Palliative care in the Greater China region

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Palliative care in the Greater China region: a systematic review of needs, models and outcomes

Running title: Palliative care in the Greater China region

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Abstract

Context. There is rapidly increasing need for palliative care in Greater China due to rapidly aging populations.

Objectives. This study aimed to systematically review and appraise evidence for palliative care needs, models of care, interventions, and outcomes in Greater China.

Methods. Four databases (MEDLINE, EMBASE, CINAHL, PsycINFO) were searched, with hand searching of local journals and databases. Narrative synthesis was applied to the qualitative and quantitative evidence.

Results. Nineteen qualitative studies and 47 quantitative studies were retained. With respect to care needs, nine themes were synthesised: pain control, reduced aggressive end-of-life care, truth telling, physical, emotional and spiritual support, and achieving preferred place of care/death. Informal caregivers expressed their needs for education and burden reduction. Healthcare professionals called for training and national policy support. Twenty-four studies evaluated interventions, mostly among advanced cancer patients. Positive effects were suggested for improvements in quality of life, pain, anxiety and depression, readmission rate, and costs. Models of care evaluated were mostly specialist palliative care delivered in various settings (hospitals, residential care and home). Outcome measures used were grouped into six categories of construct: quality of life, pain, physical assessment, psycho-spiritual assessment, quality of care, and implementation assessment. Limited rigorous randomised controlled trials is available to document intervention outcomes, and some problems (such as high attrition rates) reduced the strength of the evidence.

Conclusion. Palliative care services within Greater China should pay more attention to management of non-malignant disease, and to integration into primary services. Policy support is key to establishing culturally appropriate person-centred services.

Key words

Palliative care needs, interventions, outcomes, Greater China, systematic review

Key message

In the large and ageing Greater China populations, patients want honest communication, and for care to achieve their wishes for place of death. The current evidence base suggests effective models of care are largely focused on cancer, and little data from primary care. Outcome measures should be revalidated locally.

Introduction

Palliative care is a human right (1), but is a neglected dimension of global health. (2) About 25·5 million of 56·2 million people who died in 2015 experienced serious health-related suffering, and another 35·5 million experienced serious health-related suffering due to life-threatening and life-limiting conditions. More than 80% of these 61 million individuals live in low-income and middle-income countries (LMICs) with severely limited access to any palliative care, even oral morphine for pain relief. (2) Projections suggest that serious health-related suffering in the last year of life is projected to increase by the year 2060 from 26 to 48 million people. (3) The majority of these people (83%) will live in LMICs, and the greatest increase globally will be for cancer (109%). In upper middle-income countries (e.g. mainland China), an 87% increase in serious health-related suffering at the end of life is expected. Universal Health Coverage (UHC) (4) and World Health Assembly (WHA) Resolution (5) call for palliative care to be integrated into national health services, accessible globally for all individuals and communities in need.

The Greater China region (Hong Kong, Macau, mainland China and Taiwan) is a Chinese cultural community sharing similar values and behaviour patterns. (6, 7) In the past 30 years, this region has experienced fast-growing economic development and rapid demographic change. (8) United Nations (UN) estimates more than 14.6 billion people lived in Greater China during 2019. (9) By 2020 the proportion of the population aged over 65 in Hong Kong, Macau, mainland China and Taiwan will be 18.1%, 11.9%, 12.2% and 15.6% respectively. (10) World Health Organisation (WHO) defines Hong Kong and Taiwan as "aged societies", and Macau and mainland China as "aging societies". (11)

Evidence shows that palliative care can improve quality of life, and reduce unnecessary suffering and costs, and access to palliative care should be improved as a core component of health systems. (2) The 2015 Quality of Death Index ranked quality of death across the globe, placing Taiwan 6th, Hong Kong 22nd, and mainland China 71st (Macau was not included). (12) Palliative care provision and planning must respond to the needs of patients, family caregivers and health care professionals, and build on existing evidence. Previous reviews of palliative care needs, models of care, interventions, outcomes and outcome measures have been reported in other countries and regions. (13-16) Although palliative care research activity is increasing in Greater China (17-20), systematically appraisal of existing evidence is needed to identify gaps and inform development. This study aimed to systematically review and appraise evidence for palliative care needs, models of care, interventions, and outcomes in Greater China. The specific review questions were: (A) What is the evidence for palliative care needs among people in the Greater China region? (B) What models of care and palliative care interventions have been reported in this region? (C) What is the evidence of effectiveness? (D) What is the quality of the evidence?

Methods

This systematic review followed Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (21) and the Centre for Reviews and Dissemination (CRD) (22) guidelines to identify peer-reviewed literature. Our study was registered with PROSPERO (CRD42019152625).

Search Strategy

We searched MEDLINE (from 1946), EMBASE (from 1974), CINAHL (from 1978), and PsycINFO (from 1806) to 23rd September 2019. The published language was restricted to English, Traditional Chinese and Simplified Chinese. The search terms were shown in Table 1. Our search strategy was to run the search terms in group 1 and group 2 separately, then ran the union of these two results with "and".

Local journals in Hong Kong and Macau were hand searched in September 2019, including Medical Journal of Kiang Wu Hospital (from 2010 to 2018), Macau Journal of Nursing (from 2002 to 2018), Revista de Ciências da Saúde de Macau (from 2002 to 2010), Asian Journal of Gerontology and Geriatrics (from 2006 to 2019), Hong Kong Medical Journal (from 1995 to 2019). Local electronic databases in mainland China and Taiwan were searched in October 2019, including China National Knowledge Infrastructure (Mainland China), WanFang Data (Mainland China), Airiti Library (Taiwan), Lawdata (Taiwan), and Taiwan National Central Library system (Taiwan).

Table 1 here

Selection Criteria

Inclusion criteria: qualitative and quantitative studies focusing on adult patients (aged 18 years old or above) with incurable conditions, informal caregivers or health care providers from the Greater China region. We included the studies aimed to determine at least one of the following: care needs, models of care, interventions, outcomes, and outcome measures. Any health-related measures such as patient reported outcome measures, proxy measures, experience measures and cost measures were included.

Exclusion criteria: case studies, reviews, conference abstracts, expert opinions, programme descriptions or non-peer-reviewed publications. We excluded cross-national studies that did not disaggregate data from Greater China. The definition of key terms draws from previous reviews. (14, 23) (see Table 2)

Table 2 here

Data Extraction and synthesis

The data extraction table was developed and piloted by two reviewers (H.C. and P.G.). Data was extracted and reviewed by H.C. and consensus agreed with P.G. A third reviewer (R.H.) was consulted to resolve any disagreement. The main information extracted included first author name, publication year, study site, aim, design, study duration, number and type of participants, care setting, intervention and comparison, outcome measures, and main findings. Data synthesis was conducted following the Guidance on the Conduct of Narrative Synthesis in Systematic Reviews (24) and thematic analysis (14, 25) since both qualitative and quantitative data were included. Meta-analysis was not conducted due the heterogeneity of aims, designs and outcomes. The findings were presented in narrative form, and conceptual mapping was used to explore relationships in the data.

Quality Appraisal

The quality of included studies was assessed using the Standard Quality Assessment Criteria for Evaluating

Primary Research Papers from a Variety of Fields. (26) Our review did not adopt the summary score cutoff inclusion criterion as assessment of the quality of the existing evidence in this region was one of this review's focus. We adopted quality assessment standard from the previous studies. (14, 27) For quantitative studies, the SC was defined as follows (27): strong (SC≥0.80), good (SC=0.71-0.79), adequate (SC=0.50-0.70) and limited (SC <0.50). For qualitative studies, the SC was defined as adequate quality (SC≥0.55) and low quality (SC≤0.54). (14)

Results

The search strategy identified 16,713 studies, and an additional 32 studies were identified from hand searching. The PRISMA flow chart is shown in Figure 1. After removing 7,040 duplicates, 9,587 studies were excluded in the title screen phase. Of the 118 studies which were examined in the abstract screen phase, 52 studies did not meet inclusion criteria. This review retained 19 qualitative studies (28-46) and 47 quantitative studies (47-93). The study characteristics was shown in Table 3.

Figure 1 here
Table 3 here

Study settings

Of the 66 studies, 30/66 studies were conducted in Taiwan (28, 29, 32, 33, 39, 42, 49-53, 55, 57, 58, 60, 65, 67, 69, 71-76, 78-80, 82, 87, 88); 18/66 were conducted in Hong Kong (30, 31, 34, 35, 38, 43, 47, 48, 54, 59, 61, 63, 66, 68, 77, 83, 84, 86); 16/66 were conducted in mainland China (36, 37, 40, 41, 44-46, 62, 64, 70, 85, 89-93); 2/66 were conducted in Macau. (56, 81)

Study designs

Among the 47 quantitative studies (47-93), 34/47 studies were observational studies, including 23 cross-sectional studies (47-60, 62, 65, 69, 70, 72, 78, 89, 92, 93), 8 longitudinal studies (61, 71, 74-76, 79, 82, 88), 1 case-control study (67), and 2 cohort studies. (73, 80). Thirteen studies were experimental studies, including 8 randomised controlled trials (RCTs) (63, 77, 81, 83, 85-87, 90), 4 pre-posttest studies (64, 66, 68, 91), and 1 cost-effectiveness study. (84) Among the 19 qualitative studies (28-46), 17/19 studies were individual interviews (28-33, 35-38, 40-46), and 1 focus group interview (34) One study (39) retrospectively reviewed medical records and transformed it into quantitative data.

Study populations

The 66 included studies comprised 25,501 participants. Of these, 56/66 studies (28-33, 35, 37-39, 41, 44, 47-50, 52-55, 57-88, 90-93) collected data from patients (n=21,441), 11/66 studies (42, 43, 46, 52, 53, 56, 58, 68, 70, 82, 92) from informal caregivers (n=3,615), and 6/66 studies (34, 36, 40, 45, 51, 89) from healthcare providers (n=445). The vast majority of studies (53/66) were of cancer palliative care. (28-33, 35-41, 43, 44, 46-48, 50, 52-58, 60, 62-65, 67, 69-76, 78-82, 85-88, 90-93)

Study aims

6

Palliative care needs were described by 17 qualitative studies (28-36, 38-45) and 25 quantitative studies (47, 50-53, 55-58, 60, 61, 65, 69-72, 75, 76, 78, 80, 82, 88, 89, 92, 93). Models of care were described by 5 qualitative studies (31, 34, 35, 37, 46) and 24 quantitative studies. (48, 49, 51, 54, 57, 59, 62-64, 66-68, 73, 74, 77, 79, 81, 83-87, 90, 91) Palliative care interventions were evaluated by 2 qualitative studies (37, 46) and 22 quantitative studies. (48, 49, 54, 59, 62-64, 66-68, 73, 74, 77, 79, 81, 83-87, 90, 91)

A) Palliative care needs (n=42)

Nine themes were synthesised in thematic analysis: (1) Patients need for a better pain control (47, 55, 60, 71); (2) Patients need for reduced aggressive end-of-life care (29, 44, 45, 50, 52, 89, 92); (3) Identifying and meeting preferred place of care and death (51, 69, 70, 93); (4) Patients need for truth telling (29, 53, 56, 58, 61, 65, 72, 75, 76, 88); (5) Patients need for physical, emotional and spiritual support (28, 30-35, 38, 39, 41, 57, 78, 80, 82); (6) Healthcare professionals need for training (40, 45); (7) Informal caregivers need for end-of-life care education (43, 45); (8) Informal caregivers need for relieving care burden (43); and (9) The lack of national policy support. (36, 42, 45)

Theme 1- Patients need for a better pain control

High pain prevalence was reported across studies, with 69.9% of N=2,185 terminal cancer patients reporting they usually or almost constantly had pain (55); 47.4% of 1,370 terminal cancer from 24 hospitals reported they had unsatisfactory pain relief. (60) Among 237 hospice cancer inpatients, 31.2% found no pain improvement. (71) Pain and its management were a concern for both patients and their families with terminal cancer, with 30.8% reporting inadequate pain relief. (47)

Theme 2- Patients need for reduced aggressive end-of-life care

Patients describe preferences reported patients wished a "peaceful" and "natural" death, avoiding excessive treatment and dying with dignity. (44, 89) Aggressive treatment is common, with active anti-cancer therapies administered to terminal patients in an acute setting. (29) The movement of patients between locations to receive treatment in advanced cancer is of great concern to health care professionals. (45) Lack of information regarding palliative care may lead patients to choose life-sustaining treatments. (50)

Theme 3: Identifying and meeting preferred place of care and death

Studies concur that home is the preferred place of death. (69, 70, 93) However, barriers to uptake of home-based hospice care are: "unable to manage emergent medical conditions", "the quality of care in the hospital is better", and "insufficient number of caregivers". (51) Three studies illustrated home death is the preferred place of death for most terminal cancer patients. Chen et al. (69) recruited 1,114 terminal cancer patients in Taiwan and showed 54.7% preferred home death. Two cross-sectional studies in mainland China reported 53.64% among 522 terminal cancer patients (70) and 79.61% among 755 terminal cancer patients preferred to die at home. (93)

Theme 4: Patients need for truth telling

The family custom of "white lie" often conceals prognosis from patients, and families commonly believe that disclosure is inappropriate, although patients may believe they have information rights over family members. (29, 53, 56) There is however consensus across studies that patients report negative emotional effects from not knowing their prognosis. (61, 65, 75) Being informed of prognosis is necessary to enable patients to make informed choices, with lack of knowledge being strongly associated with choice of aggressive treatment at end of life. (72, 75, 88)

Theme 5: Patients need for physical, emotional and spiritual support

Poor symptom relief is associated with worsening psychosocial wellbeing among patients. (78) Common burdensome symptoms include disturbed sleep, fatigue, drowsiness, delirium, dyspnea. Patients called for a focus on the social impact of symptoms and a focus on education and support thorough symptoms not solely medical management. (31, 57, 78) Emotional support needs included existential distress from anticipation of a poor future, failure to engage in meaningful activities and relationships, having regrets, fear of unpredictable disease progression and death. (28, 34, 39)

Hospitalised elderly patients reported a need for spiritual care, and advanced lung cancer inpatients reported that "they didn't expect nurses to provide spiritual care, but when quality interpersonal care was given it gave them strength and spiritually supportive". (32, 33) Spiritual care promotes perceived healing, provides life wisdom and searching for belonging in the future world, while playing a pivotal role in death preparation and continuing bonds with ancestors. (30, 32-34, 41)

Theme 6: Healthcare professionals need for training

Healthcare professionals who worked with and been exposed to dying cancer patients in mainland China expressed their skill needs for end-of-life communication, psychological care, and dispelling negative myths and fears for patients (40) as well as dealing with pressure from families. (45)

Theme 7: Informal caregivers need for end-of-life care education

Spousal caregivers expressed the need for medical knowledge since they must be active participants in cancer care. (43) The healthcare professionals who worked in non-palliative care settings expressed the urgent task of educating the public on death. (45)

Theme 8: Informal caregivers need for relieving care burden

Spousal caregivers expressed their care burden in balancing between duties with care of their dying loved ones and other roles and duties to family and work. (43)

Theme 9: The lack of national policy support

Oncology health care professionals acknowledge the demand for advanced directives for terminal patients and their families but find this difficult to implement due to the lack of relevant policy and legislation. (36) For dementia patients, a suite of necessary policy initiatives were identified including advance care planning, aged care community, home-based palliative, and institutional care. (42)

Exploring relationships in the data

Nine themes were rearranged according to demanders, including care recipients (pain control, reduced aggressive end-of-life care, preferred place of care and death, truth telling, and support), informal caregivers (education and relieving care burden), and healthcare providers (training and national policy support). The conceptual model (14, 24) was used to show the relationships in the data for palliative care needs (Figure 2).

Figure 2 here

B) Models of care (n=29)

The definition of model of care in this review based on the recommendations by the Western Australian Department of Health (Table 2). (23) Models of care that delivered specialist palliative care services in various settings were reported in 15/29 studies, including hospitals (49), inpatient hospice units (31, 34, 35, 48, 57, 64, 67, 74), nursing home (66) and home-based care. (54, 62, 68, 73, 79) Models of care that provided services regardless of diagnosis were reported by 9/29 studies. These short-term services worked in an integrated way with original palliative care provision, including advance care planning (87, 91), meaning of life review (37, 63, 86), fan therapy (81), music therapy (85), nutrition support (90), and family conference. (46) Models of care to address palliative care needs during the illness trajectory were reported by 5/29 studies, including discharge planning from inpatient hospice to home care (51), and palliative care needs in patients with end-stage renal disease (59) and heart failure. (77, 83, 84) No study reported model of care on identifying partnerships between specialist palliative care services and primary and community care providers.

C) Evaluation of palliative care interventions (n=24)

Table 4 summarises the findings from studies evaluating palliative interventions. The majority of studies (16/24) (37, 48, 54, 62-64, 67, 73, 74, 79, 81, 85-87, 90, 91) recruited patients with terminal cancer. Nine studies (37, 46, 62, 63, 81, 85-87, 91) reported symptom management interventions, including advance care planning (87, 91), fan therapy (81), music therapy (85), meaning of life review (37, 63, 86), family conference (46) and the impact of diagnosis knowledge. (62) Fifteen studies assessed palliative care service delivery within inpatient settings (48, 64, 74, 90), home (54, 68, 79), and nursing home. (66) Three studies (49, 67, 73) conducted comparison between different care services. One case-control study (67) compared the effect of inpatient hospice care to usual care. A cohort study (73) compared home-based care to inpatient hospice care. A cross-sectional study (49) compared the effect of three hospice care services (inpatient hospice, home-based hospice, and hospice team consultation) in Taiwan to acute care. Palliative care services for patients with non-malignant diseases were assessed in four studies (59, 77, 83, 84), including inpatient patients with end stage renal disease (59) and a transitional home-based palliative care programme for heart failure patients. (77, 83, 84)

9

Outcomes and outcome measures

Outcomes were categorised into six types: (1) quality of life, (2) implementation assessment, (3) physical assessment, (4) pain management, (5) quality of care, (6) psycho-spiritual assessment. Quality of life was the most common outcome measured, and the most commonly used measure was the McGill scale (Table 5). Six quality of life measures have been validated within the Greater China region, including McGill (94), HCPI (48), SF-36 (59), EORTC-QOL-C30 (62), QOLC-E (63), and CHO-C (83). Implementation of palliative care was assessed in terms of cost (49, 67, 73, 84) and satisfaction of care. (49, 68, 77, 83) Four measures were used to assess physical function, including ESAS (77, 83), PPS (77, 83), modified mCCI (59) and symptom reporting form. (59, 74) Two studies used a combination of measures to assess specific physical function such as respiration (81) and nutrition. (90) VAS (79), NRS (54, 85), FLACC (85), BPI (59, 85) and opioid prescriptions rate (67) were measured for pain. Measures of quality of care comprised the rate of receiving aggressive procedures (67), home death (73) and readmission (68, 77), length of hospital stay (68, 73), effect of intensive communication on advance care plan (68) and concordance between preferred and received life-sustaining treatments. (87) Two studies (86, 87) used the HADS to assess symptoms of anxiety and depression.

The evidence of effectiveness

The effectiveness of six palliative care interventions was assessed in 9 RCTs. (63, 77, 81, 83-87, 90) Of the two studies (63, 86) focusing on the effects of the meaning of life reviews, one (63) showed a significant improvement on quality of life, but the other (86) failed to demonstrate a significant improvement on psychological symptoms. Three studies (77, 83, 84) investigated the effectiveness of a transitional home-based palliative programme, and they showed a significant reduction on readmission rate (77) and improvement in quality of life. (83) This programme (84) was also proved to be more cost-effective than the standard current palliative care service. The 5-minute fan therapy for dyspnoea (81) and music therapy for pain relief (85) demonstrated significant benefits in symptom management among patients with terminal cancer. One study on advanced care planning (87) suggested positive effects on reducing anxiety and depression, and an intervention incorporating nutrition support therapy in palliative care service showed a significant improvement on quality of life and nutrition status. (90)

The evidence from non-randomised studies was assessed in 15 studies. (37, 46, 48, 49, 54, 59, 62, 64, 66-68, 73, 74, 79, 91) Four studies (48, 64, 67, 74) investigated the effects of inpatient hospice care, and they showed a significant improvement on quality of life (48, 64), symptoms control, (74), opioids prescription (67), and a significant reduction on aggressive procedures and costs. (67) Of the four studies (54, 68, 73, 79) focusing on the effects of home-based palliative care, two studies demonstrated a significant improvement on quality of life (68), facilitating advance care planning communication (68), better pain control (79) and reducing hospital readmission rate. (68) One study (73) also showed

significant benefits in improving care quality and lowering costs without undermining survival time compared to inpatient hospice care. An intervention incorporating palliative care service in dialysis therapy for patients with end-stage renal disease suggested a positive effect on quality of life. (59) A dignity-conserving end-of-life care model for nursing home residents failed to demonstrate a significant improvement on quality of life. (66) One study (49), which compared three palliative care models (inpatient, outpatient, and hospice team consultation) with acute care in Taiwan, did not demonstrate a significant benefit in quality of life, satisfaction with care, and costs. Patients who did not know their diagnosis showed a significantly better quality of life at physical and emotional subscale compared to patients who knew their diagnosis. (62) One study on advanced care planning (91) suggested significantly positive effects on improving quality of life and facilitating terminal cancer patients to decline life-sustaining treatments. The effects of a three-week life review programme (37) and family conferences (46) were explored by using semi-structured interviews.

Quality assessment
For the 19 qualitative studies, 11/19 were appraised as adequate quality (28, 29, 31-35, 37, 38, 40, 45), and 8/19 as low quality (30, 36, 39, 41-44, 46). For the 47 quantitative studies, 18/47 were appraised as strong (52, 53, 57, 60, 67, 69, 72-77, 80, 82, 83, 87-89), 5/47 studies (59, 61, 84, 86, 93) as good, 17/47 studies as adequate (49-51, 54, 55, 58, 62, 63, 65, 66, 68, 70, 71, 78, 79, 85, 92) and 7/47 studies as limited (47, 48, 56, 64, 81, 90, 91). This review included 9 RCTs (63, 77, 81, 83-87, 90). The results of risk of bias assessment (Table 6) identified some factors which may contribute to bias, including lack of double blinding, lack of details about randomisation and blinding, high attrition rates, and not reporting sample size calculation.

Table 6 here

The comparison of studies in the Greater China region
Table 7 summarises the comparison of included studies in the Greater China region. The study populations in patients (28/56) (28, 29, 32, 33, 39, 49, 50, 52, 53, 55, 57, 58, 60, 65, 67, 69, 71-76, 78-80, 82, 87, 88) and informal caregivers (5/11) (42, 52, 53, 58, 82) were mainly from Taiwan. However, the viewpoints of healthcare providers were mostly collected from the studies in mainland China (4/6). (36, 40, 45, 89) Of the 29 studies evaluating models of care, most studies from Hong Kong (7/13) (31, 34, 35, 48, 54, 66, 68) and Taiwan (6/8) (49, 57, 67, 73, 74, 79) focused on how to deliver specialist palliative care services in various settings. The studies from mainland China (5/7) reported mainly about the integration of short-term services into the original palliative care provision. (37, 46, 85, 90, 91) Among the 24 studies evaluating palliative care interventions, in which 9 RCTs (63, 77, 81, 83-87, 90) were comprised, most studies (10/24) (48, 54, 59, 63, 66, 68, 77, 83, 84, 86) and RCTs (5/9) (63, 77, 83, 84, 86) were conducted in Hong Kong.

The studies from Taiwan demonstrated more influence on the themes of pain control (3/4) (55, 60, 71), truth telling (8/10) (29, 53, 58, 65, 72, 75, 76, 88), and support (8/14) (28, 32, 33, 39, 57, 78, 80, 82). For

the studies from mainland China, the impact was shown on the themes of reduced aggressive end-of-life care (4/7) (44, 45, 89, 92), training (2/2) (40, 45), and national policy support (2/3) (36, 45). The theme of relieving care burden was generated by one study (43) from Hong Kong. The proportion of low-quality studies among qualitative studies in Hong Kong, mainland China and Taiwan was 25%, 50%, and 25% respectively. With regard to limited quality studies among quantitative studies, the proportion in Hong Kong, Macau, and mainland China was 28.6%, 28.6%, and 42.8%.

Table 7 here

Discussion

This systematic review synthesised the available qualitative and quantitative evidence from the peer-reviewed literature and from different perspectives by using narrative approach. To our best knowledge, this is the first systematic review of existing evidence on palliative care needs, models, interventions, outcomes and outcome measures in the Greater China region. However, some evidence gaps were revealed in this review that deserve further study. A limited number of rigorous RCTs (9 [38%] of 24) evaluating palliative care interventions was identified, and few of the included studies (5 [8%] of 66) addressed the issues of palliative care provision for patients with non-malignant diseases. Furthermore, there was no study reporting models of care on identifying the partnerships between specialist expertise and primary and community services. According to the previous review (95), which collected studies from countries within the Organisation for Economic Co-operation and Development (OECD), the integration of specialist palliative care into primary and community services is important to ensure the wider coverage of palliative care for terminally ill patients without complex needs in community or at their home. This partnership may help primary care providers to strengthen their care skills (23) and may also increase the chance to achieve home death for those who prefer to die at home. (95) This review found that the majority of patients (53.64-79.61%) expressed their wishes for dying at home, which echoed the increasing preference of dying at home in the global context. (96) However, it is worth noting that the included studies of exploring place of death preferences in this review were conducted on terminally ill cancer patients with no non-malignant patients.

Improving quality of life is considered as an important goal for palliative care. The most commonly used outcome identified from this review was quality of life. However, it was hard to compare results of these studies since self-adapted instruments were used. Furthermore, various domains and number of items were measured in different quality of life measures and the results did not show a consistent pattern across all domains or subscales. Indeed, the multi-dimensional characteristic of quality of life evaluation could better capture the holistic impact of palliative care interventions. However, the impact and effect of these interventions should be interpreted with caution. Future studies should carefully select quality of life measures, which have been validated in the Greater China region and will be more contextually appropriate to use.

The need for better pain control has always been an important issue, and specialist palliative care has

been proved to provide terminally ill patients a better symptom control in previous research. (97) An unmet care need for pain control was illustrated in this review. This review also highlighted that terminal cancer patients cared in non-hospice settings (47.4-62.4%) had a higher rate of participants with uncontrolled pain compared to other palliative care settings (30.8%). However, this finding may result from the different definitions of pain control and recall time adopted in different studies, e.g., "inadequate pain control for the last three days" (47), "unsatisfactory pain relief within one week of admission" (60), and "suffering from pain at the time of interview". (55) No studies in this review discussed the cause of poor pain control. Some possible causes of poor pain control for Chinese people were reported in previous studies, including traditional belief against opioids (98-100) and poor compliance to opioids due to the use of traditional Chinese medicine for pain control. (101, 102) Five included studies (23%) reported palliative care interventions on pain management by using various outcome measures (VAS, NRS, FLACC, BPI, opioid prescriptions rate). Among these measures, the FLACC is a behavioural observation pain scale which was originally developed for infants and children assessment (103) and may be inappropriate for study (85) among communicative adults with terminal cancer.

In traditional Chinese culture, relatives' views play an important role when making end-of-life care decisions. (104) Therefore, respect for autonomy often becomes one of the major challenges for healthcare providers. (104) This review identified healthcare professionals' perspectives regarding the pressures from patients' family members. (45) The needs for "truth telling" was also related to Chinese culture. Most included studies pinpointed the association between truth telling (e.g. diagnosis disclosure) and end-of-life care outcomes (e.g. preference for life-sustaining treatments and psycho-spiritual burden). In addition, this review also identified one RCT (87) in which the effectiveness of advance care plan was evaluated. However, the results did not show statistical significance in enabling terminal patients to receive their preferred end-of-life care. The implementation of advance care planning in this region is still in the early stage, and future research is needed to develop culturally sensitive strategies, guidelines, policies, and to increase public engagement. (105-108) Within Taiwan, since this review was conducted, ACP has been culturally adapted to overcome some of the western cultural bias that underpins its concept and practice. (109, 110)

The results of end-of-life research are crucial to raise the awareness and guide the development of person-centred palliative care to formulate corresponding models of care and interventions. (14) To our best knowledge, many regions have conducted an initial well-conducted systematic review to inform national policy change or research gaps, such as Australia (95) and the Caribbean. (14) However, in the Greater China region, relevant evidence in palliative care is fragmented. Therefore, this study aimed to systematically review all available evidence in palliative care in context of Chinese culture, which included Hong Kong, Macau, mainland China, and Taiwan. However, the results showed the distribution of studies' sources were not even, in which the majority of included studies was from Taiwan (30 [46%] of 66), RCTs was conducted in Hong Kong (5 [56%] of 9), and 2 studies (2 [3%] of 66) were from Macau. These results may all reflect the difference in the development of the palliative care systems. For example, this review

identified 2 RCTs in Taiwan and mainland China evaluating the effectiveness of ACP, but the implementation of legally binding ACP is only in Taiwan and just started in 2019. (110, 111) In Hong Kong, the public consultation paper on advance directives was released in 2004, and the first guidance for hospital clinicians on advance directives was issued in 2010. (112) On the contrary, in mainland China, first national palliative care guideline was released in 2017, and the acceptance of ACP is not uniform among different provinces. (18, 113) Therefore, the difference of palliative care development could be related to the findings in palliative care needs, such as the needs of training (2 [100%] of 2) and national policy support (2 [67%] of 3) for healthcare professionals which were mainly based on the studies from mainland China.

This review has several limitations to consider. First, this review only included studies written in English, and Simplified or Traditional Chinese, which limits the possibilities to capture the articles published in other languages. However, in addition to searching in key medical databases, we also hand-searched the local journals and databases in the Greater China region. Therefore, it is unlikely that any English and Chinese articles were missed. Furthermore, since two authors involved were bilingual (English and Chinese), this review has limited the possibility of losing the original cultural meaning in the process of translation. Second, the heterogeneity of disease diagnosis, comparators, outcomes and outcome measures, varied palliative care policies, and study designs constrained the ability to conduct meta-analyses in this review. Lastly, this review only included two studies in Macau, which might limit the generalisability of our results in Macau.

Conclusions

The palliative care intervention evaluations demonstrated positive effects on improving quality of life and reducing pain, anxiety and depression, readmission rate, and costs. Nine themes were identified for care needs from perspectives of care recipients, informal caregivers, and healthcare providers. The models of palliative care play an overarching role to fulfill these unmet care needs. Some gaps still need effort to fill in future research, including the lack of rigorous RCTs, a scarcity of palliative care research on patients with non-malignant diseases and a need to further explore models of care and identify the partnerships between specialist palliative care and primary and community services. The results of thematic analysis highlighted the unmet needs from perspectives of care recipients, informal caregivers, and healthcare professionals, which may inform the development of person-centred culturally appropriate palliative care to address those needs. Policy support is key to establishing culturally appropriate palliative care services in this region and achieving UHC goals and ensure that palliative care is well integrated into existing health system and available for all individuals and communities in need in Greater China.

Disclosures and Acknowledgements

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Table 1. Search terms

Group 1	Group 2
"terminal illness" OR	"Hong Kong" OR
"advanced cancer" OR	"Macau" OR
"dying" OR	"Macao" OR
"end of life" OR	"Mainland China" OR
"hospice care" OR	"China" OR
"palliative care" OR	"Taiwan" OR
"terminal care"	"Republic of China" OR
	"the Greater China" OR
	"Chinese"

Table 2. Definitions of key terms used in this review

Terms	Definitions (14, 23)
Palliative care patient	Patients with certain primary diseases have a palliative period, the period when the disease has become progressive and emphasis is not placed on cure but quality of life that follows.
Health care needs	➢ Capacity to benefit from health care. ➢ Perceived health care needs as experienced by the patient, professionally defined health care needs as those services defined by health professionals and scientifically confirmed needs.
Models of Care	➢ Provides services for patients with life limiting illness regardless of diagnosis. ➢ Addresses the palliative care needs of patients and their families during their illness trajectory. ➢ Delivers care in any setting-hospital, palliative care unit, residential care or home. ➢ Identifies partnerships between specialist palliative care services and primary care providers.
Interventions	To relieve suffering and improve quality of life for those who are living with, or dying from, a terminal/advanced illness.
Outcomes	Change in a patient's current or future health status that can be attributed to antecedent health care.

Table 3. Summary of included studies (N=66)

First author (year)	Study settings	Aim	Methods	Participants	Sex distribution	Age (Mean/Range)	Quality score
Lin et al. (1997) (28)	Taiwan	Investigate the perceived needs.	Qualitative In-depth and semi-structured interviews	N=14 Terminal cancer patients with hospice care.	5 male/9 female	49.6/27-71	0.65
Yang et al. (1999) (29)	Taiwan	Identify attributes that define the content domain of health related QOL.	Qualitative In-depth and semi-structured interviews	N=14 Terminal cancer patients from acute ward.	66% male/34% female	46.24/21-79	0.95
Chung et al. (1999) (47)	Hong Kong	Patient-related barriers to cancer pain management.	Quantitative Cross-sectional study	N=39 Cancer patients with pain in palliative care unit.	24 male/15 female	57.5/9-77	0.45
Yeung et al. (1999) (48)	Hong Kong	Effect of inpatient hospice care.	Quantitative Cross-sectional study	N=52 Terminal cancer patients.	30 male/22 female	65.3/ not informed	0.45
Yang et al. (2001) (49)	Taiwan	Effect of different hospice care.	Quantitative Cross-sectional study	N=123 Terminal patients in medical centers.	81 male/42 female	65.12/47-68	0.70
Mak (2002) (30)	Hong Kong	Gain an understanding of what it means to die a "good death".	Qualitative Semi-structured interviews	N=33 Terminal cancer patients from inpatient hospice unit.	17 male/16 female	67/34-86	0.30
Chiu et al. (2004) (50)	Taiwan	Terminal cancer patients' wishes and determine influencing factors toward the provision of ANH.	Quantitative Cross-sectional study	N=197 Terminal cancer patients in inpatient hospice unit.	102 male/95 female	62.7/ not informed	0.70
Hu et al. (2004) (51)	Taiwan	Association between the patient-related barriers of discharge to palliative home care.	Quantitative Cross-sectional study	N=229 Palliative care workers in inpatient hospice unit. 166 nurses, 38 physicians, and 25 others.	34 male/195 female	31.1/ not informed	0.60
Tang et al. (2005) (52)	Taiwan	Concordance in preferences for EOL care goals and LSTs between patients and their primary caregivers.	Quantitative Cross-sectional study	N=617 dyads Terminal cancer patients- family caregivers.	Patients: 58.5% male/41.5% female. Caregivers: 36.6% male/63.4% female.	Patients: not informed /22-89. Caregivers: not informed /23-82.	0.80
Tang et al. (2006) (53)	Taiwan	Congruence of knowledge, experiences, and preferences for disclosure of diagnosis and prognosis.	Quantitative Cross-sectional study	N=617 dyads Terminal cancer patients- family caregivers.	Patients: 58.5% male/41.5 female. Caregivers: 36.6% male/63.4% female.	Patients: not informed /22-89. Caregivers: not informed /23-82.	0.90

Yan et al. (2006) (54)	Hong Kong	Effect of home-based palliative care.	Quantitative Prospectively, descriptively cross-sectional study	N=85 Terminal cancer patients.	37 male/48 female	63.39/38-93	0.65
Chen et al. (2006) (55)	Taiwan	Appropriateness of cancer pain management.	Quantitative Cross-sectional and descriptive study	N=2,185 Terminal cancer patients in non-hospice settings.	53.4% male/46.6% female	not informed /18-98	0.65
Ding et al. (2007) (56)	Macau	Attitude of families towards prognosis disclosure.	Quantitative Cross-sectional study	N=50 Advanced cancer patients' families.	14 male/36 female	58.46/ not informed	0.45
Lai et al. (2007) (31)	Hong Kong	Describe the experience of dyspnea and helpful interventions.	Qualitative Semi structured and open-ended interactive interviews	N=11 Advanced lung cancer patients from inpatient hospice unit.	8 male/3 female	65.5/54-75	0.80
Chio et al. (2008) (32)	Taiwan	Explore the lived experiences of spiritual suffering and the change mechanism in healing processes.	Qualitative Semi-structured interview	N=33 Terminal cancer patients from inpatient oncology ward.	37% men/63% female	55/37-76	0.65
Fang et al. (2008) (57)	Taiwan	Prevalence, detection and treatment of delirium.	Quantitative Prospectively cross-sectional study	N=228 Terminal cancer patients in inpatient palliative care unit.	116 male/112 female	64.57/ not informed	0.90
Tang et al. (2008) (58)	Taiwan	(1) patients' awareness of their prognosis, (2) the extent of patient–family caregiver congruence on the preferences for EOL care, (3) perceived caregiving burden of family caregivers.	Quantitative Cross-sectional study	N=1,108 dyads Patients with terminal cancer in oncology inpatient units.	Patients: 59.5% male/40.5% female Caregivers: 36.3%/63.7% female	Patients: not informed /18-91 Caregivers: not informed /18-85	0.70
Yong et al. (2009) (59)	Hong Kong	Symptom burden and QOL of ESRD patients.	Quantitative Prospective cross-sectional study	N=179 ESRD patients in a medical center.	Male: Female, 1:0.97.	61.9/ not informed	0.75
Shih et al. (2009) (33)	Taiwan	Explore the core constitutive patterns of spiritual needs.	Qualitative Participatory observation and in-depth interviews	N=35 Elderly terminal cancer patients from acute wards.	19 male/16 female	75.36/not informed	0.60
Mok et al. (2010) (34)	Hong Kong	Explore the phenomenon of existential distress.	Qualitative Focus group interviews	N=23 Health professionals from inpatient palliative care unit. 2 physician, 13 nurse, 2 occupational therapist, 2 chaplain, 3 social worker, 1 physiotherapist.	4 male/19 female	not informed /not informed	0.85

Mok et al. (2010) (35)	Hong Kong	Explore the phenomenon of spirituality and spiritual care.	Qualitative Hermeneutic interview	N=15 Advanced lung cancer patients from inpatient palliative care.	7 male/8 female	62.9/53-89	0.70
Tang et al. (2010) (60)	Taiwan	Pain intensity, pain relief experiences, and clinicians' pain management practices.	Quantitative Cross-sectional study	N=1,370 Terminal cancer patients.	53.4% male/46.6% female	57.6/18-98	0.80
Chan (2011) (61)	Hong Kong	Patients' and their families' awareness of the prognosis.	Quantitative Retrospectively longitudinal study by using clinical data mining	N=935 Palliative care patients who died between 2003 and 2005 in inpatient palliative care units.	534 male/401 female	74.1/ not informed	0.75
Fan et al. (2011) (62)	Mainland China	Association between the disclosure of cancer diagnosis and QOL.	Quantitative Cross-sectional study	N=173 Terminal cancer patients in home-based hospice.	94 male/79 female	61.13/19-86	0.60
Wang et al. (2011) (36)	Mainland China	Explore the attitudes on advance directives (AD).	Qualitative Semi-structured interviews	N=8 Health professionals who worked in oncology hospitals.	2 male/6 female	not informed /25-42	0.30
Xiao et al. (2012) (37)	Mainland China	Elicit patients' perceptions of their participation in a life review programme.	Qualitative Three-week life review programme	N=26 Advanced cancer patients in home-based hospice settings.	15 male/11 female	59.12/39-76	0.85
Mok et al. (2012) (63)	Hong Kong	Effectiveness of the meaning of life intervention.	Quantitative Pilot RCT	N=84 Advanced cancer patients in a oncology inpatient ward	45 male/39 female	64.6/ not informed	0.58
Shen et al. (2012) (64)	Mainland China	Effect of hospice intervention.	Quantitative Pre-posttest study	N=691 Terminal cancer patients	348 male/343 female	62.18/19-81	0.40
Kao et al. (2012) (65)	Taiwan	Association between truth telling and their emotional disturbance.	Quantitative Cross-sectional study	N=100 Terminal cancer patients in the shared hospice care.	62 male/38 female	58.46/not informed	0.65
Ho et al. (2013) (66)	Hong Kong	Effectiveness of the novel palliative care model for nursing home residents.	Quantitative Pre-posttest study	N=9 Terminally ill residents in the nursing homes.	2 male/7 female	92/82-102	0.50
Hwang et al. (2013) (67)	Taiwan	Effect of hospice care for geriatric HCC.	Quantitative Nationwide, population-based study with propensity score matching control	N=1,458 HCC inpatients who were over 65 years.	983 male/475 female	75/not informed	0.86
Ho et al. (2013) (38)	Hong Kong	Examine the concepts of dignity and liminality at the end of life.	Qualitative Meaning-oriented interview	N=18 Terminal cancer patients from an outpatient palliative care program.	8 male/10 female	74.1/44-92	0.70

Cheng. (2014) (39)	Taiwan	Understand the fear of death, spirituality and good death.	Qualitative Retrospectively reviewed medical record and transformed it into quantitative data.	N=50 Terminal cancer patients from inpatient hospice units.	29 male/21 female	58/ not informed	0.40
Chan et al. (2014) (68)	Hong Kong	Effectiveness of an 8 weeks palliative care programme.	Quantitative Pre-posttest study and semi-structured interviews	N=108 dyads Patients with life expectancy <6 months.	47 male/61 female	73.48/ not informed	0.60
Chen et al. (2014) (69)	Taiwan	Determinants of home-death preference.	Quantitative Cross-sectional study	N=2,188 Terminal cancer patients under nonhospice care.	1,233 male/955 female	58/18-98	0.95
Gu et al. (2015) (70)	Mainland China	Preference of POD and the factors associated with the preference.	Quantitative Cross-sectional study	N=522 dyads Patients with terminal cancer.	279 male/243 female	not informed /21-95	0.65
Lee et al. (2015) (71)	Taiwan	Time-dependent relationship between psychospiritual distress and cancer pain management.	Quantitative Prospective longitudinal study	N=237 Terminal cancer patients in inpatient palliative care unit.	111 male/126 female	64.05/not informed	0.55
Liu et al. (2015) (72)	Taiwan	Determinants of preferences for various aggressive EOL care.	Quantitative Cross-sectional study	N=2,325 Terminal cancer patients.	1,318 male/1,007 female	not informed	0.80
Chiang et al. (2016) (73)	Taiwan	Effect of home hospice care during the last month of life and the predictors of receiving home hospice care.	Quantitative Nationwide population-based retrospective cohort study	N=568 Advanced lung cancer patients.	349 male/219 female	not informed	0.91
Lee et al. (2016) (74)	Taiwan	Symptom severity and the factors associated with symptom improvement.	Quantitative Prospectively longitudinal study	N=824 Advanced cancer patients in a palliative care unit.	480 male/344 female	not informed/21-97	0.90
Tang et al. (2016) (75)	Taiwan	Associations of accurate prognostic awareness and prognostic acceptance with psychological distress, existential suffering, and QOL.	Quantitative Longitudinal study	N=380 Patients with terminal cancer.	187 male/138 female	not informed	0.86
Tang et al. (2016) (76)	Taiwan	Longitudinal changes in LST preferences and their associations with accurate prognostic awareness, physician patient EOL care discussions, and depressive symptoms.	Quantitative Longitudinal study	N=302 Terminal cancer patients.	57% male/43% female	not informed	0.86
Wong et al. (2016) (77)	Hong Kong	Effects of home-based transitional palliative care for	Quantitative RCT	N=84 End-stage HF patients.	43 male/41 female	78.3/not informed	0.93

patients with end-stage HF.

Wang et al. (2016) (78)	Taiwan	The mediating or moderating role of spiritual well-being.	Quantitative Cross-sectional study	N=85 Terminal cancer patients in inpatient palliative care unit.	40 male/45 female	59.52/not informed	0.60
Liu et al. (2016) (79)	Taiwan	Effect of hospice home care intervention on pain control.	Quantitative Retrospectively longitudinal study by analyzing medical records	N=33 Terminal cancer in home-based hospice.	13 male/20 female	68.82/ not informed	0.55
Dong et al. (2016) (40)	Mainland China	Explore the experiences of caring for dying cancer patients.	Qualitative Semi-structured interviews	N=37 Healthcare professionals who have worked with and been exposed to dying cancer patients for at least half a year in a cancer center hospital. 15 physicians, 22 nurses.	15 male/22 female	Physicians, 34.56/27-54. Nurses, 29.34/24-49.	0.80
Li et al. (2017) (41)	Mainland China	Explore the psychological reactions and needs.	Qualitative In-depth and semi-structured interviews	N=15 Terminal cancer patients from a cancer center hospital.	not informed	not informed	0.30
Huang. (2017) (42)	Taiwan	Explore the definition of end of life, time of intervention and strategy of palliative care, and the development of service mode in compliance with the need of dementia patient.	Qualitative In-depth and semi-structured interviews.	N=19 10 patients with dementia, 9 families	Patients, 4 male/6 female. Families, 2 male/7 female.	not informed	0.30
Tang et al. (2017) (80)	Taiwan	To examine changes in and determinants of SPB and its longitudinal impact on preferences for EOL care.	Quantitative Prospective cohort study	N=380 Terminal cancer patients.	187 male/138 female	not informed	0.86
Wong et al. (2017) (81)	Macau	Effectiveness of using an electric fan on dyspnea.	Quantitative Phase 2 RCT	N=30 Advanced cancer patients in inpatient hospice.	14 male/16 female	not informed	0.46
Kuo et al. (2018) (82)	Taiwan	Modifiable factors associated with high SPB over patients' last year of life.	Quantitative Prospective, longitudinal study	N=280 dyads Terminal cancer patients and their family caregivers.	Patients: 59.4% male/40.6% female. Caregivers:40.2 male/ 59.8% female	not informed	0.95
Ng et al. (2018) (83)	Hong Kong	Effectiveness of a home-based palliative HF program.	Quantitative RCT	N=84 End-stage HF patients.	43 male/41 female	78.3/ not informed	0.88
Wong et al. (2018) (84)	Hong Kong	Cost effectiveness analysis of a home-based palliative HF	Quantitative Cost-effectiveness analysis	N=84 End-stage HF patients.	43 male/41 female	78.3/ not informed	0.79

		program.	alongside an RCT				
Zhang et al. (2018) (85)	Mainland China	Effectiveness of music therapy.	Quantitative RCT	N=185 Terminal gynecological cancer patients in inpatient palliative unit.	0 male/185 female	53.39/ not informed	0.50
Chung et al. (2018) (43)	Hong Kong	Explore the spousal experience with their dying loved ones suffering from terminal cancer.	Qualitative Semi-structured interviews and interpretive description	N=15 Spousal caregivers who cared for their loved ones, whom died of terminal cancer	7 male/8 female	51.13/35-79	0.50
Huang et al. (2018) (44)	Mainland China	Explore the feelings and wishes of patients who are going through the dying process.	Qualitative Face-to-Face Interview with open-ended questions	N=16 Terminal cancer patients	not informed	not informed	0.45
Lai et al. (2018) (45)	Mainland China	Explore the experiences of caring for patients at the end-of-life stage in non-palliative care settings.	Qualitative Semi-structured interviews	N=26 13 Physician, 13 Nurse	Physicians, 5 male/8 female. Nurses, 0 male/13 female.	Physicians, 39.00/ not informed. Nurses, 37.15/ not informed.	0.80
Liu et al. (2018) (46)	Mainland China	Understand the role of family conferences.	Qualitative In-depth and semi-structured interviews with open ended questions	N=15 Caregivers of terminal cancer patients	8 male/7 female	not informed /36-68	0.20
Kwan et al. (2019) (86)	Hong Kong	Effectiveness of a nurse-led short-term life-review intervention.	Quantitative RCT	N=109 Advanced cancer patients receiving palliative care.	62 male/47 female	64.4/28-89	0.71
Tang et al. (2019) (87)	Taiwan	Effectiveness of a longitudinal ACP intervention.	Quantitative RCT	N=430 Terminal cancer patients.	303 male/127 female	not informed	0.88
Wen et al. (2019) (88)	Taiwan	Factors facilitating or hindering concordance between preferred and received LSTs in the last 6 months of life.	Quantitative Longitudinal, observational study	N=380 Terminal cancer patients	120 male/98 female	not informed	0.91
Yang et al. (2019) (89)	Mainland China	Association between good death and identify associated factors.	Quantitative Cross-sectional study	N=122 Nurses in charge of 258 patients during their dying period.	2 male/120 female	29.66/ not informed	0.90
Ma et al. (2019) (90)	Mainland China	Effectiveness of nutrition support therapy.	Quantitative RCT	N=160 Terminal cancer patients	87 male/73 female	not informed /52-79	0.38
Zu et al. (2019) (91)	Mainland China	Effect of ACP intervention.	Quantitative Pre-posttest study	N=90 Terminal cancer patients	52 male/38 female	55.28/18-78	0.27
Qao et al. (2019) (92)	Mainland China	Consistency on EOL decision making.	Quantitative Cross-sectional study	N=268 dyads Terminal cancer patients in hospitals and their caregivers.	Patients: 167 male /101 female. Caregivers: 88 male	Patients: 64.73/27-89. Caregivers:	0.70

| | | | | | /180 female. | 39.89/23-86. | |
| Liao et al. (2019) (93) | Mainland China | Preferences for POD and the predictors. | Quantitative Cross-sectional study | N=775 Terminal cancer patients. | 421 male/354 female | 50.09/18-84 | 0.75 |

Abbreviations: RCT, randomized controlled trial; QOL, quality of life; EOL, end-of-life; LSTs, life-sustaining treatments; ANH, artificial nutrition and hydration; POD, place of death; ESRD, end-stage renal disease; HCC, hepatocellular carcinoma; ACP, advance care planning; SPB, self-perceived burden; HF, heart failure

Table 4. Summary of studies assessing palliative interventions (N=24)

Studies	Designs	Participants	Interventions	Comparisons	Outcomes and outcome measures
Yeung et al. (1999) (48), Hong Kong.	Cross-sectional	52 terminal cancer patients.	Inpatient hospice care (at least 7 days).	NA	**QOL (HCPI):** significantly positive effect at "alleviating pain" and "respecting personal life, religion, and values". Significantly negative effect at "maximize self-care and mobility", "help to dispel fear toward death", "gain enough rest and sleep", "be available and willing to listen and give reassurance", "provide appropriate, satisfying diet and help to improve appetite", and "help to fulfill unfinished business".
Yang et al. (2001) (49), Taiwan.	Cross-sectional	123 terminal patients.	Hospice inpatients (n=26), hospice team consultation (n=36), home hospice care (n=23), acute care (n=38).	NA	**QOL (self-developed tool):** no difference. **Satisfaction with care (self-developed tool):** no difference. **Healthcare cost:** no difference. **Nurses' work satisfaction (self-developed tool):** the group of hospice inpatients tended to be significantly (p=0.026) higher than the other groups.
Yan et al. (2006) (54), Hong Kong.	Cross-sectional	85 terminal cancer patients.	Home-based palliative care.	NA	**QOL (McGill QOL-HK):** the physical and existential domains scored were relatively low. The sexual functioning and support yielded the highest scores. **Pain intensity (NRS):** The majority of the subjects (87.1%) indicated that pain was the worst physical symptom, with a mean pain score of 4 (SD=2.3).
Yong et al. (2009) (59), Hong Kong.	Cross-sectional	179 end-stage renal disease patients	Receiving palliative care plus dialysis (PC, n=45).	Receiving dialysis (DA, N=134).	**Symptom burdens (self-developed end-stage renal disease 23 symptom intensity-NRS):** the mean number of symptoms was no difference between two groups. **Comorbid conditions (mCCI):** significantly higher in the PC group. **QOL (SF-36-Chinese):** the DA group scored significantly lower than the Hong Kong population in all eight domains, whereas the PC group scored lower only in four domains. **Pain (BPI-Chinese):** no difference between two groups.
Fan et al. (2011) (62), mainland China.	Cross-sectional	173 terminal cancer patients in home-based hospice.	Knowing diagnosis (n=87).	Not knowing diagnosis (n=86).	**QOL (EORTC QLQ-C30 v3.0):** patients who did not have knowledge of their diagnosis demonstrated significantly better at physical and emotional subscale.
Mok et al. (2012) (63), Hong Kong.	Pilot RCT	84 patients with advanced cancer.	Meaning of life (n=44).	Usual care (n=40).	**QOL (QOLC-E):** significantly improved in total score and the existential distress subscale. **Single-item global QOL scale:** significantly improved.

Shen et al. (2012) (64), mainland China.	Pre-posttest	691 patients with terminal cancer.	Inpatient hospice care for 30 days.	NA	**QOL (McGill QOL):** significantly improved in most domains, but no difference in "sex life" and "enjoyable dining experience" domain.
Xiao et al. (2012) (37), mainland China.	Semi-structured interviews	26 advanced cancer patients in home-based hospice settings.	Three-week life review programme	NA	**Programme description, perceptions of this programme, barriers to reviewing a life.**
Ho et al. (2013) (66), Hong Kong.	Pre-posttest	9 terminally ill residents in the nursing homes.	Dignity-conserving end-of-life care model for 6 months.	NA	**QOL (McGill):** significant deterioration in physical domain; significant improvement in the support domain. **QOL (single-item global QOL scale):** no differences. **Nursing Facilities QOL (NF-QoL):** no differences.
Hwang et al. (2013) (67), Taiwan.	Propensity score matching case-control	1,458 hepatocellular carcinoma who were over 65 years.	Inpatient hospice care (n=729).	Usual care in acute wards (n=729).	**Rate of receiving aggressive procedures:** significantly less in the hospice care group **Opium alkaloids usage:** significantly higher prescription rate in hospice care group. **Medical expenses:** significantly less cost in the hospice care group.
Chan et al. (2014) (68), Hong Kong.	Pre-posttest study and semi-structured interviews	108 dyads, patients with life expectancy <6 months.	Home-based palliative care programme for 8 weeks.	NA	**QOL (McGill-HK):** significantly improved in physical and support domains. **Family Satisfaction Scale (FAMCARE):** no difference. **Effectiveness of the intensive communication on ACP (self-developed tool):** significantly improved. **Hospital readmission and the length of each hospital stay:** significantly reduced.
Chiang et al. (2016) (73), Taiwan.	Cohort	568 advanced lung cancer patients.	Home-based hospice care (n=330).	Inpatient hospice care (n=238).	**Care quality:** significantly higher rate of dying at home and lower rate of staying in hospital >14 days in their last month of life in the home-based hospice care group. **Survival curve:** no differences. **Healthcare cost:** significantly higher cost in the inpatient hospice care group.
Lee et al. (2016) (74), Taiwan.	Prospectively longitudinal	824 advanced cancer patients.	Receiving inpatient palliative care for 7 days.	NA	**Physical and psychosocial distress (Symptom Reporting Form):** the day of palliative care administration was a predominantly significant factor associated with all symptoms' improvement.
Wong et al. (2016) (77), Hong Kong.	RCT	84 end-stage heart failure patients.	Transitional home-based palliative program for 12 weeks (n=43).	Usual care plus two placebo social calls per month (n=41).	**Primary outcome (readmission rate):** significantly higher in usual care group. **Secondary outcomes: Symptom intensity (ESAS):** significantly higher clinical improvement in depression, dyspnoea and total score at 4 weeks.

					Functional status (PPS): no difference within or between groups over time. **QOL (McGill-HK):** significantly improved in psychological, support, overall domains, and total scores. No difference in physical and existential domains. **QOL (CHQ-C):** significantly improved in dyspnoea, emotional, and mastery domains, and total scores. No difference in fatigue domains. **Satisfaction with care:** significantly higher in intervention group.
Liu et al. (2016) (79), Taiwan.	Retrospectively longitudinal study by analyzing medical records	33 terminal cancer in home-based hospice.	Home-based hospice.	NA	**Pain (VAS):** the average VAS at 2 weeks was significantly lower than baseline.
Wong et al. (2017) (81), Macau.	Phase 2 RCT	30 patients with advanced cancer in inpatient hospice.	5-minute fan therapy (n=15).	Accompanied by their caregivers (n=15).	**Dyspnea (verbal NRS):** significant improved in intervention group. **Respiratory rate and SpO2:** no differences.
Ng et al. (2018) (83), Hong Kong.	RCT	84 end-stage heart failure patients.	Transitional home-based palliative program for 12 weeks (n=43).	Usual care plus two placebo social calls per month (n=41).	**Primary outcome (McGill-HK):** significant improvement in the physical, psychological, existential domains, and total scores. No difference in support and Global QOL. **Secondary outcomes:** **HF-specific QOL (CHQ-C):** no differences. **Symptom burden (ESAS):** no differences. **Functional status (PPS):** no differences **Patient satisfaction:** significant higher in intervention group.
Wong et al. (2018) (84), Hong Kong.	Cost-effectiveness analysis alongside a RCT	Same as above.	Same as above.	Same as above.	Transitional home-based palliative care program is more cost-effective than customary palliative care service.
Zhang et al. (2018) (85), mainland China.	RCT	185 patients with terminal gynecological cancer in inpatient palliative unit.	Music therapy (5 times/week, and each at least 30 mins) for 7 days (n=92).	Usual care (n=93).	**Pain intensity (NRS):** significantly improved in intervention group. **Pain intensity (FLACC):** no differences. **BPI pain interference score:** significantly improved in mood, relations with others, and sleep. No differences in walking and enjoyment of life.
Liu et al. (2018) (46), mainland China.	Semi-structured interviews	15 caregivers of terminal cancer patients	Family conferences in inpatient oncology ward.	NA	Key elements of successful family conferences.
Kwan et al. (2019) (86), Hong Kong.	RCT	109 patients with advanced cancer.	Nurse-led short-term life-review (n=54).	Attention care (n=55).	**Spiritual (sub-scale of the McGill-HK):** no difference. **Anxiety and Depression (HADS-Chinese):** no difference.

Tang et al. (2019) (87), Taiwan.	RCT	430 terminal cancer patients.	Theory-based, individualized, interactive ACP intervention (n=215).	Sham treatment of symptom management education (n=215).	**Concordance between preferred and received LSTs:** no difference. **Anxiety and Depression (HADS):** significantly fewer in ACP intervention group. **QOL (McGill- with 3 items omitted):** no difference.
Ma et al. (2019) (90), mainland China.	RCT	160 patients with terminal cancer.	Palliative care and nutrition support therapy for 6 weeks. (n=80).	Palliative care (n=80).	**Nutrition status:** significant improvement in the body mass index, albumin, hemoglobin, and subjective global assessment. **QLQ (EORTC QOL-C30):** significant improvement in the physical, cognitive and symptomatic domain.
Zu et al. (2019) (91), mainland China.	Pre-posttest	90 patients with terminal cancer.	Receiving ACP intervention.	NA	**QOL (QOLC-E):** significant difference in total scores and 5 domains (negative emotion, isolation, social support, healthcare professionals' attention and self-existent disturbance). **Preferences for LSTs:** significantly changing preferences from accepting to declining.

Abbreviations: NA, not applicable; RCT, randomised controlled trial; QOL, quality of life; LSTs, life-sustaining treatments; ACP, advance care planning; HCPI, Hospice Care Performance Inventory; NRS, numerical rating scale; HK, Hong Kong; mCCI, modified Charlson Comorbidity Index; SF-36, 36-Item Short Form Health Survey; EORTC-QLQ, European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire; QOLC-E, Quality-of-life concerns in the end of life questionnaire; ESAS, Edmonton Symptom Assessment Scale; PPS, palliative Performance Scale; VAS, visual analog scale; BPI, Brief Pain Inventory; FLACC, Face, Legs, Activity, Cry, Consolability Scale; HADS, Hospital Anxiety and Depression Scale.

Table 5. Summary of outcomes and outcome measures reported in the quantitative studies which evaluated palliative care interventions

Outcomes	Outcome measures
Quality of life	Patients: McGill quality of life (54, 64, 66, 68, 77, 83, 87), Hospice Care Performance Inventory (HCPI) (48), 36-Item Short Form survey (SF-36)-Chinese (59), European Organization for Research and Treatment of Cancer Quality of life Questionnaire (EORTC QLQ-C30) (62, 90), Quality of life concerns in the end of life (QOLC-E) (63, 91), single-item global quality of life scale (single-item global QOL) (63, 66), Chronic Heart Failure Quality of life-Chinese (CHQ-C) (83), self-developed quality of life measure (49). Nurses: NF-QOL (66)
Implementation assessment	Service cost (49, 67, 73), cost-effectiveness study (84), satisfaction of care (patients (49, 77, 83), nurses (49), and families (68)).
Physical assessment	Edmonton Symptom Assessment Scale (ESAS) (77, 83), Palliative Performance Scale (PPS) (77, 83), modified Charlson Comorbidity Index (mCCI) (59), self-developed symptom reporting form (59, 74), respiratory assessment (dyspnoea NRS level, respiratory rate, and SpO2) (81), and nutrition status assessment (body mass index, albumin, hemoglobin, subjective global assessment) (90).
Pain management	Visual analogue scale (VAS) (79), Numeric rating scale (NRS) (54, 85), Face, Legs, Activity, Cry, Consolability Scale (FLACC) (85), Brief Pain Inventory (BPI) (59, 85), opioid prescriptions rate (67).
Quality of care	Rate of receiving aggressive procedures (67), rate of home death (73), the length of hospital stay in last month of life (68, 73), readmission rate (68, 77), self-developed measure for the effect of intensive communication on advance care plan (68), the concordance between preferred and received life-sustaining treatments (87).
Psycho-spiritual assessment	Hospital Anxiety and Depression Scale (HADS) (86, 87), McGill-spiritual subscale (86)

Table 6. Risk of bias assessment of included randomised controlled trials (n=9)

Studies	Random allocation	Blinding	Sample size calculation	Numbers of participants*	Numbers of attrition*	Attrition Rate (%)
Mok et al. (63)	Computerized random-number generator.	Outcome assessor was not blinded to group assignment.	No	44/40	15/11	31.0
Wong et al. (77), Wong et al. (84), Ng et al. (83)	Computer software Research Randomizer.	Research assistants who were trained and blind to the grouping.	Yes	43/41	0/0	0
Wong et al. (81)	Not reported.	Single blind.	No	15/15	0/0	0
Ma et al. (90)	Random number table.	Not reported.	No	80/80	0/0	0
Tang et al. (87)	Computer generated random sequence sealed in consecutively numbered opaque envelopes.	Data collectors were blinded.	Yes	230/230	21/24	9.8
Kwan et al. (86)	Sequentially numbered opaque sealed envelopes.	The participants and the person collecting data were blinded.	Yes	54/55	5/15	18.4
Zhang et al (85)	Random number table.	Single blind.	No	93/92	0/0	0

* Numbers in study group/ Numbers in control group

Table 7. The comparison of included studies in the Greater China region

| Study settings	Hong Kong	Macau	Mainland China	Taiwan
Study populations (n=66)	18 (27.3)	2 (3.0)	16 (24.2)	30 (45.5)
Patients (n=56)	16 (28.6)	1 (1.8)	11 (19.6)	28 (50.0)
Informal caregivers (n=11)	2 (18.2)	1 (9.1)	3 (27.3)	5 (45.5)
Healthcare providers (n=6)	1 (16.7)	0 (0)	4 (66.7)	1 (16.7)
Models of care (n=29)	13 (44.8)	1 (3.4)	7 (24.1)	8 (27.6)
Delivered specialist palliative care services (n=15)	7 (46.7)	0 (0)	2 (13.3)	6 (40.0)
Short-term services integrated in palliative care (n=9)	2 (22.2)	1 (11.1)	5 (55.6)	1 (11.1)
Care needs during the illness trajectory (n=5)	4 (80.0)	0 (0)	0 (0)	1 (20.0)
Palliative care interventions (n=24)	10 (41.7)	1 (4.2)	7 (29.2)	6 (25.0)
Randomised controlled trials (n=9)	5 (55.6)	1 (11.1)	2 (22.2)	1 (11.1)
Palliative care needs (n=40)	8 (20.0)	1 (2.5)	9 (22.5)	22 (55.0)
Better pain control (n=4)	1 (25.0)	0 (0)	0 (0)	3 (75.0)
Reduced aggressive end-of-life care (n=7)	0 (0)	0 (0)	4 (57.1)	3 (42.9)
Preferred place of care and death (n=4)	0 (0)	0 (0)	2 (50.0)	2 (50.0)
Truth telling (n=10)	1 (10.0)	1 (10.0)	0 (0)	8 (80.0)
Physical, emotional and spiritual support (n=14)	5 (35.7)	0 (0)	1 (7.1)	8 (57.1)
Training (n=2)	0 (0)	0 (0)	2 (100.0)	0 (0)
End-of-life care education (n=2)	1 (50.0)	0 (0)	1 (50.0)	0 (0)
Relieving care burden (n=1)	1 (100.0)	0 (0)	0 (0)	0 (0)
National policy support (n=3)	0 (0)	0 (0)	2 (66.6)	1 (33.3)
Quality assessment of qualitative studies (n=19)	6 (31.6)	0 (0)	7 (36.8)	6 (31.6)
Adequate quality (n=11)	4 (36.4)	0 (0)	3 (27.2)	4 (36.4)
Low quality (n=8)	2 (25.0)	0 (0)	4 (50.0)	2 (25.0)
Quality assessment of quantitative studies (n=47)	12 (25.5)	2 (4.3)	9 (19.1)	24 (51.1)
Strong (n=18)	2 (11.1)	0 (0)	1 (5.6)	15 (83.3)
Good (n=5)	4 (80.0)	0 (0)	1 (20.0)	0 (0)
Adequate (n=17)	4 (23.5)	0 (0)	4 (23.5)	9 (53.0)
Limited (n=7)	2 (28.6)	2 (28.6)	3 (42.8)	0 (0)
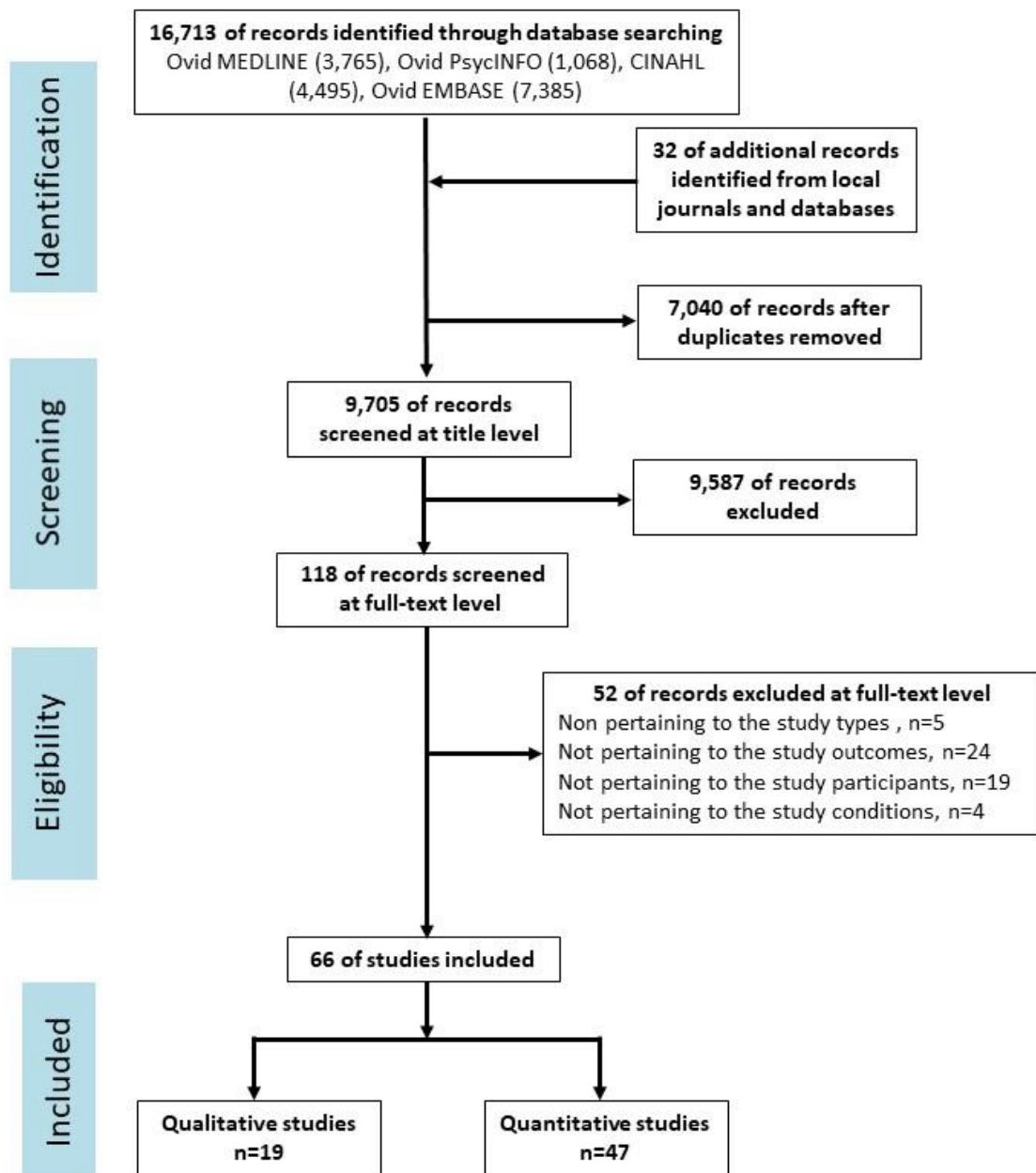
Figure 1. Study selection

Figure 2. Conceptual model of palliative care needs