant improvement in competency in coping with death. Three studies evaluate the satisfaction of curriculum design or the content of the program [31, 33, 54]. The evaluation reported that most of the participants were satisfied with the programs. There was one study that evaluated

the level of satisfaction of family members of the patients with advanced chronic disease who attended the PCE program. The family members reported being satisfied with the improvement of the patients' symptoms [42].

There were seven studies that employed qualitative methods to evaluate the effectiveness of the PCE programs [27, 36, 48, 51, 53, 55, 63]. The evaluated areas included: the content of the program and curriculum design [27, 36, 48, 53, 63], benefits of the simulation learning [55], and satisfaction of the learning experience [48]. The evaluations indicated the PCE programs helped participants to cope with death and dying and end-of-life care in a more positive way [36, 53, 63]. The satisfactory rates of the learning experience ranged from 88% [55] to 100% [48, 51].

There was one study that used mixed-method evaluation [34]. Both quantitative and qualitative data showed improving confidence and competence of healthcare professionals in palliative care.

## **Discussion**

This article reported a systematic review of 39 studies on PCE with a combined sample size of 5,879 participants. The analysis of the PCE programs shows that the majority audience were healthcare professionals, followed by family caregivers and a small number of indigenous community carers, patients and volunteers. This finding is consistent with the newly published systematic reviews on the effectiveness of educational interventions on palliative care, which indicate that most educational programs on palliative care target healthcare workers [64, 65, 66, 67]. The current study reveals that the public and policymakers were not included as an audience in the included studies. The public and policymakers are among those who require education to increase their awareness and change their attitudes, and knowledge related to palliative care [68]. The expansion of target

audience to include public and policymakers will help open dialogues on palliative care and offer a broader opportunity to evaluate the effectiveness of PCE.

The current findings show that symptom management and communication are two dominant themes in the PCE programs. In the included studies, the focus of symptom management is on pain management, which reflects the finding in Wilkie and Ezenwa's review, that pain management is the core element in palliative care [69]. Apart from physical symptom management, there are two PCE programs [45,49] that touched on the topic of depression for the dying. Research has identified that end of life patients often experience feelings of hopelessness with symptoms of anxiety and depression, leading to suicidal ideation in the worst cases [70, 71]. This limitation of the PCE programs warrants future research into this area. Besides symptom management, the current review suggests that communication is also an important element in PCE. This finding is consistent with de Haes and Teunissen's review that identifies the importance of palliative care communication [72]. The areas of communication covered in the reviewed PCE programs include the skills of building a relationship with the dying patients and their families, delivering information, giving advice, and handling emotions during communication [28, 30, 31, 32, 33, 43, 44, 45, 48, 50, 51], which also reflect the findings in de Haes and Teunissen's review [72].

The findings of educational resources used in PCE programs suggest a high level of a variety of educational resources because most programs used self-developed teaching materials. Several PCE programs utilised eLearning resources [36,46,55,63]. This mirrors the findings in Boland et al.'s review regarding the variety of the educational resources in the reviewed studies and that eLearning is growing in PCE [65].

The current review indicates that the PCE programs are effective in improving knowledge, attitude and confidence in palliative care. They are also effective according to the satisfaction



of participant learning experience. This finding is supported by the recent systematic reviews that demonstrate that educational interventions have positive effects in improving healthcare professionals' knowledge and practice in palliative care [64, 65, 66, 67]. According to Kirkpatrick's training program evaluation model [73], there are four levels to evaluate the impact of an educational program: 1) Reaction (participant feeling about the training program); 2) Learning (participant improvement in knowledge, skills, and attitude changes as a result of the training); 3) Behaviour (participant change in behaviour in the workplace as a result of the training); and 4) Organisational results (organisation benefits resulting from the training). Studies included in this review are largely at Level 1 and Level 2 of Kirkpatrick's model, which warrants future studies to evaluate the Level 3 and Level 4 effects of PCE.

The main limitation of the current study is that a meta-analysis was not conducted to evaluate the PCE programs' effectiveness under review. A meta-analysis was not conducted for two reasons. Firstly, the majority of studies included in the systematic review could not be included in the meta-analysis because these studies did not report pre- and post-test scores before and after the participants underwent the PCE program. Only eight studies provided such information. Secondly, these eight studies employed self-developed measures to evaluate effectiveness. There was a lack of standardised scales to measure pre- and post-test scores, resulting in a high level of methodological heterogeneity. While the effectiveness of the included PCE programs could not be meta-analysed in this review, the programs' effectiveness is evaluated via the narrative synthesis.

Despite the limitation, this systematic review offers some implications for public health. The current review shows that PCE is effective, but only reaches a fraction of people, mainly healthcare professionals and family caregivers, which warrants a call for a public health strategy in PCE. A public health strategy advocates an approach to translating palliative care

knowledge and skills into evidence-based, cost-effective interventions that can reach a wider population [74]. PCE for the public and policymakers thus may function as a tool to construct significance and stimulate policy development, which may bolster the credibility of palliative care as a ‘public health issue’ [75]. Identifying palliative care as a public health issue will help develop stronger palliative care policy and practice, and convey valuable resources from the field of public health to palliative care [75].

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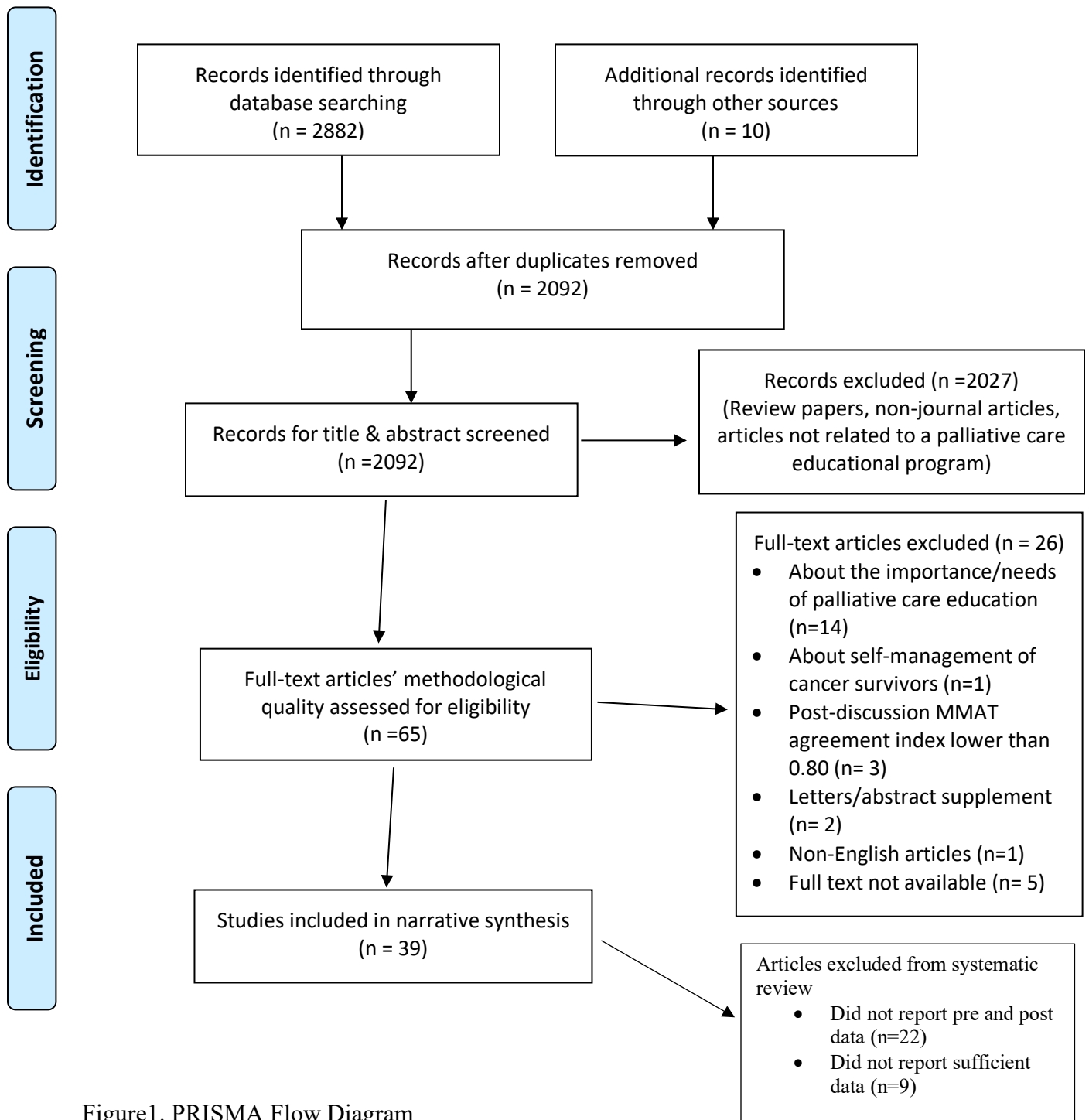


Figure1. PRISMA Flow Diagram

Table 1. Overview of the studies reviewed

Article referencing	Country	Type of research and educational approach	Content of the program	Targeted audience/ participants	Educational resources
Bagatell R, et al., 2002 <sup>[25]</sup>	USA	Quantitative study  Interactive learning approach	Six-Session seminar series: 1. Defining death in medical and legal terms 2. Symptom management 3. Roundtable discussion 4. Caring for patients of cultural and linguistic different (CALD) background 5. Death in the context of family 6. Impact of death on doctors, nurses and their families	12 Paediatric residents	No information
Bangerter LR, et al., 2018 <sup>[61]</sup>	14 Countries	Qualitative study  Interactive learning approach	1. Patient/family/caregiver engagement 2. Integrating health and community-based social care 3. Eliciting and honouring patient preferences 4. Building evidence-based palliative care 5. Learning from system failures 6. Delivering end of life care in low-resource countries	66 health leaders from 14 countries	Self-developed Salzburg Global Seminar (SGZ)
Bobianski K, et al., 2016 <sup>[55]</sup>	USA	Qualitative study  Simulation-based learning approach	1. An end-of-life scenario was established in a home-based setting in the community simulation apartment 2. The simulation scenario included recognising traditions from the Chinese culture (views of dying in the home, spiritual beliefs and the use of Eastern treatment remedies) 3. Students role played family members, the registered nurse (RN) and nursing students	60 nursing students	Dying in America (2014); Specific case studies related to CALD groups; and a community simulation apartment.
Braun KL, et al., 2006 <sup>[60]</sup>	USA	Quantitative study  No information provided in publication	Five end-of-life topics: 1. Advance care planning 2. Funeral and memorial services 3. Care for the dying 4. What to do when a loved one dies 5. Help for the bereaved	570 family caregivers, including White, Asian, Pacific Islanders and mixed White-Asian-Pacific Islander ethnicity.	Educational booklet - The Complete Life Booklet

Brezis M, et al., 2017 <sup>[46]</sup>	Israel	Qualitative study  Simulation-based learning	Six scenarios based on the following four topics: 1. To elicit preferences for EOL care from a patient or from a relative; 2. to handle conflicts between siblings or within the team; 3. to handle requests to do “everything”; 4. to explain whether to put in a feeding tube.	1,324 healthcare workers (physicians, nurses, social workers, dieticians, clinical psychologists, physiotherapists, senior executives)	Simulation of six EOL scenarios; three published papers in relation to EOF care; the Dying Patient Act; video-based group discussion
Browning DM & Solomon MZ, 2005 <sup>[43]</sup>	USA	Qualitative study  Interdisciplinary educational approach	Five curriculum modules: 1. Engaging with Children and Families 2. Relieving Pain and Other Symptoms 3. Analysing Ethical Challenges in Paediatric End-of-Life Care 4. Responding to Suffering and Bereavement 5. Improving Communication and Strengthening Relationships	The curriculum was promoted at the Initiative for Paediatric Palliative Care (IPPC) National Conference in 2003, participants included 500 Healthcare practitioners, social workers, psychologists, chaplains, child life specialists, administrators, and researchers.	IPPC: Printing materials of the modules and selected published papers
Carter BS & Swan RS, 2012 <sup>[44]</sup>	USA	Quantitative study  No information	Five topics for a one-day training: 1. Communication and decision making, 2. ethics, 3. cultural humility, 4. family- and patient-centred care, and 5. pain and symptom management.	26 participants: seven physicians, eight nurses, four social workers, three child life specialists, two chaplains, two bereaved parents.	Printed topical material, PowerPoint presentation slides, award-winning case-based videotape prompts and discussions from IPPC
Chung K, et al., 2017 <sup>[37]</sup>	USA	Qualitative study  No information	A 10-minute hospice video in Spanish featuring a real patient with end-stage of Alzheimer: 1. The patient and the patient’s family members providing an illustration of a core hospice concept—supporting not only the patient but also caregivers 2. Interviews with many bilingual interdisciplinary hospice team members to illustrate another core concept of hospice care—the interdisciplinary team	90 students, hospice staff members, Latino caregivers, physicians and palliative care nurses participated in different stages of developing the video	A 10-minute hospice video

Claxton-Oldfield S, et al., 2007 <sup>[38]</sup>	Canada	Quantitative study No information	The training program consisted of nine sessions presented in three-hour blocks during a nine-week period: 1. Introduction to palliative care 2. Understanding the dying person's experience—spiritual issues 3. Understanding the dying person's experience—communication 4. Understanding the dying person's experience—aspects of physical care, and final hours (the dying process) 5. Understanding the dying person and families' experience—grief, and bereavement 6. What happens after death occurs 7. Volunteer grief/home support worker grief, coping with stress 8. The role of the volunteer, home support worker: personal care of the client 9. Home support workers: pain and symptom management/nutrition	17 Palliative care volunteers	Self-developed Palliative Care Volunteer Training Program
Cruz-Oliver DM, et al., 2016 <sup>[26]</sup>	USA	Quantitative study No information	1. PowerPoint Presentation Introduction: A seven-slide PowerPoint presentation that contains hyperlink to the telenovela 'Caregivers Like Me'. 2. Caregivers Like Me Telenovela: A video soap opera (telenovela) about a caregiver struggling to care for her loved one at home and how health-care providers help her keep patient at home. 3. PowerPoint Presentation Conclusion.	145 Latino family caregivers	Self-developed PPTs and the Caregivers like Me telenovela.
Cruz-Oliver DM, et al., 2018 <sup>[27]</sup>	USA	Qualitative study No information	Same as in Cruz-Oliver, et al. (2016)	145 Latino family caregivers	Same as in Cruz-Oliver, et al. (2016)

<p>Ferrell BR, et al., 1998<sup>[28]</sup></p>	<p>USA</p>	<p>Quantitative study No information</p>	<p>Five Modules over a six-month period:  1. General overview of palliative care and end of life issues  2. Pain management  3. Symptom management  4. Communication with patients and their families  5. The death event</p>	<p>52 Nurses, home aids and other healthcare professionals</p>	<p>Self-developed Home Care Outreach for Palliative Care Education (HOPE): The materials included an outline of lecture content, presentation of a case study, key references, a list of resources, and a bibliography for further reading. An additional "agency resource kit" was also developed, including videotapes, books, and other written materials.</p>
<p>Ferichs L, et al., 2012<sup>[29]</sup></p>	<p>USA</p>	<p>Quantitative study Indigenous learning approach</p>	<p>1. Introduction to end-of-life caregiving  2. Medication management  3. advance directives,  4. Caregiving in the last days  5. Ethical and legal issues</p>	<p>315 family caregivers from ten tribal communities in the Northern Plains region participated in the program.</p>	<p>Focus-group-tested materials of the Northern Plains Comprehensive Cancer Control Program (NPCCCP) specifically for Native American communities, including presentations, small group discussions, and interactive games.</p>
<p>Hagiwara Y, et al., 2008<sup>[50]</sup></p>	<p>USA</p>	<p>Qualitative study No information</p>	<p>Curriculum for medical students to lead family meetings in palliative care:  1. 60-minute online communication module on conducting a family meeting  2. 60-minute small group activity (role-paly the tasks of leading a family meeting)</p>	<p>674 medical students</p>	<p>Self-developed 60-minute online module on how to conduct a family meeting</p>



<p>Hales M &amp; Hawryluck L, 2008<sup>[52]</sup></p>	<p>Canada</p>	<p>Quantitative study Interactive learning approach</p>	<p>One-day workshop:  1. Cultural issues  2. Ethical and legal standards of substitute decision making  3. Communication within the health care team  4. Conflict among substitute decision makers  5. Organ and tissue donation  6. Intractable conflict</p>	<p>36 Critical care practitioners</p>	<p>End of Life Decision Making Performance Improvement Coaching Program: Educational materials were developed to reinforce key learning points, adapting modules from the Ian Anderson Continuing Education Program in End of Life Care from the University of Toronto and the Trillium Gift of Life Network.</p>
<p>Healy J, et al., 2017<sup>[47]</sup></p>	<p>USA</p>	<p>Quantitative study Experiential learning approach</p>	<p>Activity palliative care day:  1. Educational event where role-play modelled by attending or fellow physician using the bedside teaching tool with a standardized patient/family member  2. Practice using the bedside teaching tool with a colleague, record in log, and submit through student blackboard system</p>	<p>247 third-year medical students</p>	<p>The curriculum consists of a case-based module The Last Hours of Life, demonstration, and learner role-play using the bedside teaching tool</p>

Holmstrom EC, 2013 <sup>[56]</sup>	USA	Qualitative study  No information	The curriculum includes a wide range of topics: 1. Spirituality 2. Cultural beliefs, values and traditions of African Americans that may influence end-of-life care 3. The impact of racial disparities throughout the healthcare continuum 4. Barriers to quality care for African Americans with serious illness and strategies to improve their care	A planning committee (the number of committee members unknown) was formed, consisting of the medical director and nurse manager for the palliative care service, the director of diversity, the hospital's community health nurse, and the palliative care chaplain.	APPEAL: A Progressive Palliative Care Educational Curriculum for Care of African Americans at Life's End. Resources included: The Unbroken Circle: A Toolkit for Congregations around Illness, End of Life, and Grief; and other resources from the National Hospice and Palliative Care Organization (NHPCO) such as the 'African American Outreach Guide' and 'It's About How You Live in Faith: Community Outreach Guide' .
Jacobs HH, et al., 2009 <sup>[30]</sup>	USA	Quantitative study  Cognitive learning approach	The curriculum consists of ten modules: 1. Introduction to paediatric palliative nursing care 2. Special considerations in paediatric palliative care 3. Communication 4. Ethical/legal issues discusses 5. Cultural considerations 6. Pain management 7. Symptom management 8. Care at the time of death 9. Loss/grief/bereavement 10. Models of excellence	211 Paediatric nurses	End-of-Life Nursing Education Consortium (ELNEC): The 1,000-page ELNEC-PPC curriculum, including lecture notes, PowerPoint slides, experiential teaching strategies, case studies, and key references for each of the ten modules

Kataoka-Yahiro MR, et al., 2017 <sup>[58]</sup>	USA	Quantitative study  Cognitive learning approach	A ten-week palliative and hospice care training for ethnic diverse staff in nursing homes: 1. Advance care planning—Making choices known 2. Planning ahead—Funeral and memorial services 3. Preparing to say good-bye—Care for the dying 4. When death occurs—What to do when a loved one dies 5. Help for the bereaved—The healing journey	52 staff members from two nursing homes	Along with the culturally specific strategies, the training included use of role modelling (e.g., invitation of community leaders or advisors during the dying process), case-study discussion using storytelling and problem-solving, and use of visual information (e.g., photos of local people—patient and families in Hawaii and places in Hawaii).
Kelley ML, et al., 2018 <sup>[57]</sup>	Canada	Mixed-method study  Indigenous learning approach	Four customised palliative care programs in First Nations communities: 1. Fort William First Nation 2. Naotkamegwanning First Nation 3. Peguis First Nation 4. Six Nations of the Grand River Territory	94 First Nations community carers, (elders/knowledge carriers and external health care providers)	"The Developing Palliative Care Programs in First Nations Communities Workbook" was created. The workbook, organised according to the First Nations' adapted model, outlines the capacity development approach and provides practical resources developed in the four communities.

Konrad SC, 2010 <sup>[53]</sup>	USA	Qualitative study  Browning & Solomon's (2006) relational learning approach	1. Diverse death and grieving rituals and customs, ethical dilemmas, theories of grief and bereavement 2. Assignment based on Selzer's (1998) short story "Whither Thou Goest" to reflect students' moral, ethical and personal responses to the characters' dilemmas in the story 3. Assignment to conduct a mini-survey or conceptual paper in relation to death and grief	35 social work students	Death, Loss & Grief in Social Work Practice, including empirical articles, book chapters, short stories, poetry, film clips and guest lectures
Leow M, et al., 2015 <sup>[49]</sup>	Singapore	Quantitative study  Psychoeducational approach	Caring for the Caregiving Program (CCP): 1. Cope with stress, frustration, depression and grief 2. Improving communication between the patient and caregiver 3. Social support 4. Knowledge on advanced care planning, community resources and managing the death of a patient	80 hospice caregivers	The CCP consisted of a one-hour face-to-face session, a video clip, two follow-up phone calls, and an invitation to an online social support group.
Lillyman S, et al., 2011 <sup>[48]</sup>	UK	Qualitative study  Interactive learning approach	Themes from the storyboarding: 1. Decision making for not resuscitating a patient 2. Beliefs and practices around death and dying in different religions 3. Lack of confidence when dealing with cardiac arrest situations 4. Communication and interpersonal skills for approaching a family 5. Understanding the boundaries of care 6. Support expected by families from professional staff when a patient is dying	41 second-year nursing students	Storyboarding technique: Storytelling and sharing using words and drawings

Malloy P, et al., 2014 <sup>[31]</sup>	USA	Qualitative study  No information	Five-day course with eight modules: 1. Introduction to palliative nursing 2. Pain management 3. Symptom management 4. Ethical issues 5. Cultural and spiritual considerations 6. Communication 7. Loss, grief, and bereavement 8. Final hours	38 nursing leaders from fourteen countries	End-of-Life Nursing Education Consortium (ELNEC): Computer lab for literature searches, visited a local hospice, reviewed the WHO measures for palliative care as a public health issue, received instruction on quality improvement efforts, discussed ways to advocate for palliative care, and worked in small groups to set professional goals.
Murakami M, et al., 2015 <sup>[32]</sup>	Japan	Mixed-method study  Simulation-based learning approach	Two-day Neonatal EOF Care Education Program with six modules 1. Introduction to the main concepts of neonatal EOL care 2. Ethical decision making 3. Care of the dying neonate 4. Bereavement care for families 5. Communication with families 6. Support for nurses	30 nurses in neonatal intensive care units	Relevant reading materials, PowerPoint slides, and simulations of neonatal EOL care were used based on the existing palliative/EOL care training programs based on existing palliative/EOL care training programs.
Price J, et al., 2014 <sup>[51]</sup>	UK	Qualitative study  Interactive learning approach	One-day program: 1. Hospice site visit in the morning 2. Health care and nurse education in the US and UK 3. Case studies covering the areas of ethical issues, loss, child/family-centered care, communication, inter-professional roles, and care and service provision.	69 participants: 44 nursing students from the US and 15 nursing students and 10 midwifery students from the UK	Presentations, case studies and group discussions

Rawlinson F & Finlay L, 2002 <sup>[33]</sup>	UK	Quantitative study  No information	The Diploma program in Palliative Medicine (DPM): <ol style="list-style-type: none"> <li>1. Communication with patients and their families</li> <li>2. The treatment of pain</li> <li>3. Assessment and diagnosis of pain</li> <li>4. Multi-professional team working</li> <li>5. Psychological responses to illness and bereavement</li> <li>6. The concept of palliative care</li> <li>7. Management of gastrointestinal symptoms</li> <li>8. Management of other symptoms</li> <li>9. Treatment and progression of incurable disease</li> <li>10. Ethical issues surrounding death and dying</li> <li>11. Management of neurological symptoms</li> <li>12. Judging quality of life</li> <li>13. Other professionals' attitudes to death and dying</li> <li>14. Patients' spiritual and religious needs</li> <li>15. Organization of palliative care services</li> <li>16. Controlled drug regulations)</li> <li>17. Death certification and the coroner</li> <li>18. Euthanasia and the medical prolongation of life</li> <li>19. Procedures for relatives following a death</li> <li>20. Allocation of scarce resources</li> <li>21. Cultural issues</li> <li>22. Financial issues and allowances available</li> <li>23. Aids and appliances</li> </ol>	263 past students of the Program	A distance learning course of palliative medicine
Schiffman JD, et al., 2008 <sup>[41]</sup>	USA	Quantitative study  No information	Six-hour Paediatric Palliative Care Curriculum (PPCC) with six sessions: <ol style="list-style-type: none"> <li>1. Personal coping skills</li> <li>2. Being a caring professional</li> <li>3. Recognise cultural and familial differences</li> <li>4. Pain management</li> <li>5. Practical issues</li> <li>6. Meeting a bereaved parent</li> </ol>	48 paediatric resident doctors	EOL literature & local expert discussion

Schim SM & Raspa R, 2007 <sup>[54]</sup>	USA	Qualitative study  Narrative -learning approach	The WSU End-of-Life Interdisciplinary Project (EOLIP, four hours/week for fifteen weeks): 1. Introduction 2. Narrative theory and My Life (video) 3. Medical conversations about dying 4. Death as a developmental story 5. Physical processes—What happens at death? 6. Information needs at the EOL 7. Ethical/moral stories 8. Legal stories 9. Spiritual stories 10. Professional and health systems stories 11. Political and economic stories 12. Alternative and complementary methods 13. Hearing family stories 14. Death as a cultural story 15. Summary and course evaluation	Master's and doctoral level students (number unknown)	Unknown
Selmen L, et al., 2016 <sup>[34]</sup>	UK	Mixed-method study  Cognitive learning approach	Two-day Transforming End of Life Care (TEoLC): 1. Understanding the last days of life and healthcare professionals' duties 2. Managing uncertainty and the AMBER Care Bundle 3. Helping people achieve preferred place of care and managing Fast Track discharges 3. Symptom assessment and management 4. Medication issues in palliative care including ethics and the law 5. Advance care planning and the final days of life 6. Difficult conversations and addressing uncertainty 7. Spiritual and cultural aspects of dying 8. Family support and bereavement	236 healthcare professionals worked in hospitals (42%), community (55%) and research & student placements (3%).	Self-develop resources of TEoLC, the course teaching including lectures, group work related to case studies and clinical scenarios (e.g., discharge planning), interactive workshops, and question and answer sessions.

Simons M. 2004 <sup>[35]</sup>	USA	Qualitative study  No information	End of Life Program 1. Information to patient/loved ones before and after death 2. Angel cart for relaxation and pain control 3. Massage therapy 4. Food 5. Open visiting hours 6. EOF rooms 7. Music 8. Chaplain services 9. A memory box 10. Specially trained volunteers	Nurse leaders (number unknown)	No information
Stein GL, et al., 2009 <sup>[59]</sup>	USA	Quantitative study  No information	Cultural Proficiency in EOL Care Practice with six three-hour modules: 1. Culture and cultural proficiency 2. Principles of palliative care 3. Death and bereavement 4. Ethics, law, and policy; organ donation 5. Family perspectives on giving and receiving care 6. Professional issues of leadership/institutional issues	56 healthcare practitioners	Cultural Proficiency in EOL Care Practice: Lectures and discussions
Tsai SSL, et al., 2008 <sup>[39]</sup>	Taiwan	Quantitative study  No information	Four-hour multi-module curriculum: 1. Principles of palliative care 2. Clinical management of palliative care 3. Beliefs about ethical decision-making in palliative care	259 fifth-year medical students	The palliative care curriculum included a 1-hour lecture, 1-hour patient contact, 1-hour literature reading, and 1-hour discussion.
Turner L, et al., 2015 <sup>[63]</sup>	Australia	Qualitative study  No information	90-minute compulsory class on palliative care (details unknown)	20 social work students	Materials on the Palliative care Curriculum for Undergraduate Students (PCC4U) website.



Waters CM, 2000 <sup>[62]</sup>	USA	Quantitative study Interactive learning approach	A two-hour Community-centred Educational Group Forum on EOL care directives, involving listening, dialogue and action (Content of the forum unknown)	27 African American community carers	Unknown
Weissman DE, et al., 1999 <sup>[45]</sup>	USA	Qualitative study No information	Seven educational domains: 1. Symptom control 2. Communication skills 3. Use of technology in EOL care 4. Ethics 5. Needs and values of the patient and family 6. Other care setting 7. Legal issues	In Acute Care Hospital settings	Unknown
Wong FKY, et al., 2001 <sup>[36]</sup>	Hong Kong	Qualitative study Problem-based learning approach	Three problems of death and dying with three scenarios each were constructed for discussion: 1. A child with leukaemia 2. A middle-age woman with lung cancer 3. A suicidal patient	72 fourth-year nursing students	The learning package titled "A PBL Manual for Self-Directed Learning in Applied Psychology: A Practice Guide", outlining the process of PBL, the roles and responsibilities of students and tutors, the learning objectives, the learning resources, guidelines for group discussion, the construction of the learning journals, and the student self-evaluation worksheets.

Woo J, et al., 2011 <sup>[42]</sup>	Hong Kong	Quantitative study  No information	End of Life Qualitative Improvement seminar: 1. Definition and trajectories of various end-stage diseases 2. Common end-stage symptoms 3. Symptom management	89 patients with advanced chronic diseases not opting for active treatment	The EOL Qualitative Improvement seminar: consisting of service reengineering, provision of guidelines and educational material, and interactive sessions to achieve cultural change among staff.
Yoshioka S, et al., 2014 <sup>[40]</sup>	Japan	Quantitative study  No information	Five-session of the End of Life Nursing Education Consortium (ELNEC): 1. Basic knowledge about care for family and theories related to EOF nursing care 2. Basic knowledge of family assessment 3. Presentation of case studies based on family assessment 4. Pain management 5. General symptom management	25 nurses in general ward	The End of Life Nursing Education Consortium (ELNEC): the family assessment sheet, lecture materials, PowerPoint presentations