# Rapid Scoping Review of Service Delivery Models to Maximise Quality of Life for Older People at the End of Life

## Final draft report on findings and recommendations

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# Table of Contents

## List of Tables and Figures

**Tables:**

**Figures:**

# EXECUTIVE SUMMARY

## Context

### Background and remit

Healthy ageing goes beyond a focus on longevity. It concerns how to support a duality of living as well as possible, whilst adapting successfully to gradual deterioration. With advancing age comes multi-morbidity and frailty, and a prolonged, uncertain trajectory of functional decline that lasts years rather than months. The amelioration of distressing symptoms and concerns is important and International policy advocates a system wide response with palliative and end of life care integrated into all health systems. The WHO Member States' commitment to Universal Health Coverage (UHC) provides an opportunity to widen access to optimal models of care for people with advanced conditions, and realignment of health systems to the needs of an ageing population. To achieve UHC requires rapid understanding on what service delivery models exist, and how to realign health systems to meet the complex needs associated with advanced age. A global perspective that considers the sustainability and scalability of system change across settings is required.

We aimed to provide a rapid, comprehensive and objective synthesis of available evidence on service delivery models to optimise quality of life for older people at the end of life. Our remit included health, social and welfare services across all countries and objectives included to: describe overarching service delivery models; outline target outcomes; summarize impact on quality of life, functional capacity, and dignity; scrutinize expenditure data; and consider scalability and sustainability with respect to costs, workforce implications, and population coverage.

### Methods and included literature

A rapid scoping review was chosen to systematically search, select, and synthesize knowledge around our aims to map key concepts, types of evidence, and gaps in research. Systematic reviews published 2000- 2017 that examined service delivery models aimed at maximising quality of life in older people at the end of life were included. Operationally, we defined reviews of older people as those where at least 50% of the included population were >60 years old, and end of life as participants described as being in the last 1-2 years of life, with or using a service typically accessed during advanced stages of disease. Our search retrieved 2238 review articles of which 72 were eligible. All WHO regions were represented within the reviews, though predominantly studies were from the Americas (52/72), European (46/72) and Western Pacific (28/72) regions. The majority of reviews (55/72) included studies from high income countries, though studies were reported from Upper Middle, Lower Middle and Low income countries. Review samples sizes ranged from 87 to 254,717, encompassing data from over 784, 983 individuals.

## Key findings

### Service delivery models

We identified two overarching classifications of service models: Integrated Geriatric Care, detailed mainly for an earlier trajectory of functional decline; and Integrated Palliative Care for commonly a later trajectory of functional decline and dying. The importance of multi-disciplinary working was identified and common model components comprising care centred on the person; education; and multi-provider workforce. We identified three overarching processes to deliver integrated care and manage the continuum of care overtime: Comprehensive Assessment; Case Management; and Collaborative Working across disciplines and organizations to plan and deliver services.

### Target outcomes

One-hundred and seventeen separate outcomes were grouped into five main themes; quality of life, encompassing symptoms, morale, empowerment and well-being; functional outcomes; dignified end of life care, including perceived quality and satisfaction with care; health service use and costs; and survival, generally used as a proxy for potential risk of harm. Quality of life and satisfaction with care were most commonly assessed as markers of successful ageing and dying. Integrated Geriatric Care models placed greater emphasis on targeting physical function, while Integrated Palliative Care tended to focus relatively more on the management of symptoms and concerns.

### Impact

Across 47 reviews and 9 meta-analyses there was consistent evidence of effectiveness for both approaches on the main outcome of quality of life. Pooled analyses for health-related quality of life (physical and psychological), global symptoms and individual symptoms all demonstrated effectiveness. Of 28 reviews reporting narrative synthesis focusing on quality of life (excluding symptoms), 13 were interpreted as effective, 11 inconsistent and 4 found no effect. In no case was a model found to be associated with harm. Evidence of impact on symptoms, patient function, and dignified end of life care was typically interpreted, across meta-analyses and narrative synthesis, as effective or inconsistent. 5 reviews performed meta-analysis on mortality; all but one found no effect while one found reduced mortality.

Health economic data was reported in less than half of the reviews, and cost saving or cost-effectiveness was inconclusive. Source of health care expenditure and the analytic perspective of cost calculations were not clearly distinguishable. However, most studies adopted a health system perspective combining patient expenditure and resource use in the health care system. Sources of societal costs beyond informal care were not identifiable. The generalizability of the evidence from high income countries to low- or middle-income countries is limited with uncertainty about which models are most cost-effective or appropriate to resource-constrained contexts.

## Implications and recommendations

### Policy

- High level global and regional boards working for older people include representation from geriatric care and palliative care to ensure the perspectives of these stakeholders are heard.
- Particular attention should be paid to improving access to palliative care beyond the last months of life, across settings, and based on likelihood of benefit rather than prognosis.
- A key resource pack, based on findings of this review, should be produced for policy makers, detailing how to assess need and likelihood of benefit, service delivery examples, quality indicators and outcome measures.

### Practice

- Service providers should maintain a primary focus on valuing quality of life, adopt a positive approach to collaborative working, seek out learning opportunities from colleagues, and participate in research around new models of care.
- Services should routinely measure care quality, outcomes, and experience for this group.
- Case examples that demonstrate effective collaborative working between health and social care providers should be identified and shared.
- Routine assessment of education needs of the workforce and evaluation of educational approaches to support learning across specialties and professions is required.

### Research

- A subsequent review focused on primary studies would further this work by identifying theoretical models around specific service delivery models, and could include a meta-regression to link different service delivery models to different health outcomes.
- A discrete choice experiment would improve understanding around the priorities of older people at the end of life, what they value and would trade off, and how they would like future services to be delivered.
- Key triggers or prompts for palliative care involvement have not been agreed and are currently based on professional opinion. A systematic review of trial inclusion criteria would serve to provide an evidence-based set of triggers for palliative care.
- Primary studies evaluating models of care in LMICs are required, prioritising clinical and cost effectiveness trials.
- A better understanding of what quality of life means to older people at the end of life is required, including how this evolves with functional decline, shifting demands and recalibration of expectations. This should be mapped onto outcomes to develop a set of key metrics for quality of life and quality of care.
- There remains a need to cost service delivery models that enable older people to live and die well in their last years of life. We encourage economic analyses that span health and social care, include all sources of finance to understand health inequalities, and define the perspective taken according to local context.

## BACKGROUND

The world's population is ageing, with an unprecedented rise in the number of people aged 60 years and above. By 2050 the population aged over 60 years is set to double. The majority (80%) will live in low and middle income countries (LMICs) with the largest proportional increase in the oldest old [1], including centenarians[2]. Health and social care needs among older people can be complex. With advancing age comes multi-morbidity and frailty [3], and a prolonged, uncertain trajectory of functional decline lasting years rather than months. Ageing is heterogeneous with multiple interacting factors related to the individual (e.g. ethnicity), their health status (e.g. morbidities) and environment (e.g. care setting, resources).

Healthy ageing in the last years of life goes far beyond a focus on longevity. It concerns how to support a duality of *living as well as possible* by maximising function and preventing or minimising complications, whilst *adapting successfully* to gradual deterioration [4]. The amelioration of distressing symptoms and concerns is important. Prevalence and level of symptom distress is often high for older people living with advanced conditions and with little differentiation between cancer or non-cancerous conditions [5]. The realisation from health and social care services that the end of life is nearing for older people is often gradual and uncertain. Recognition of dying is often limited to the last days or weeks of life, particularly for those with frailty and non-malignant conditions including dementia [6]. This late recognition of nearness to end of life can impede care, with overuse of aggressive treatments with often little benefit that compromise quality of life [7], and under treatment of symptoms and concerns, notably pain, anxiety and breathlessness [8]. Poor communication from practitioners on the goals and plans of care, and limited involvement of the older person in decision making processes is also acknowledged [9].

International policy advocates a system wide response to global ageing with palliative and end of life care (EoLC) as a key part of the solution[1]. Palliative care aims to improve the quality of life of patients living and dying with chronic progressive and life-threatening conditions and their families, by the prevention and relief of suffering. This is achieved through the early identification and impeccable assessment and treatment of symptoms and problems, including physical, psychosocial and spiritual [10, 11]. EoLC is a component of palliative care. EoLC intends to enable people to live as well as possible in advancing age, support decline during the loss of capacity, provide integrated care across settings, avoid aggressive care towards the end of life, and allow people to die in comfort with a sense of safety and security, and loved ones nearby [12]. In 2014 the World Health Assembly (WHA)[13] resolved for palliative care to be integrated into all health systems. The WHA conceptualised palliative care as relevant across the illness trajectory, encompassing EoLC, delivered by all those providing care to people living and dying with chronic progressive conditions, with the shared goals to improve quality of life and to enable people to die peacefully. Palliative care is considered internationally as an essential health service for all people living with chronic progressive conditions [14].

Globally, there is a breadth of service delivery models for palliative and EoLC care for older people with systematic reviews considering: a specific condition e.g. dementia [15]; care setting e.g. care homes[16]; and provision by specialists and generalists in palliative care, including geriatric care [17-20]. These models advocate comprehensive assessment with emphasis on supporting functional and mental capabilities, and intention to enable pursuit of things important to the older person. Care delivery is by multi-disciplinary teams. There is increasing understanding that optimal care provision requires integration of services across health and social care systems [21]. In LMICs there is a particular reliance on delivery through community based programmes and home based care [22, 23], and service access is often hampered when confined to large urban centres [24]. The WHO Member States' commitment to Universal Health Coverage (UHC) by 2030 provides an opportunity to widen access to optimal models of care for people with chronic progressive conditions, and realignment of health systems to the needs of an ageing population. To achieve UHC requires rapid understanding on what the 'best' systems and models of service delivery are, and how to realign care to meet the complex health needs associated with advanced age. A global perspective is required that considers the applicability, potential effectiveness and sustainability of system change and service models across low-, middle- and high-income settings.

The global inequity in the provision of palliative and EoLC [25] places an imperative to identify models of care and interventions that may be scalable in LMICs. The field of global health palliative care has been established to enable us to develop and evaluate models of care that are appropriate for diverse health systems [26]. Ageing is a relatively new epidemiological phenomenon in many LMICs, placing different stressors on health services due to the high prevalence of HIV in regions where treatment is being rolled out, the additional stressors on family caregivers who may also be subsistence earners, or caregivers to grandchildren who have been orphaned [27-30]. In addition, the health system challenges may be different, for example the availability of analgesia is a pressing policy issue for many countries [31-33].

Given the heterogeneous nature of ageing and the breadth of service models to deliver palliative and EoLC, scoping of systematic reviews on the effectiveness of models to improve the quality of life in older adults provides a way to conduct a rapid systematic synthesis of the breadth of evidence. Systematic scoping can build evidence on the conceptual models of service delivery, outcomes and effectiveness and resource requirements for delivery. This evidence can inform the priorities for policy, practice and research including identifying contemporary themes, topics and questions.

# AIM AND OBJECTIVES

This scoping review aimed to provide a rapid, comprehensive and objective synthesis of available evidence on service delivery models to optimise quality of life for older people at the end of life. Our remit included health, social and welfare services across all countries, with particular attention to LMICs. Our objectives were to:

- Describe the available evidence for service delivery models aiming to maximize quality of life for older people at the end-of-life in terms of overarching models, their context, and components.
- Outline the range of outcomes measured in their evaluations, including but not limited to domains of quality of life, function, and dignity.
- Summarize the reported impact of common service delivery models on patients' quality of life, functional capacity, and dignity.
- Scrutinize how expenditure data is measured from a patient/caregiver, societal and health system perspective.
- Consider the scalability and sustainability of service delivery models with respect to implementation requirements, cost, workforce implications, and population coverage.
- Identify research gaps and priorities, and experts and teams in a position to contribute positively and inform a research agenda.

# METHODS

## Design

A rapid scoping review was chosen to systematically search, select, and synthesize knowledge around our aims to map key concepts, types of evidence, and gaps in research [34].The review was planned in accordance with the Centre for Reviews and Dissemination (2009) [35] guidance on conducting reviews and reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement [36].

## Eligibility criteria

Systematic reviews published between January 2000 and October 2017 that examined service delivery models aimed at maximising quality of life in older people at the end of life were included. Operationally, we defined reviews of older people as those where at least 50% of the included population were >60 years old, and end of life as participants described as being in the last 1-2 years of life, using a service typically accessed during advanced disease stage (e.g. specialist palliative care, nursing home) or with advanced disease, i.e. advanced or metastatic cancer; chronic respiratory disease GOLD stage III-IV / grade C-D; heart failure New York Heart Association stage III or IV; progressive neurological disease; or frailty. We defined a service delivery model as ‘an overarching design for healthcare service provision with multiple components and interacting elements’ [37]. We excluded reviews focused on a single component intervention, e.g. provision of assistive devices, and delivery models focussing on post death intervention were classed as outside the scope of the review. We included reviews with data on outcomes relating to function, quality of life, and dignified end of life care. These included but were not limited to physical function, activities of daily living (ADLs), falls, dependency, quality of life, symptoms, autonomy, empowerment, goal attainment, psychosocial or spiritual distress, and satisfaction. Eligible reviews had to draw on more than one data source [38] and aim to identify studies using effectiveness designs of a primary randomised controlled, controlled before-after, interrupted time series, or repeated measures study. Narrative reviews, or those describing case studies or series, or descriptive studies only, were not eligible.

## Search strategy

An electronic search strategy was developed with an information specialist using a combination of full-text search terms and MeSH terms around the population, intervention, and outcomes. This was developed for MEDLINE and adapted where necessary for all other databases. MeSH terms included “Terminally ill” or “Palliative Care” AND “Hospice and palliative care nursing” or “Hospice care” AND “Quality of life”, “Pain management” or “Activities of daily living”. All key search terms were used as free-text, and with use of truncation symbol to retrieve variations in the terminology (see Appendix 2). A search was conducted in MEDLINE, CINAHL and EMBASE electronic databases, and the Cochrane Database of Systematic Reviews. Searches were restricted to human subjects and to systematic reviews using a filter developed by Lunny et al [39]. There was no restriction on language of publication. Grey literature was searched using hand searching, scanned reference lists, textbooks and policy documents, and by contacting experts in the field to seek potentially relevant research material, including ongoing and unpublished research.

## Data Collection and Analysis

### Selection of studies

A reference management system (Endnote version x8)[40] was used to manage electronic database hits and remove duplicates. A calibration process took place with two reviewers (LI, CES) independently reviewing 50 random citations to test the application of the eligibility criteria. Once an agreement of >90% was achieved, all the titles and abstracts were screened by groups of reviewers (CES and LI, CE, DY and LJB, AB and MM, AC and AO). Full-text articles were retrieved for titles/abstracts that meet the review criteria or when information in the title and abstract was insufficient to determine eligibility. In case of discrepancy, full texts were appraised by the project leads and through group discussion.

## Assessment of methodological quality in included studies

Reviews selected for inclusion were assessed for methodological quality using A Measurement Tool to Assess Systematic Reviews (AMSTAR) tool [41], which has demonstrated satisfactory reliability and construct validity[42]. AMSTAR covers eleven key constructs: a priori design; duplicate study selection and data extraction; comprehensive literature searching; inclusion of grey literature; list of studies; study characteristics; assessment of scientific quality; use of scientific quality; methods of combining findings; publication bias; and conflicts of interest.  A point is allocated for the presence of each criterion (unweighted) and a higher score indicates higher methodological quality. We categorised reviews scoring 0-4 as low quality, 5-8 as moderate quality, and 9-11 as high quality [43].

## Data extraction and analysis

A standardized data extraction form was developed, piloted, and data from eligible reviews was extracted by groups of reviewers (CES and LI, CE, DY and LJB, AB and MM, AC and AO). Data was retrieved on the countries and health care systems represented by primary studies in the review, models of care, target population, outcome measures, impact on clinical and cost outcomes, stated limitations, scalability and sustainability, prominent authors to recommend as ‘experts’ and implications for future research.

Results from the data extraction were described and synthesised narratively. The retrieved literature was summarised by publication date, the WHO regions, countries and income status according the World Bank Classification represented within reviews. Service delivery models were explored using the CATWOE Checklist (Customers, Actors, Transformation World View, Owner, External influences) [44, 45], to understand systems elements. We anticipated heterogeneity of the type of data and level of detail, therefore rather than identify distinct model types with descriptions of how components interact in each model, the analysis was synthesised into the three themes: i) overarching service models, ii) service delivery context, and iii) common model components.

Outcome measures were summarised by frequency counts and grouped into domains around quality of life, functional capacity, dignified end of life care, as well as healthcare use and costs. To assess the impact of service delivery models on these outcome domains, we presented all quantitative statistics from meta-analyses grouped by outcome domain. Where narrative synthesis was presented, findings was categorised as: effective, inconsistent, not effective, or harmful on each outcome domain, and summarised by frequency counts. Outcomes were then linked to the Overarching Service Models and Common Model Components by citation linking at the level of each systematic review, and described narratively. Expenditure data was summarised by the frequency of review reporting, costs measured, and the perspectives used. Throughout the analysis we paid particular attention to evidence relating to LMICs.

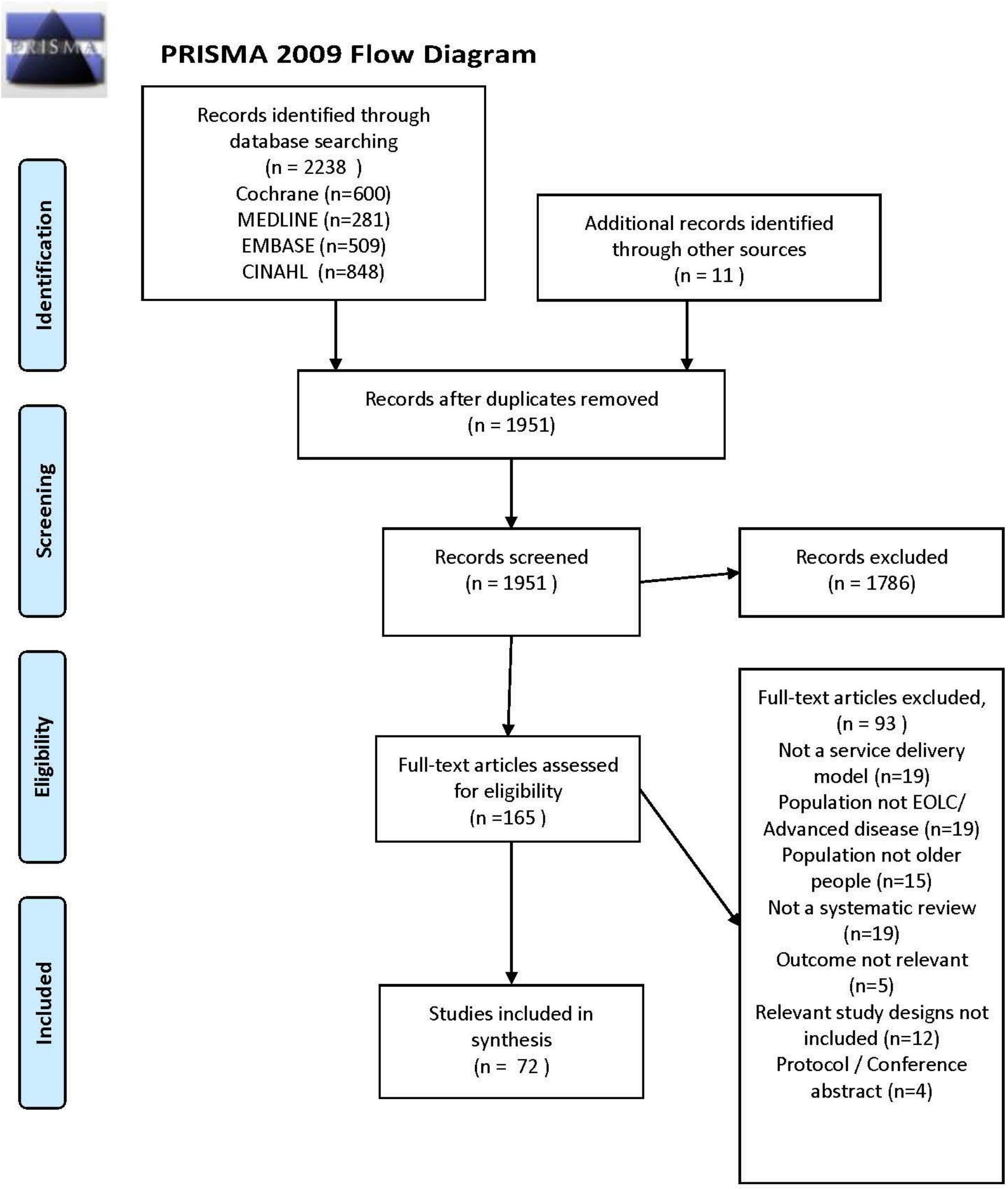
We examined for reporting on scalability/sustainability of proposed models of care. These were appraised for level of coverage for LMICs, generalizability of recommendations to diverse health systems, diagnostic groups, and political and socio-cultural diversity of the patient populations. This guided our decision making process on whether to combine low-middle and high income findings at the point of data integration [46]. To inform the development of recommendations for LMICs, reviews that included studies from LMICs were assessed for the extent to which they were inclusive of the structure of health systems [46], disease epidemiology, and concerns of older people, unique population characteristics like literacy, the youth bulge and older persons being a minority, and systemic challenges that compromise palliative care service development for example the lack of access to opioids and poor development of health services for older persons [1]. We paid attention to the unique needs of older people with HIV, cancer and other non-communicable diseases as well as evidence on outcomes of care and recommendations for scale up in resource limited settings. Best practice service delivery models were identified and characterised the using the CATWOE Checklist [45]. Considering the importance of value in service delivery [47] we identified low-cost models associated with desirable outcomes. We synthesised the implications of findings for policy and for areas for further research narratively, stratifying by level of economic development.

# RESULTS

## Study retrieval

Our search retrieved 2238 articles. After de-duplication and title/abstract screening, 165 full-text articles were retrieved for further appraisal, of which 72 separate review articles were eligible.

Figure 1. PRISMA flow diagram



*From:* Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

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There was an increasing number of systematic reviews published over time (2000-05 n=8; 2006-10 n=11; 2011-15 n=33; 2016-17 n=21) and the majority of reviews (49/72, 68%) limited their search strategy to articles published 2000 onwards. All WHO regions were represented within the reviews, though predominantly studies were included from the Americas (n=52), European (n=46) and Western Pacific (n=28) regions. Lead authors were most frequently employed in the USA (n=18), UK (n=16), Canada (n=8) and Australia (n=8). In the African region, studies from Sub-Saharan Africa [48], Kenya [49], Zambia and South Africa [50] were included within reviews; from the South East Asia region studies from India [50], Nepal, and Pakistan [51] were represented; and from the East Mediterranean region studies from Israel [52-56] were reported (table 1).

The majority of reviews (55/72, 76%) contained studies from high income countries, though studies were included from Upper Middle income countries e.g. South Africa [50]; Lower Middle countries, e.g. India [50, 51], Pakistan [51] and Zambia [50] and Low income countries, e.g. Nepal [51]. See Appendix 3 for a full list of countries by WHO region. Most reviews 71/72 (99%) contained effectiveness data of which 20/72 (28%) reported on a meta-analysis. One review failed to identify eligible studies on effectiveness [57]. Data from over 784, 983 individuals were available. Review samples sizes ranged from 87 to 254,717 when stated. See table 1 for information on characteristics of all the included reviews.

## Quality appraisal

The methodologic score median was 6 (range 0-11) out of a possible 11. Overall, 20/72 (28%) studies were categorised as low quality, 42/72 (58%) as moderate quality and 10/72 (14%) studies as high quality. As quality markers, methods used to combine studies were appropriate in 63/72 (88%) studies, 53/72 (74%) studies used *a priori* design, and 51/72 (71%) used a comprehensive literature search strategy. However, only 22/72 (31%) studies detailed in the inclusion criteria status of publication (e.g. grey literature), 21/72 (29%) studies included a conflict of interest or assessed the likelihood of publication bias, and only 12/72 (17%) studies provided a full list of included and excluded studies (see appendix 4). A post-hoc decision was made not to use quality criteria in any sensitivity analysis due to the heterogeneity across studies.

Table 1. Overview of the included systematic reviews

| Author, year, citation | Aim | WHO regions | World Bank Classifications | Included studies (n) | Descriptive studies (n) | Effectiveness studies (n) | Meta-analysis (y/n) | Participants (n) | AMSTAR total score |
|---|---|---|---|---|---|---|---|---|---|
| Alcide, 2015 [58] | To assess the literature regarding hospice social work intervention outcomes | Americas | High | 5 | 1 | 4 | N | 449 | 6 |
| Bai, 2013 [59] | To identify clinical interventions for improving the quality of life of people with advanced hepatocellular carcinoma | Americas, Europe, Western Pacific | High, Upper-Middle | 18 | 0 | 18 | N | 3,092 | 4 |
| Bainbridge, 2016 [55] | To determine which components of in-home End of Life Care programs are most commonly associated with better outcomes than usual care | Americas, Eastern Mediterranean, Europe, Western Pacific | High | 19 | 2 | 17 | N | - | 6 |
| Bakitas, 2015 [50] | To synthesize evidence relating to palliative care in the rural setting | Africa, Americas, Europe, South-East Asia, Western Pacific | High, Upper-Middle, Lower-Middle | 39 | 23 | 5 | N | 873 | 3 |
| Bakker, 2011 [60] | To review the evidence for hospital-wide interventions for older patients | Americas, Europe | High | 20 | 0 | 20 | N | - | 6 |
| Brereton, 2017 [44] | To identify the existing range of models of palliative care that have been evaluated | - | High | 18 | 12 | 6 | Y | - | 9 |
| Candy, 2011 [61] | To identify the current evidence on the effectiveness of hospices, and hospice care in a patient's home and in nursing homes | Americas, Europe, Western Pacific | High | 18 | 0 | 18 | N | 254,717 | 7 |
| Candy, 2012 [62] | To describe the spiritual and religious interventions for adults in the terminal phase of the disease and evaluate their effect on well-being | Americas | High | 5 | 0 | 5 | N | 1,130 | 8 |

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| Carpenter, 2017 [63] | To review the care of patients discharge to nursing facilities following hospital-based palliative care consult | Americas, Europe, Western Pacific | High | 12 | 9 | 3 | N | 1,263 | 3 |
| Catania, 2015 [64] | To determine to what extent interventions focussed on measuring quality of life in palliative care practice are effective in improving patient outcomes | Americas, Europe | High | 10 | 0 | 10 | N | 1,702 | 8 |
| Conroy, 2011 [56] | To assess the role of comprehensive geriatric assessment in older patients who were treated and discharged from hospital | - | - | 5 | 0 | 5 | y | 2, 287 | 8 |
| De Coninck, 2017 [65] | To assess effectiveness of occupational therapy to improve performance in daily living activities in community-dwelling physically frail older people | Americas, Western Pacific | High | 9 | 0 | 9 | Y | 3,163 | 7 |
| Diop, 2017 [66] | To characterize interventions and effectiveness of palliative care for advanced heart failure patients | Americas | High | 15 | 0 | 15 | Y | 20,105 | 8 |
| Dy, 2008 [67] | To better understand the conceptualization of satisfaction with end-of-life care and the effectiveness of palliative care interventions | NA | NA | 72 | 21 | 51 | N | - | 0 |
| Dy, 2013 [68] | To investigate if interventions focusing on continuity, coordination, and transitions of care for patients with advanced and serious illness improve patient and caregiver centred outcomes | NA | NA | 23 | 0 | 23 | N | 5,666 | 6 |
| Easton, 2016 [69] | To identify the structures and processes in residential aged care settings and if they are cost effective, to identify if the costs and outcomes for residents with dementia have been assessed | Americas, Europe, Western Pacific | High | 19 | 0 | 19 | N | 11,852 | 6 |
| Ekdahl, 2015 [70] | To summarize the evidence for the effects of comprehensive geriatric assessment initiated in hospital compared with usual care in a population of frail and moderately frail patients aged >= 65 years who were acutely admitted to hospital | Americas, Europe | High | 17 | 0 | 17 | y | 6,005 | 6 |

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|---|---|---|---|---|---|---|---|---|---|
| Eklund, 2009 [71] | To review integrated and coordinated interventions targeting frail elderly people living in the community | Americas, Europe | High | 9 | 0 | 9 | N | 2,259 | 4 |
| El-Jawahri, 2011 [19] | To review palliative care interventions and their effect on patients' quality of life, symptoms and other end-of-life outcomes | Americas, Europe | High | 22 | 0 | 22 | N | 10, 596 | 3 |
| Ellis, 2011 [72] | To determine the effectiveness of inpatient comprehensive geriatric assessment for frail older adults admitted to hospital as an unplanned emergency | Americas, Europe, Western Pacific | High | 22 | 0 | 22 | Y | 10,315 | 8 |
| Fox, 2012 [73] | To determine effectiveness of acute geriatric unit care, based on all or part of the Acute Care for Elders (ACE) model and introduced in the acute phase of illness or injury | Americas, Europe | High, Upper-Middle | 13 | 0 | 13 | Y | 6,839 | 9 |
| Frank, 2015 [74] | To discuss models of care for frail seniors provided in primary care settings | Americas | High | 6 | 2 | 4 | N | 3,044 | 0 |
| Garcia-Perez, 2009 [75] | To compare specialised palliative care models effectiveness or cost-effectiveness | Europe | High | 4 | 0 | 4 | N | 2,198 | 7 |
| Gomes, 2013 [76] | To quantify the effect of home palliative care services on patients' odds of dying at home | Americas, Europe, Western-Pacific | High | 23 | 0 | 23 | Y | 41,603 | 10 |
| Hall, 2011 [77] | To determine effectiveness of multi-component palliative care service delivery interventions for residents of care homes for older people | Americas | High | 3 | 0 | 3 | N | 735 | 11 |
| Haun, 2017 [78] | To compare the effects of early palliative interventions versus treatment as usual/standard care on health related quality of life, symptoms and survival among adults with advanced cancer | Americas, Europe, Western Pacific | High | 7 | 0 | 7 | Y | 1,614 | 9 |
| Health Quality Ontario, 2014 [79] | To determine whether an optimal team-based model of care exists for service delivery at end of life | Europe, America, Western Pacific | High | 10 | 0 | 10 | Y | 2,602 | 7 |

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|---|---|---|---|---|---|---|---|---|---|
| Higginson, 2010 [80] | To address whether palliative care teams improve symptoms and quality of life for patients with advanced cancer and their caregivers | Europe, Americas, Western Pacific | High | 40 | 32 | 8 | Y | - | 6 |
| Higginson, 2002 [46] | To determine whether hospital-based palliative care teams improve the process or outcomes of care for patients and families at the end of life | Europe, Americas | High | 13 | 0 | 13 | y | - | 8 |
| Higginson, 2003 [81] | To determine the effect of palliative and hospice care teams | Europe, Americas | High | 44 | 0 | 44 | Y | - | 9 |
| Hodgkinson, 2011 [82] | To identify which staffing models in the long term aged care sector are best for patient and staff outcomes | Americas, Europe | High | 2 | 0 | 2 | N | - | 10 |
| Hopman, 2016 [83] | To describe comprehensive care programs targeting multi-morbid and/or frail patients and to estimate their effectiveness regarding improvement of patient outcomes, health care utilisation and costs | Europe, Americas, Western Pacific | High | 19 | 0 | 19 | N | 7,946 | 6 |
| Joseph, 2016 [84] | To synthesise evidence on the effectiveness of structured interdisciplinary collaboration on patient satisfaction and hospital admission and re-admission rates for adults receiving home hospice services | - | - | 0 | 0 | 0 | N | - | 3 |
| Kane, 2015 [85] | To examine the evidence for patient centred care in chronic heart failure | Americas, Europe | High | 10 | 0 | 10 | N | 2,540 | 6 |
| Kavalieratos, 2016 [49] | To determine the association of palliative care with quality of life, symptom burden, survival and other outcomes for people with life-limiting illnesses and their caregivers | Africa, Americas, Europe, Western Pacific Region | High, Lower-Middle | 43 | 0 | 43 | Y | 12,731 | 8 |
| Kim, 2016 [86] | To investigate the relationship between primary care involvement in end-of-life care and health and utilization outcomes | Americas, Europe, Western Pacific | High | 13 | 13 | 0 | N | 95,006 | 5 |
| Latour, 2007 [87] | To summarize evidence for the effectiveness of post discharge nurse-led case management for complex patients | - | - | 10 | 0 | 10 | N | 5,092 | 7 |

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|---|---|---|---|---|---|---|---|---|---|
| Lorenz, 2008 [18] | To assess evidence about interventions to improve palliative and end-of-life care | Americas, European, Western Pacific | High | 89 | | 89 | N | - | 8 |
| Lowthian, 2015 [88] | To examine the effectiveness of emergency department community transition strategies to support safe community transition | Americas, European, Western Pacific | High | 9 | 0 | 9 | y | 22,502 | 5 |
| Luckett, 2014 [89] | To identify and synthesise recommendations for population based palliative care from international policy and the evidence for improvements on patient, family and health system outcomes. | - | High, Upper-Middle | 43 | 0 | 43 | y | - | 5 |
| Lupari, 2011 [90] | To review research and service evaluation evidence of nurse-led case management services targeting older people with multiple chronic conditions in their own homes | Americas, Europe | High | 8 | 4 | 4 | N | - | 6 |
| Maharaj, 2016 [91] | To identify and appraise the evidence needs, models of care, interventions and outcomes of palliative care in the Caribbean | Americas | High, Upper Middle | 9 | 9 | 0 | N | - | 5 |
| Martinez, 2014 [92] | To evaluate the effectiveness of health care interventions targeting pain in patients with advanced cancer | Americas, Europe, Western Pacific | High | 19 | 0 | 19 | N | 2,027 | 4 |
| May, 2014 [47] | To review the economic evidence on specialist palliative care consultation teams in the hospital setting | Americas | High | 10 | 9 | 1 | N | 40,069 | 4 |
| McAlister, 2004 [93] | To investigate the evidence for the effectiveness of multidisciplinary teams in heart failure | Americas, Europe, Western Pacific | High | 29 | 0 | 29 | Y | 6,320 | 4 |
| Nevis, 2014 [94] | To review the effectiveness of educational interventions for health care providers, patients nearing the end of life, and informal caregivers to improve patient and informal caregiver outcomes | Americas, Europe | High | 6 | 0 | 6 | N | 3,170 | 7 |

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| Nordly, 2016 [95] | To overview the organisation and outcomes of home-based specialised palliative care for patients with advanced cancer | Europe, Western Pacific | High | 8 | 0 | 8 | N | 1,590 | 5 |
| Oeseburg, 2009 [96] | To evaluate the effects of patient case advocacy case management on service use and healthcare costs for impaired older adults or adults with a chronic somatic disease living in the community | Americas, Europe | High | 9 | 0 | 9 | N | 15,746 | 7 |
| Pham, 2014 [97] | To evaluate the cost-effectiveness of end-of-life care interventions | - | - | 6 | 0 | 6 | N | 3,009 | 3 |
| Phillips, 2013 [98] | To determine the efficacy of comprehensive discharge planning plus post discharge support for older inpatients with chronic heart failure | Americas, Europe, Western Pacific | High | 18 | 0 | 18 | Y | 3,304 | 8 |
| Phillips, 2004 [99] | To determine the evidence for case conferencing as an intervention to improve palliative care outcomes for older people living with advanced dementia in nursing homes | Americas, Europe, Western Pacific | High | 9 | 5 | 4 | N | 293 | 7 |
| Pillotto, 2017 [20] | To consider implementation of comprehensive geriatric assessment programs in different healthcare settings | - | - | 39 | 0 | 39 | N | 75,181 | 4 |
| Procter, 2012 [57] | To consider how specialist palliative care professionals can engage with other health professionals to ensure that a collaborative approach to end of life care | Europe | High | 5 | 5 | 0 | N | 87 | 5 |
| Puts, 2017 [100] | To consider evidence on interventions to prevent and reduce frailty in community-dwelling older adults | Americas, Europe, South-East Asia, Western Pacific | High | 14 | 0 | 14 | N | 3,632 | 8 |
| Richards, 2003 [101] | To determine effectiveness and cost of interventions intended to improve access to health and social care for older patients following discharge from acute hospitals | Europe, Americas, Western Pacific | High | 15 | 0 | 15 | N | 5,718 | 4 |

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|---|---|---|---|---|---|---|---|---|---|
| Rizzo, 2016 [102] | To assess the current evident on the efficacy and cost-effectiveness of social work interventions in aging | Americas | High | 42 | 0 | 42 | N | 19,416 | 3 |
| Robinson, 2009 [48] | To identify, evaluate and synthesize the published literature on rural palliative care | Africa, Americas, Europe, Western Pacific | High, Upper Middle | 5 | 5 | 0 | N | - | 5 |
| Roczen, 2016 [103] | To examine whether and how the integration of palliative care practices into intensive care units is associated with clinical and nonclinical outcomes | Europe, Americas | High | 12 | 0 | 12 | N | 7,629 | 4 |
| Ruiz-Iniguez, 2017 [104] | To assess the effectiveness of nursing interventions on the quality of life of palliative patients in home-based care | - | - | 8 | 2 | 6 | N | 343 | 6 |
| Ryburn, 2009 [105] | To review the ‘real world’ potential (i.e. efficacy and effectiveness) of restorative approaches towards home care for frail older adults | Americas, Europe, Western Pacific | High | 3 | 0 | 3 | N | 1,782 | 4 |
| Sampson, 2005 [106] | To review of the scientific literature regarding the efficacy of a palliative care model in patients with dementia | Americas | High | 3 | 0 | 3 | N | 263 | 6 |
| Shepperd, 2016 [107] | To determine if providing home-based end-of-life care reduces the likelihood of dying in hospital and what effect this has on patients’ symptoms and quality of life | Europe, Americas | High | 4 | 0 | 4 | Y | 823 | 9 |
| Simoens, 2010 [54] | To review the costs of treating terminal patients, with focus on the level, distribution and drivers of costs of treating terminal patients | Americas, Eastern Mediterranean, Europe, Western Pacific | High | 15 | 15 | 0 | N | 30,647 | 6 |
| Singer, 2016 [108] | To inform how payers and providers should identify patients with ‘‘advanced illness’’ and the specific interventions they should implement | - | - | 124 | 0 | 124 | N | - | 3 |
| Singh, 2015 [51] | To appraise the evidence for palliative care models, interventions and outcomes in South Asia | South-East Asia | Lower-Middle, low | 16 | 12 | 4 | N | 148 | 5 |

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| Soares,2012[109] | To review the effects of discharge interventions on patient safety, e.g adverse events, and evaluate the effects in terms of effectiveness and efficiency of care processes | - | - | 37 | 10 | 23 | N | - | 3 |
| Stuck, 2002 [110] | To evaluate the effect of preventative home visits on functional status, nursing home admission and mortality | Americas, Europe, Western Pacific | High | 18 | 0 | 18 | Y | 13,447 | 6 |
| Windham, 2003 [111] | To identify effectiveness of care management strategies and outcome measures likely to be helpful in establishing the overall clinical efficacy in congestive heart failure | - | - | 32 | 0 | 32 | N | 6,919 | 1 |
| You, 2012 [53] | To evaluate the effects of case management in community aged care on client and carer outcomes | Americas, Europe, Western Pacific | High | 15 | 0 | 15 | N | Range 60-8095 | 6 |
| You, 2013 [52] | To evaluate the effects of case management in community aged care interventions on service use and costs | Americas, Europe, Western Pacific | High, Upper Middle | 21 | 0 | 21 | N | Range 60-8095 | 5 |
| Young, 2017[112]. | To assess the effects of long-term home or foster care versus institutional care for functionally dependent older adults | Americas, Europe, Western Pacific | High | 10 | 0 | 10 | N | 16,377 | 10 |
| Zimmermann, 2008 [113] | To systematically review the evidence for effectiveness of specialized palliative care | Americas, Europe | High | 22 | 0 | 22 | N | Range 69-4804 | 9 |

## Service delivery models

### Overarching Integrated Service Delivery Models and Processes for Delivery

We identified clusters of service delivery models that formed two overarching classifications defined as: Integrated Geriatric Care detailed mainly for an earlier trajectory of functional decline; and Integrated Palliative Care for commonly a later trajectory of functional decline and dying. The palliative care classification comprised models of specialist palliative care where palliative care formed the majority of service delivery models, or with an element of generalist palliative care in end of life care provided by non-specialists [53, 111]. The overarching classifications articulate the requirement to provide services drawn from palliative care, community care and older people's specialities. Table 2 overviews a proposed typology comprising the two overarching classifications and three overarching processes, and figure 2 the relationship between the classifications and the processes. Two reviews encompassed a very broad approach to palliative care with unspecified detail on the palliative care providers. These reviews were not included in the overarching classification [51, 113].

We identified three overarching processes to deliver integrated care across services and manage the continuum of care overtime. These comprised: 1) comprehensive assessment meaning a person centred assessment of need across physical, psychological, social and spiritual domains discussed both in general terms and within specific models of assessment, notably the Comprehensive Geriatric Assessment [70, 72]; 2) case management that was primarily concerned with co-ordination of care for a patient and their carers through the assignment of a case; and 3) collaborative working across disciplines and organizations to plan and deliver services to meet an individual's health and social care needs and their families and those close to them (table 2).

Table 2. Typology of service delivery models

| **Overarching Service Delivery Models** | **Supporting evidence** |
|---|---|
| Integrated Geriatric Care | [64] [65] [66] [67] [68] [69] [19] [72] [73] [74] [78] [83] [85] [49] [86] [109] [88] [93] [99] [102] [105] [111] [52] [112] |
| Integrated Palliative Care<br>(specialist palliative care and generalist palliative care) | [55] [50] [63] [19] [75] [76] [77] [78] [80] [46] [81] [84] [49] [89] [91] [47] [93] [95] [97] [57] [102] [48] [103] [114] [108] [51] [79, 111] [52] |
| **Overarching methods to integrate and manage the continuum of care** | **Supporting evidence** |
| Comprehensive Assessment | [60] [69] [70] [49] [88] [20] [100] [101] [102] [105] [111] [113] [97] |
| Case Management | [60] [56] [67] [69] [71] [19] [72] [78] [82] [83] [49] [87] [109] [88] [90] [92] [93] [96] [99] [98] [100] [101] [102] [105] [115] [110] [111] [53] [52] [112] |
| Collaborative Working | [59] [60] [44] [65] [66] [67] [68] [69] [70] [71] [19] [72] [74] [75] [78] [116] [80] [81] [83] [84] [85] [49] [86] [109] [88] [47] [93] [96] [99] [57] [100] [102] [48] [103] [105] [51] [111] [52] [112] [113] [81] |

Delivery of palliative care unspecified [51, 113]

## Service delivery context

The reviews consistently identified the importance of the multi-disciplinary team with a breadth of disciplines involved in the delivery of end of life care to older people. The main disciplines were nurses, physicians and social workers (see Appendix 5). Noteworthy, is the importance of physiotherapists reported in 14 models [20, 49, 56, 65, 69-71, 73, 85, 105, 108, 109, 111, 114] which underscores the importance of functionality and rehabilitation as a continuum in end of life care for older people [105]. Only 5 reviews identified the involvement of volunteers in the delivery of service models [50, 51, 55, 62, 110] . The under use or under reporting of volunteers is an important consideration given the resource implications, the uncertain dying trajectory of older people, and the considerable expertise of those who live alongside older people in their homes. Models that cited other lay involvement besides volunteers, such as older people's carers, most commonly also involved healthcare professionals such as community practitioners and long-term condition specialists, such as cardiologists [52, 111].

Detail on the integration and continuity of care between services, particularly between health and social care was difficult to extract from the high-level description in the systematic reviews. However, noteworthy in integrating health and social care were models that had a specific social worker presence (see appendix 5), and those that were embedded in older peoples' everyday lives, for example residential care facilities [69]. Most service models fell on a continuum of service delivery between specialist palliative care, hospital care, long term specialists and geriatrics, for example Dy et al 2008 [67]. Only a minority clearly identified a reach across the whole continuum of primary and secondary generalist palliative care and community participation to specialist palliative care, for example Singh et al focusing on LMICs [51].

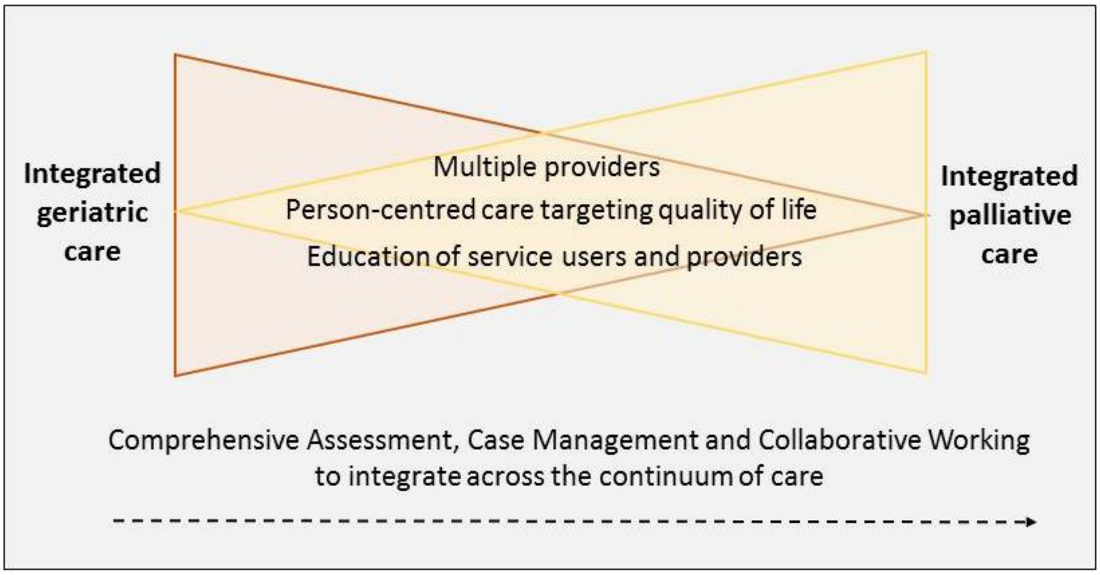
### Model components

Three common model components were identified across Integrated Geriatric Care and Integrated Palliative Care. The components comprised: 1) care centred on the person; 2) education; and 3) workforce (see appendix 6, and figure 2). Data on the components for care centred on the person and education was sufficient to sub-divide into discrete activities. Care centred on the person was the most frequent component and often reported as either multicomponent (physical, psycho-social, and spiritual) or a single domain of physical care, for example symptom management (e.g. the Health Quality Ontario exercise programmes)[79]. Some reviews reported whole models around improving physical care for older people, for example, Acute Care for Elders programme [73]. Psychosocial interventions were often mentioned, but spiritual components less so. It is difficult to draw conclusions from this analysis, although this might be due to the level of data and type of measure reported in a systematic review. Less discernible may be more diffuse and integrating elements between for example physical and mental suffering. Education was subdivided into the recipients of: patient/caregiver, for example a comprehensive care programme [83]; and staff, for example, role of specialist palliative care teams [80]. Notable, were the components that develop the wider workforce's capacity to support end of life care for older people, for example in nursing homes [77].

### Evidence from LMICs

Overall, the reviews reported on a large variety of service delivery models, but data was too scarce to develop an informed picture of the distinct models implemented in different countries. This limits the application of the proposed overarching integrated models and processes of delivery for LMICs (figure 2). Only four systematic reviews included studies from lower-middle income countries/areas comprising Zambia [50], South Africa [50], Kenya [49], Sub-Saharan Africa [48], India [50, 51], Pakistan [51], and Nepal [51]. Of these, only one review focused exclusively on studies from LMICs in South East Asia [51]. They reported on a wide range of service models including; a combination of free community-based outpatient clinics, home care service, inpatient units including hospice, cancer centres, combined cancer centre and palliative care training centre, pain clinic, domiciliary services, palliative care education centres and programmes, outreach link clinics, telephone support line, counselling service, bereavement services, medicines support, training for family members, and rehabilitation services [51]. The other three reviews [48-50] included a majority of studies from high-income countries in Europe and North America.

Figure 2. Overarching integrated service delivery models and processes to maximise quality of life for older people in the last years of life



Adapted from Hawley [117]

## Outcomes measured

In total 117 separate outcomes were measured across the reviews (see table 3). There was a large diversity and lack of consistency at the level of each outcome. Only 25/117 (21%) of outcomes were used in a meta-analysis in one or more reviews. Outcomes were grouped into five main themes; (i) quality of life, which in keeping with our inclusive definition encompassed symptoms, morale, empowerment and well-being; (ii) functional outcomes; (iii) dignified end of life care, which included perceived quality of care and satisfaction with care; (iv) health service use and costs; and (v) survival, generally used as a proxy for potential risk of harm. Of the individual outcomes, the most common were quality of life (43/72, 60%), satisfaction with care (37/72, 51%), survival (28/72, 39%), physical function (25/72, 35%), health care costs (25/72, 35%), hospital length of stay (23/72, 32%) and psychiatric symptoms (23/72, 32%). Across the reviews pain (n=17/72 24%), overall symptom control (n=16/72 22%) and depression (n=12/72 17%) were the most common outcomes concerning symptoms.

Table 3. Outcomes measured ordered by frequency of reporting

| **Quality of life** | **References** | **Total** |
|---|---|---|
| Quality of life | [19, 20, 44, 46, 49-51, 55, 56, 58, 59, 62, 64, 66, 68-71, 75, 76, 78-83, 85, 87, 89, 92-95, 99, 101, 102, 104, 108, 111-113, 118, 119] | 43 |
| Psychiatric symptoms including depression, anxiety and mood | [19, 20, 44, 49, 50, 53, 58, 59, 64, 69-71, 73, 75, 77, 78, 83, 85, 89, 102, 108, 118, 119] | 23 |
| Pain | [19, 44, 48, 51, 55, 75-77, 80, 81, 92, 94, 95, 97, 102, 118, 119] | 17 |
| Symptom control / management /burden of multiple symptoms (physical and psychological) | [19, 44, 46, 55, 58, 64, 75, 79-81, 86, 89, 94, 103, 114, 119] | 16 |
| Psychological and Spiritual well being | [19, 53, 59, 64, 89, 119] | 6 |
| Empowerment | [62, 74, 75, 85, 102] | 5 |
| Dyspnoea | [95, 102, 118] | 3 |
| Patient morale | [101, 105] | 2 |
| Well-being | [62, 101] | 2 |
| Fatigue | [102] | 1 |
| Insight | [89] | 1 |
| Patients perception of health | [101] | 1 |
| **Function** | | |
| Function | [19, 20, 53, 56, 60, 63-65, 69, 72-74, 76, 83, 85-87, 89, 95, 101, 110-112, 114, 118] | 25 |
| ADLs / impairment | [20, 65, 70, 72, 85, 88, 100-102, 105, 118] | 11 |
| Cognitive function | [20, 53, 56, 69-72, 89] | 8 |
| Falls | [20, 73, 82, 105] | 4 |
| Mobility | [20, 65, 105] | 3 |
| Social participation | [65, 69, 101] | 3 |
| Social support | [101, 102] | 2 |
| Exercise performance | [85] | 1 |
| Frailty | [100] | 1 |
| **Dignified End of Life Care** | | |
| Satisfaction with care – patient and caregiver | [19, 20, 44, 46, 49, 51, 53, 55, 57, 59, 63, 66-68, 71, 74-77, 79-81, 83, 84, 87, 89, 90, 92, 94, 97, 101, 102, 108, 109, 113, 114, 119] | 37 |
| Living will / advanced directive / power of attorney / do no resuscitate order | [63, 68, 77, 85, 106, 118] | 6 |
| Quality of care | [20, 63, 69, 90, 102] | 5 |
| Communication / Interaction | [63, 69, 102] | 3 |
| Goals of care discussions documented | [63, 66] | 2 |
| Preparation for end of life | [89] | 1 |
| Quality of death | [46] | 1 |
| **Health service use** | | |
| Length of hospital stay | [19, 20, 46, 52, 60, 63, 68, 72-75, 77, 79, 85, 92, 94, 96, 99, 101, 102, 106, 111, 118] | 23 |
| Readmission | [19, 20, 56, 60, 63, 66, 70, 72, 73, 84, 85, 87, 99, 101, 102, 106, 109, 118] | 18 |
| Hospital admission | [19, 52, 68, 74, 77, 79, 84-86, 93, 96, 97, 102, 111, 114] | 15 |
| Place of death | [44, 46, 48, 55, 66, 68, 76, 77, 79, 95, 114, 119] | 12 |
| Emergency department visits | [19, 52, 63, 79, 85-87, 94, 96, 97, 102, 105] | 12 |
| Hospice use / referral | [19, 48, 49, 66, 68, 77, 85] | 7 |

| | | |
|---|---|---|
| Medication use | [69, 71, 77, 98, 102, 111] | 6 |
| Place of residence | [20, 52, 56, 72, 76, 105] | 6 |
| Discharge location | [20, 60, 63, 73, 106] | 5 |
| ICU use | [79, 86, 92, 94] | 4 |
| Medication related problems | [82, 89, 109, 118] | 4 |
| Use of burdensome interventions | [63, 89] | 2 |
| Nursing home admission | [96, 110] | 2 |
| Use of non-palliative services | [49, 106] | 2 |
| Delay in diagnosis / treatment | [109, 114] | 2 |
| Hospice length of stay | [85, 86] | 2 |
| Days spent at home | [20] | 1 |
| Referral to community services / post discharge use of services | [101] | 1 |
| Discharge rate | [102] | 1 |
| Total length of time in palliative care | [46] | 1 |
| Length of nursing home stay / use of formal / informal community services | [52] | 1 |
| Use of outpatient / inpatient services | [83] | 1 |
| Unmet service needs | [53] | 1 |
| Adverse health outcomes | [109] | 1 |
| **Costs** | | |
| Health care costs | [19, 44, 49, 52, 54, 55, 60, 63, 66, 69, 71, 73, 75, 83, 86, 89, 90, 92, 96, 97, 101, 102, 114, 118, 119] | 25 |
| Nursing home costs | [99, 101, 102] | 3 |
| Cost-effectiveness | [69, 97] | 2 |
| Quality adjusted life years / days | [69, 97] | 2 |
| Self-reported health care costs | [102] | 1 |
| Caregiver costs | [114] | 1 |
| **Survival** | | |
| Survival | [19, 20, 49, 53, 56, 60, 63, 66, 70, 72, 73, 78, 80, 83, 86, 93, 95, 97-99, 101-103, 106, 109-112] | 28 |

Both Integrated Geriatric Care (n=25) and Integrated Palliative Care (=30) placed equal emphasis on quality of life (17/25, 68% vs. 19/30, 63%) and health service use (17/25, 68% vs. 19/30, 63%) measures. Variation according to the overarching model was also observed. Outcome measures relating to symptoms were more common in Integrated Palliative Care (21/30, 70%) as compared to Integrated Geriatric Care (11/27, 44%). In contrast, Integrated Geriatric Care models more frequently used outcomes relating to physical function (15/25, 60% vs. 8/30, 27%) and, to a lesser extent, survival (14/25 56% vs. 40% 12/30).

## Impact of service delivery models

Table 4 presents the findings from the meta-analysis and meta-synthesis data. Forty-seven reviews analysed the impact on quality of life outcomes, nine of which reported meta-analysis [49, 56, 65, 70, 73, 78, 99, 118, 120]. Pooled analyses were reported for health-related quality of life (physical and psychological), global symptoms and individual symptoms. All of the pooled estimates of effect demonstrated effectiveness on quality of life outcomes. Twenty-eight reviews reported narrative synthesis focusing on quality of life (excluding symptoms), 13 of which reported the models were effective [19, 49-51, 55, 59, 64, 66, 71, 79, 85, 102, 108], while a further 11 studies found inconsistent evidence [20, 62, 68, 81, 82, 87, 92, 95, 101, 111, 113], and 4 found no effect of the models on quality of life[80, 83, 94, 104]. Symptoms were reported in narrative form in 37 of the reviews, 19 of which found the models to be effective,[44, 46, 48, 49, 51, 55, 60, 64, 66, 69, 71, 75, 79, 80, 92, 102, 103, 105, 106] , 16 inconsistent[19, 50, 53, 58, 59, 62, 76, 85, 94, 95, 97, 98, 108, 112, 113, 118] and two found no effect[77, 83]. In no cases were the models found to be associated with harm.

The impact of service delivery models on patient function was reported in 25 reviews. Six reviews provided meta-analysis for function outcomes [56, 65, 70, 72, 73, 110], including physical function, cognitive function, mobility and dependence. Three reviews found that the models were effective at improving function outcomes[56, 65, 73], while three found mixed results with some evidence of effect depending on the population characteristics, functional outcomes measured or components of the model [70, 72, 110]. Nineteen studies provided narrative results, which were compatible with the meta-analysis findings. Eight found the models to be effective [60, 64, 69, 71, 82, 85, 102, 105], eight inconsistent [20, 53, 55, 83, 95, 100, 101, 112], and a further three reviews found no evidence of effect [77, 87, 88].

The impact of the models on dignified end of life care was reported by 39 studies. However, only one systematic review study pooled quantitative findings for the impact of models on dignified end of life care, which related to satisfaction [81]. This model was found to be effective for caregiver satisfaction but no evidence of effect for patients' satisfaction. Across the 38 reviews that narratively synthesised the impact on dignified end of life care, 24 found the models to be effective [19, 44, 49-51, 55, 59, 62, 63, 67-69, 74, 75, 77, 79, 80, 85, 87, 103, 108, 109, 118, 119], ten inconsistent [20, 66, 76, 82, 83, 98, 101, 107, 112, 113] and four reported no effect [53, 57, 71, 94]. In no case was a model found to be associated with harm.

Mortality was assessed in fourteen reviews, five of which performed meta-analysis [49, 56, 78, 99, 110]. Of these, all but one found no effect on mortality while one found reduced mortality in a subgroup of 'younger' older people [110]. Nine further reviews reported findings on survival in narrative form. Most reported no effect (n=5) [62, 63, 77, 83, 111] or inconsistent findings (n=3) [20, 76, 101], with only one review reporting that the model of care reduced mortality [60]. No reviews found increased mortality among those receiving the model of care compared to usual care.

Due to included reviews often spanning more than one overarching service delivery model or method to integrate and manage the continuum of care (see Table 2), we could not confidently link models to levels of effectiveness on specific areas of impact. It was not possible to judge the relative effectiveness of different models or methods from available data. However, there was evidence supporting a positive effect on quality of life relating to each of the overarching service delivery models and methods. Interpretations of narrative and quantitative findings were either effective or inconsistent in the majority of cases.

Table 4. Reported impact of common service delivery models

| Outcome | Narrative findings | Meta-analysis | Outcome | Findings and Interpretation | |
|---|---|---|---|---|---|
| Quality of life | Quality of Life<br>Effective: [102], [85], [51], [19], [64], [49], [108], [66], [71], [79], [59], [55], [50]<br>Inconsistent:[95],[20],[62, 111], [101], [82], [92], [113], [87], [68], [81]<br>No effect: [83], [94], [104], [80] | Lorenz (2008) [118] | Pain | Effect size 0.13 (95% CI 0.11 to 0.63) | Effective |
| | | Conroy (2011) [56] | QOL- physical<br>QOL-mental component | MD 0.2 (95% CI -1.9 to -2.3)<br>MD 0.6 (95% CI -1.3 to -2.5) | Effective<br>Effective |
| | | De Coninck (2017) [65] | Fear of falling | SMD 0.17 (95% CI 0.29 to 0.05) | Effective |
| | | Kavalieratos (2016) [49] | QOL (1-3 month)<br>Symptom burden 1-3 month 10 studies | SMD 0.46 (95% CI 0.08 to 0.83)<br>SMD -0.66 (95%CI -1.25 to -0.07) | Effective<br>Effective |
| | Symptoms<br>Effective: [102], [69], [51], [64], [49], [92], [105], [106], [48], [103], [66], [71], [46], [80], [79], [55], [60], [44], [75]<br>Inconsistent [95], [98], [97], [85], [19], [62], [118], [94], [108], [112], [53], [113], [58], [59], [50], [76]<br>No effect: [83], [77] | Ekdahl, (2015) [70] | Depression | SMD 0.17, P = 0.02 | Effective |
| | | Fox (2012) [73] | Delirium | RR 0.73 (95% CI 0.61 to 0.88) | Effective |
| | | Phillips, (2004) [99] | QOL | P=0.01 (no other figures given) | Effective |
| | | Haun (2017) [78] | Levels of depressive symptom<br>Symptom intensity<br>Health related QOL | SMD -0.11 (95% CI -0.26 to 0.03)<br>SMD-0.23 (95%CI -0.35 to -0.10)<br>SMD 0.27 (95% CI 0.15 to 0.38) | Effective, very low certainty<br>Effective, low certainty<br>Effective |
| | | Higginson (2003) [81] | Pain –<br>Other symptoms – effective | OR 0.38 (95% CI 0.23 to 0.64)<br>OR 0.51 (95% CI 0.30 to 0.88) | Effective<br>Effective |
| Function | Effective:[102], [69], [85], [64], [82], [105], [71], [60]<br>Inconsistent:[95], [20], [100], [101], [83], [112], [53], [55] | Stuck (2002); [110] | Functional decline | RR 0.76 (95% CI 0.64 to 0.95) | Inconsistent. Effective in trials of multi-dimensional assessment |
| | | Conroy (2011); [56] | Function | SMD 0.41 (95% CI 0.21 to 0.61) | Effective |
| | | De Coninck (2017); [65] | IADL<br>Mobility<br>Disability | SMD 0.30 (95% CI 0.50 to 0.11)<br>SMD 0.45 (95% CI 0.78 to 0.12)<br>SMD 0.19 (95% CI 0.4 to 0.06) | Effective<br>Effective<br>Effective |

| | | | | | |
|---|---|---|---|---|---|
| | No effect: [88], [87], [77] | | Social participation | SMD 0.44 (95% CI 0.69 to 0.19) | Effective |
| | | Ekdahl, (2015); [70] | Personal ADLs | SMD 0.21 (95% CI 0.05 to 0.37) | Inconsistent. Effective depending on frailty |
| | | Fox (2012)[73] | Falls | RR 0.51 (95% CI 0.29 to 0.88) | Effective |
| | | | Functional decline at discharge | RR 0.87 (95% CI 0.78 to 0.97) | Effective |
| | | Ellis (2011); [72] | Dependence | OR 0.94 (95% CI 0.81 to 1.10) | No effect |
| | | | Activities of daily living | SMD 0.06 (95% CI -0.06 to 0.17) | No effect |
| | | | Cognitive function | SMD 0.08 (95% CI 0.01 to 0.15) | Effective |
| | | | Death or deterioration | OR 0.76 (95% CI 0.64 to 0.90) | Effective |
| Dignified EOLC | Effective:[69], [85], [51] [19], [63], [62], [49], [118], [108], [103], [109], [87], [68], [67], [80], [79], [59], [55], [50], [44], [77], [74], [75], [119]<br>Inconsistent:[98], [20], [101], [83], [82], [114], [112], [113], [66], [76]<br>No effect: [57], [94], [53],[71] | Higginson (2003) [81] | Caregiver satisfaction | OR 0.17 (95% CI 0.03 to 0.96) | Effective |
| | | | Patient satisfaction | Numbers not given | No effect |
| Health service use | Effective: [19, 53, 66, 75, 77, 79, 80, 85, 86, 97, 98, 102, 104, 105, 119]<br>Inconsistent: [20, 49, 60, 62, 63, 71, 78, 83, 87, 96, 101, 109, 111, 118]<br>Ineffective: [94, 106] | Stuck (2002) [110] | Nursing home admission | High intensity care (>9 visits)<br>RR 0.66 (95% CI 0.48 to 0.92)<br>0-4 visits RR =1.05 (95% CI 0.85 to 1.30) | Effective if high intensity intervention (>9 visits); otherwise 0-4 not effective.<br>Overall no effect |
| | | Conroy (2011) [56] | Institutionalisation | RR 0.75 (95% CI 0.44 to 1.29) | No effect |
| | | | Readmission | RR 0.95 (95% CI 0.83 to 1.08) | No effect |
| | | Fox (2012) [73] | Shorter length of hospital stay | MD 0.61 (95% CI 1.16 to 0.05) | Effective |
| | | | Discharge to a nursing | | |

|  |  |  |  |  |  |
|---|---|---|---|---|---|
|  |  |  | home<br>Discharge to home | RR = 0.82 (95% CI 0.68 to 0.99)<br>RR 1.05 (95% CI 1.01 to 1.10) | Effective<br>Effective |
|  |  | Phillips, (2004) [99] | Readmission<br>Length of stay | RR 0.75 (95% CI 0.64 to 0.88)<br>RR -0.37 (95% CI -0.15 to 0.60) | Effective<br>No effect |
|  |  | McAlister (2004) [93] | All cause hospitalisation | RR 0.84 (95% CI 0.75 to 0.93) | Effective |
|  |  | Shepperd, (2016) [107] | Dying at home | RR 1.33 (95% CI 1.14 to 1.55) | Effective, high quality evidence |
|  |  | Gomes, (2013) [76] | Death at home<br>Death not in nursing home | (P value=0.02)<br>(P value=0.60) | Effective<br>No effect |
| Survival | Effective<br>[60]<br>Inconsistent<br>[20], [101], [76]<br>No effect<br>[111], [63], [62], [83], [77] | Stuck (2002); [110] | Mortality: Younger study populations ages 72.77 - 77.5<br>Older study populations for ages 80 - 81.6 years | RR 0.76 (95% CI 0.65 to 0.88)<br>RR 1.09 (95% CI 0.92 to 1.28) | Effective<br>No effect |
|  |  | Conroy (2011) [56] | Mortality | RR 0.92 (95% CI 0.55 to 1.52) | No effect |
|  |  | Kavalieratos (2016); [49] | Survival | HR 0.90 (95% CI 0.69 to 1.17) | No effect |
|  |  | Phillips, (2004) [99] | Mortality | RR 0.87 (95% CI 0.73 to 1.03) | No effect |
|  |  | Haun (2017) [78] | Mortality | HR 0.85 (95% CI 0.56 to 1.28) | No effect, very low certainty |

Key: CI = confidence interval, HR = hazard ratio, IADL = instrumental activities of daily living, MD = mean difference, OR = odds ratio, RR = risk ratio, SMD = standardised mean difference,

## Health service use and expenditure data

Health service use was reported by 38 studies, 7 of which performed meta-analyses. Three of these meta-analyses reported that the models were effective for health service use outcomes [73, 93, 114], two showed inconsistent results [76, 98] and 2 showed that the models were ineffective for health service use outcomes [56, 110]. Thirty-one studies reported narrative findings for effect on the model on health service use. 15 reviews showed the models were effective for health service use outcomes [19, 53, 66, 75, 77, 79, 80, 85, 86, 97, 98, 102, 104, 105, 119], 14 showed inconsistent results [20, 49, 60, 62, 63, 71, 78, 83, 87, 96, 101, 109, 111, 118] and 2 reviews showed that the models were ineffective for health service use outcomes [94, 106].

Overall, health economic data were not always presented and cost saving or cost-effectiveness from the reported data was inconclusive. Thirty-two reviews (32/72, 44%) reported costs and/or cost-effectiveness of delivery models of care for old people at the end of life. Due to diversity in health care delivery and financing systems, sources of health care expenditure, e.g. private or public, were not distinguished clearly. It was not always possible to identify the analytic perspectives (or viewpoints) of cost calculation or economic analysis either. However, the majority of reviews adopted a health system's perspective and combined individual patient expenditure and resource use of the health care system. Sources of societal costs beyond informal care costs were not identifiable from the reviews.

In interventions found to have lower costs than control (e.g. usual care) [101], cost saving was achieved by reducing the resource use or using the less expensive resources. Reduction in acute care utilisation (e.g. admissions to hospital, length of stay, A&E visits) was often found in these interventions [73, 93, 99, 102]. On the other hand, interventions with higher costs than the control reported costs of staffing and education as a reason [69]. One review found the intervention cost-effective when using patient related quality of care but not cost-effective when functional health or quality adjusted life years (QALY) was used [69]. Another study reported inconclusive cost-effectiveness of palliative care and asserted that the cost savings might come from shifting care in hospital to community settings [89].

Identifying the types and sources of finance can help assess the burdens of illness and care. Often, studies collected limited information on resource use or failed to collect the data. This may have led to failure in finding cost savings or cost-effectiveness of the intervention. Resource use beyond individuals and health care systems, which are often financed based on taxes, social insurance and private insurance, was rarely collected and reported. Informal care costs and opportunity costs of lost work were not used, or opportunity costs of lost productivity of patients.

## Scalability and sustainability

Forty-four reviews (44/72, 61%) provided useful information to inform the assessment of scalability and sustainability, of which three [48-50] included studies from Africa. However, when considering the concept of 'scalability' it is essential to determine the feasibility and acceptability of evidence generated in settings different from where they are intended for scale-up. Some of the models may not be scaled up or replicated in other settings due to differences between settings and contexts where the studies were conducted. Settings may have unique external factors, differences in psychosocial and cultural characteristics in the populations included, differences in health structural systems and definitions of palliative care [44, 59, 63, 69, 71, 77, 86, 106, 113]. Other studies failed to provide a comprehensive description of the service composition (e.g. staff involved in the delivery of care)[104]. This limits judgement on the scalability and sustainability of the proposed service delivery model. The decision on which models of care to scale up should be based on palliative care costs and outcomes. These are determined notably by patient characteristics, models of care, disease stage and patient age. For this reason, scalability has to be sensitive to the specific types of patients targeted by a specific model of care and the packages of services that go with the model of care [54].

Two reviews found community involvement to be pivotal to any future plans for developing primary palliative care services in the rural area [50, 55]. Community involvement has several implications. Firstly, to enhance education within the community for primary care clinicians to integrate 24-hour palliative care access in the rural area for all patients with life-threatening illness, and widening access to include patients with cancer and non-cancer conditions. Educational approaches for rural practitioners may be, for example, web-based and/or use onsite incentives. Secondly, Family Physicians should be involved in developing and implementing strategies that meet the needs of individual patients and communities [74], with a requirement to increase training in geriatric care.

The wider generalizability of the evidence from high income countries to LMICs is limited. It is difficult to conclude which of the models could be scaled up in resource limited settings, particularly when there is great uncertainty about which are most effective, cost-effective or appropriate to different contexts. It is wiser to base such decisions on the preferences of local providers and commissioners and the availability of the required staff, resources and facilities. For LMICs in South Asia [51], India had the strongest evidence base, while countries like Afghanistan, Sri Lanka, Bhutan, the Maldives and Bangladesh lagged behind. This is a likely indicator of limited palliative care activity [121].

The palliative care public health approach was a best practice example from India. Although the evidence is largely from a population with a high literacy rate and low population growth rate, the work in India informs scalability processes for palliative care services [51] both in India and African countries [121]. The processes were informed by an international classification system that stresses factors to precede initiating a service in a country, notably capacity building activities, for example developing related health and education policies [122]. Emphasis is placed on integrating with the institutionalised health care system, as well as systems of family and community support, cultural, spiritual, and socioeconomic support systems and public engagement. However, in different contexts there may be different capacity building exercises that are not reflected in the literature, and therefore further evaluation of this model is needed to tease out successful strategies and key lessons.

# DISCUSSION

Our findings indicate two overarching classifications of integrated care comprising clusters of models that focus primarily on Integrated Geriatric Care or Integrated Palliative Care. There is evidence of effectiveness for both approaches on the main outcome of quality of life. Both approaches intended to improve quality of life, but with different emphasis to attainment. The Integrated Geriatric Care model placed greater emphasis on improving physical function, while Integrated Palliative Care tended to focus more on management of symptoms and concerns. However, both approaches had areas of synergy with emphasis on person centred care and core activities notably care centred on the person and education of staff and patients/carers. The findings denote the opportunity and imperative of integration between the two approaches with a shifting focus between respective care provision accessed according to patient needs and likely benefit. Integrated care is conceptualised as primarily concerned with services working together with commissioners and policy makers, to create an alignment of services and packages of care [1]. We identified overarching processes to integrate care comprising comprehensive assessment, case management and collaborative working.

Our findings indicate that access to services needs to be realigned to likelihood of benefit or intended outcomes of care provision delivered through emphasis on person-centred care, rather than time and ‘markers’ of, for example, prognostication. This indicates requirement for a paradigm shift in older age and EoLC within (or even from) alignment to prognostication, with emphasis instead on allowing, costing and providing access based on perceived benefits or intended outcomes. This places person-centred care at the centre of care delivery and increasing emphasis on a people-centred approach to health system design and delivery [123]. Older people often live with a multitude of needs and concerns commonly associated with non-communicable multi-morbidities that increase with advancing age and unpredictable disease trajectories [1]. Transitions between care settings are common for older people nearing the end of life, particularly moving from home to hospital in high income countries [124, 125]. Our overarching models and underpinning processes and activities proposes a realignment of health services of moving away from temporality to a model of benefit and goal based care to meet older people's often increasingly complex needs. Triggers for access are person-centred, for example troublesome symptoms and intended outcome of reduced symptom burden. This requires multiple points of access to services across the illness trajectory at points of anticipated or actual deterioration. It is widely advocated that palliative care should be delivered on the basis of need and benefit, not diagnosis or prognostication [126]. There are exemplars of these types of Integrated Palliative Care service delivery models based on need and benefit for older people in, for example COPD [127], heart failure [128], dementia [129], frailty and multi-morbidities[130] and long-term care [131].

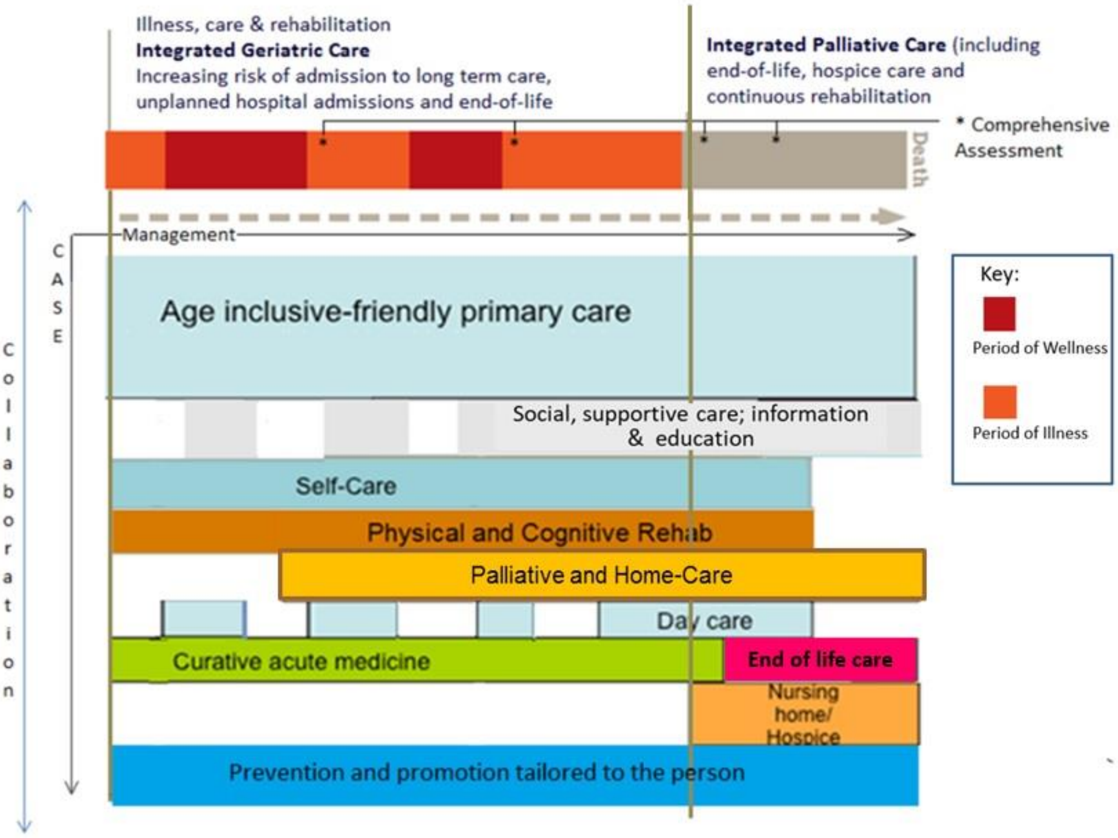
For older people with end of life needs, the integration and coordination of care between services are recognised as essential to live life as well as possible [132]. The central tenet of the proposed models is integration between geriatric and palliative care with overarching processes of care centred on the person, comprehensive assessment, collaborative working and case management that emphasizes care coordination (figure 2). Integrated Geriatric Care is conceptualised as person-centred care with emphasis on strengthening and maintaining capacity and function, and/or reversal of causes of acute decline [132]. Attention to acute decline is important. Older people living with frailty experience diminishing physiological reserves and increasing risk to marked points of decline from an often seemingly minor health event, for example, infection, and poor outcomes, for example end of life [3].

Integrated Palliative Care encompasses specialist palliative care that includes hospice care (with inpatient hospice, day hospice, hospice at home) as well as a range of other specialist advice, support and care [133], and generalist palliative care involving delivery by non- specialists of EoLC in the last year of life [134]. Generalist palliative care may be delivered with appropriate training and knowledge of palliative care at the primary and secondary levels by: a 'palliative care approach' delivered by health and social care practitioners, for example care home staff; and 'general palliative care' where palliative care forms part of health practitioners' role for example in primary care and those treating patients with chronic progressive conditions, for example dementia [126]. The *Lancet Commission* in 2017 detailed an Essential Package for palliative care that encompasses the three levels of specialist, primary and secondary. The package is designed to be scalable across contexts by incorporating lowest cost with for example staff models based on practitioner competencies not discipline [123]. For example, tasks undertaken by specialised medical physicians in high-income countries could in LMICs be delegated to general practitioners and nurses with the necessary training to support the delivery of effective palliative care. Lowther et al's [135] randomised trial conducted in Kenya is an important example of training generalist nurses in the delivery of integrated palliative care in HIV care and treatment with evidence of effect on quality of life and psychosocial wellbeing.

The proposed overarching integrated models and processes (figure 2) draws on theoretical models on the provision of Integrated Palliative Care for people with progressive conditions. These theoretical models comprise central tenets of: 1) provision of Integrated Palliative Care early in the disease trajectory, but with service models tailored to different conditions, for example non-malignant, and contexts, for example LMICs [136]. Palliative care can be delivered alongside condition specific services, including services with disease modifying intent [137, 138]; and 2) the provision of more dynamic integrated involvement of palliative care with shifting service provision aligned to a person's needs and intended outcomes, for example maintaining function, reducing symptom burden [130, 139, 140]. The dynamic integrated involvement is vital to realign services to the often long duration, and fluctuating and uncertain disease trajectories in non-malignant conditions.

The meta-analysis data from the systematic reviews showed effectiveness on the main outcome of quality of life for the two overarching models Integrated Geriatric Care [65] and Integrated Palliative Care [49, 56]. Effectiveness was also apparent on the respective models' predominant outcome focus on function [73] and reducing symptom burden [78, 81]. One systematic review on the Acute Care for Elders model showed effectiveness for both outcomes of function and symptom burden, and expenditure data on health service use [73]. However, the meta-analysis data was derived exclusively from high income countries with no representation of LMICs. Data for LMICs was limited to narrative data from two systematic reviews. The narrative findings suggested effectiveness of Integrated Geriatric Care [51] and Integrated Palliative Care [50, 51] on quality of life. Importantly, review work by the *Lancet Commission* demonstrated that in LMICs the introduction of the Essential Package of palliative care could increase effective uses of health service resource by, for example reducing end of life hospital admissions. This is turn reduces risk of catastrophic health care expenditure, a main cause of impoverishment in LMICs [123].

Figure 3. Range of service packages to meet the needs of older people in the last years of life to be included within Universal Health Coverage



*Modified from a WHO Kobe Centre working framework [Ong, unpublished; Ong and Evans, 2014[141]], adapted based on review findings.*

How countries, health-care systems and institutions tailor integration must build on resources, population need and characteristics, and the level of primary palliative care available [126, 138]. Figure 3 details the proposed breadth of possible packages of services to deliver the continuum of care across the illness trajectory and care settings. A diversity of service provision is required to optimally manage the complex and multifaceted needs experienced by older people to enable them to live life well and die in comfort and at peace. The packages attempt to widen access to palliative care for people with chronic progressive conditions by encompassing the requirements for Universal Health Coverage to integrate palliative care into all health services [13]. However, the majority of the evidence drawn upon to inform the models in figure 2 and figure 3 are from high income countries with an assumption of service availability, for example of primary palliative care. Greater consideration is required on incorporating the *Lancet Commission* Essential Package of palliative care to deliver integrated community orientated programmes for LMICs [123], in particular the consideration of human resources and the involvement of volunteers in service delivery models. Only five systematic reviews reported service delivery models that involved volunteers, and only two included LMICs [50, 51].

The systematic reviews reported a range of outcomes. This denotes the breadth of intended benefits from the service delivery models. Successful ageing and successful dying both focused on outcomes of promoting quality of life. None advocated longevity as the intended benefit. Outcomes for quality of life encompassed the diverse and complex effects of a person's physical health, psychological state, personal beliefs and social relationships including, for example, physical symptoms, psychological and spiritual wellbeing, patient perceptions of health and empowerment. However, as people age, their quality of life is largely determined by their ability to access needed resources to pursue personal goals. The systematic review findings little considered the relationship between quality of life outcomes to salient features in an individual's environment, for example poverty [1]. The effectiveness and sustainability of a service delivery model is critically influenced by how they are implemented in a given context, yet these areas are often poorly considered in research evaluating models of care [142].

The two overarching models of integrated care both included benefit of quality of life and used processes of person centred care, comprehensive assessment, collaborative working and case management. However, they also had different areas of focus: Integrated Geriatric Care on maintaining/improving function with less attention to palliative care; and Integrated Palliative Care on reduction of symptom burden with less attention to function, for example through palliative rehabilitation [143]. This slightly different focus between the models affords the opportunity for exported learning from one speciality to another. Furthermore, the commonality of education as a key component of service delivery models reported in 59/72 reviews (82%) provides opportunity to exploit this key component to support learning between specialities. However, the differences between the models in intended patient outcomes opens up the question as to when a patient is most likely to benefit from each approach. The differences suggest that access to a service is linked to time (e.g. point of diagnosis) and prognostication. We propose that care provision is on a continuum with a shifting focus that is informed by comprehensive assessment to understand individual's personal goals and intended outcomes of care across physical, psychological, social and spiritual domains, and delivered through overarching processes of collaborative working between settings, services and disciplines and case management to coordinate care provision and tailor to individual needs.

## Methodological reflections

Ageing, quality of life, and end of life are very broad concepts and for the purposes of this review each had to be defined and operationalised. We used WHO definitions and international consensus statements to guide our choices, then worked with information specialists to limit the extent to which our choices narrowed our scoping of the evidence. Our electronic search was limited to three databases that primarily indexed on English language publications. Relying exclusively on database searching is unreliable when trying to identify literature around complex interventions [144]. Therefore, our extended search strategy included scanning reference lists, using personal knowledge, and making external contacts. Specifically, we called upon experts and active researchers across Africa and Latin-America to share grey literature and scope local databases on our behalf. We also drew on resource to translate non-English language reviews as required, e.g. Ruiz Ingez et al published in Spanish [104]. The relative gap in knowledge reported from LMICs may reflect the perspective taken by our review teams, but the finding corroborates previous reviews on service delivery models in, for example, continuity and coordination of care [145]. The resource required to undertake effectiveness evaluations and limited academic partnerships may have prevented dissemination of relevant evaluation studies.

Our choice to scope systematic reviews allowed us to incorporate multiple search strategies including our own search strategies, and those from the respective 72 systematic reviews we identified. We are therefore confident this represents a comprehensive review of the published literature on the effectiveness of service delivery models to maximise quality of life for older people in the last 1 or 2 years of life. However, drawing on systematic reviews rather than primary studies did limit our ability to describe diffuse and integrating elements in detail. In particular, reviews reported the target population of services but provided limited information on referral criteria or triggers. Often reviews reported on different service delivery models grouped by their setting or overarching aim, so we had to interpret from the qualitative descriptions provided within the text. The case examples we provide above go some way to offer more information and help service providers understand how integrated care might be realised on the ground. In addition, we could not easily compare and contrast model components or directly link different service models to the reported outcomes and impact.

## Implications and recommendations

### Policy

- High level boards within global and regional organisations working for older people should include representation from geriatric care and palliative care across all care settings, to ensure the perspectives of these stakeholders help shape and refine future clinical and research agendas. Appendix 7 details potential individuals identified from this scoping review.
- Policy makers should pay particular attention to improving access to palliative care beyond the last months of life, across settings, and based on likelihood of benefit and intended outcomes of care provision rather than prognosis.
- There remains an urgent need for health system change to improve palliative care as part of UHC. Based on findings from this review, a key resource pack should be produced for policy makers, detailing how to assess patient need and likelihood of benefit, service delivery exemplars, quality indicators and outcome measures.

### Practice

- Service providers should maintain a primary focus on valuing quality of life, adopt a positive approach to collaborative working, seek learning opportunities from colleagues, and adopt a readiness to participate in research around new service delivery models.
- Services should routinely measure quality of life and perceived quality of care in this group. Person-centred approaches demand that each individual's priorities are understood and acted upon to maximise quality of life.
- Integration between health and social care providers was seldom demonstrated and there remains too little information on projects spanning health and social care services. Case examples that demonstrate effective collaborative working should be identified and shared.
- The overarching service delivery models identified in this review benefit from multi-professional and multi-provider working. Routine assessment of education needs of the workforce and evaluation of educational approaches to support the export of learning across and within specialties and/or professional groups is required.

### Research

- This scoping review has identified overarching service delivery models linked to improved health outcomes important to older people at the end of life. A subsequent review focused on primary studies would further this work by identifying theoretical models around specific service delivery models. The meta-analyses we identified suggest a meta-regression may be viable to link different service delivery models to health outcomes.
- Integrated geriatric and palliative care service delivery models must be person-centred. A discrete choice experiment would improve understanding around the priorities of older people at the end of life, what they value and would trade off, and how they would like future services to be delivered.
- Modern approaches to palliative care, based on need and likelihood of benefit rather than prognosis, are especially suited for older people where prognostication is uncertain. Key triggers or prompts for palliative care involvement have not been agreed and are based on professional opinion. A systematic review of trial inclusion criteria would serve to provide an evidence-based set of triggers for palliative care.
- The evidence has limited coverage for resource limited settings, which is highly relevant given LMICs will experience the largest proportional increase in the oldest old. We recommend primary studies evaluating models of care in LMICs, prioritising trials of clinical and cost effectiveness, to provide evidence aligned to disease epidemiology, available resource, and cultural practices.
- A better understanding of what quality of life means to older people at the end of life, and mapping onto existing outcome measures would help develop a set of metrics to measure quality of life (and quality of care), including how this evolves over time in the face of progressive functional decline, shifting demand and recalibration of expectations.
- Work on costing is constrained to end of life care and high income countries. There remains a need to cost service delivery models that enable older people to live and die well in their last years of life. This being a pivotal factor to sustainability and scaling up exemplar models of care. We encourage economic analyses that span health and social care, include all sources of finance to understand health inequalities among this population, and define the perspective taken according to the local environment and conditions of the intervention.

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# Appendix 1. Glossary of terms

Active ageing – the process of optimising opportunities for health, participation and security in order to enhance quality of life as people age.

Activities of daily living – the basic activities necessary for daily life such as bathing or showering, dressing, eating, getting in or out of bed or chairs, using the toilet and getting around inside the home.

Advance directive / living will – a mechanism by which competent individuals express their wishes so that should circumstances arise in which they no longer are able to make decisions regarding medical treatment, their preferences are respected; advance directives are made by writing living wills or granting power of attorney to another individual.

Care co-ordination- a proactive approach in bringing care professionals and providers together around the needs of service users to ensure that people receive integrated and person-focussed care across various settings.

Caregiver – a person who provides care and support to someone else, such support may include: helping with self-care, household tasks, mobility, social participation and meaningful activities; offering information, advice and emotional support, as well as engaging in advocacy, providing support for decision-making and peer support, and helping with advance care planning; offering respite services; and engaging in activities to foster intrinsic capacity. Caregivers may include family members, friends, neighbours, volunteers, care workers, and health professionals.

Case management – a collaborative process of planning services to meet an individual's health needs through communication with the individual and their service providers and coordination of resources.

CATWOE – A checklist for solving problems or defining a goal developed by Peter Checkland as part of his soft systems methodology. It consists of the elements Clients, Actors, Transformation, Welktanschauung (worldview), Owner, and Environmental Constraints.

Chronic condition – a disease, disorder, injury or trauma that is persistent or has long-lasting effects.

Collaborative working- a multi-professional approach to patient care with a structured management plan, scheduled patient follow-ups, and enhanced inter-professional communication.

Comprehensive assessment – a multidimensional assessment of an older person that includes medical, physical, cognitive, social and spiritual components; may also include the use of standardised assessment instruments and an interdisciplinary team to support the process.

Continuity of care- the degree to which a series of discrete health care events is experienced by people as coherent and interconnected over time, and consistent with their health needs and preferences.

Cost Benefit Analysis - one of the tools used to carry out an economic evaluation. The costs and benefits are measured using the same monetary units (for example, pounds sterling) to see whether the benefits exceed the costs.

Cost Effective Analysis – an analysis that assesses the cost of achieving a benefit by different means. The benefits are expressed in non-monetary terms related to health, such as symptom-free days, heart attacks avoided, deaths avoided or life years gained (that is, the number of years by which life is extended as a result of the intervention). Options are often compared on the cost incurred to achieve 1 outcome (for example, cost per death avoided).

End of life care- care provided to those in the last 1 – 2 years of life.

Frailty- a clinically recognizable state of older adults with increased vulnerability, resulting from age-associated declines in physiologic reserve and function across multiple organ systems, such that the ability to cope with everyday or acute stressors is compromised.

Functional ability – the health-related attributes that enable people to be and to do what they have reason to value; it is made up of the intrinsic capacity of the individual, relevant environmental characteristics and the interactions between the individuals and these characteristics.

Functioning – an umbrella term for body functions, body structures, activities and participation; it denotes the positive aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors).

Generalist palliative care- care provided to those affected by life-threatening diseases as an integral part of standard clinical practice by any healthcare professional who is not part of a specialist palliative care team.

Health – a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity.

Health Care Costs - the actual costs of providing services related to the delivery of health care, including the costs of procedures, therapies, and medications. *Direct costs* usually represent the costs associated with medical resource utilization, which include the consumption of in-patient, out-patient, and pharmaceutical services within the health care delivery system. The term *indirect costs* has come to be defined as the expenses incurred from the cessation or reduction of work productivity as a result of the morbidity and mortality associated with a given disease. Indirect costs typically consist of work loss, worker replacement, and reduced productivity from illness and disease.

Holistic assessment- assessment of all the domains of an individual including physical, psychological, spiritual, social and emotional domains.

Impairment – a loss or abnormality in body structure or physiological function (including mental functions); abnormality is used strictly to refer to a significant variation from established statistical norms (that is deviation from a population mean within measure standard norms).

Informal care – unpaid care provided by a family member, friend, neighbour or volunteer.

Integrated Geriatric Care- care conceptualised as person centred care mainly given at an earlier trajectory of functional decline, focussing on quality of life with emphasis on strengthening and maintaining function.

Integrated Palliative Care conceptualised as person centred care commonly accessed at a later trajectory of functional decline and dying, focussing on quality of life with emphasis on reducing symptom distress and concerns.

Meta-Analysis - a method often used in systematic reviews to combine results from several studies of the same test, treatment or other intervention to estimate the overall effect of the treatment.

Mobility – moving by changing body position or location, or by transferring from one place to another; by carrying, moving or manipulating objects; by walking, running or climbing; and by using various forms of transportation.

Mortality rate - the proportion of a population that dies within a particular period of time. The rate is often given as a certain number per 1000 people.

Multi-disciplinary team- a group of health care workers who are members of different disciplines each providing specific services to the patient.

Multimorbidity – the co-occurrence of two or more chronic medical conditions in one person.

Noncommunicable diseases – diseases that are not passed from person to person; the four main types of noncommunicable disease are cardiovascular diseases (such as heart attacks and stroke), cancers, chronic respiratory diseases (such as chronic obstructive pulmonary disease and asthma) and diabetes.

Older person – a person whose age has passed the median life expectancy at birth.

Palliative care- an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Participation – a person's involvement in a life situation; it represents the societal perspective of functioning.

Person-centred care- care affording people dignity, compassion and respect, offering coordinated and personalised care, support or treatment, and supporting people to recognised and develop their own strengths and abilities to enable them to live an independent and fulfilling life.

Population ageing – a shift in the population structure whereby the proportion of people in older age groups increases.

Primary Care- healthcare delivered outside hospitals. It includes a range of services provided by GPs, nurses, health visitors, midwives and other healthcare professionals and allied health professionals such as dentists, pharmacists and opticians. It includes community clinics, health centres and walk-in centres.

Psychological well being – feelings of life satisfaction, happiness, and sense of purpose and meaning in life.

Quality of life- an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features in their environment.

Randomised Controlled Trial - a study in which a number of similar people are randomly assigned to 2 (or more) groups to test a specific drug, treatment or other intervention. One group (the experimental group) has the intervention being tested, the other (the comparison or control group) has an alternative intervention, a dummy intervention (placebo) or no intervention at all. The groups are followed up to see how effective the experimental intervention was. Outcomes are measured at specific times and any difference in response between the groups is assessed statistically. This method is also used to reduce bias.

Rehabilitation – a set of measures aimed at individuals who have experienced or are likely to experience disability to assist them in achieving and maintaining optimal functioning when interacting with their environments.

Self-care – activities carried out by individuals to promote, maintain, treat and care for themselves, as well as to engage in making decisions about their health.

Service delivery model- overarching design for healthcare service provision which consists of defined core elements.

Specialist palliative care- service of health care professionals from at least two different professions that provides or coordinates comprehensive care for patients. It encompasses hospice care (including inpatient hospice, day hospice, hospice at home) as well as a range of other specialist advice, support and care such as that provided by hospital palliative care teams.

Spiritual well being - ability to experience and integrate meaning and purpose in life through a person's connectedness with self, others art, music, literature, nature, or a power greater than oneself.

Survival – the state or fact of continuing to live or exist, typically in spite of difficult circumstances.

Systematic Review - a review that summarises the evidence on a clearly formulated review question according to a predefined protocol, using systematic and explicit methods to identify, select and appraise relevant studies, and to extract, analyse, collate and report their findings. It may or may not use statistical techniques, such as meta-analysis.

Well being – a general term encompassing the total universe of human life domains, including physical, mental and social aspects, that make up what can be called a “good life”.

## Appendix 2. Search Strategy for Medline

| | Population EoL /advanced disease | Intervention e.g. hospital | Outcome |
|---|---|---|---|
| MESH terms | Exp Terminally ill /<br>Exp Terminal care/<br>Palliative Care/<br>Frailty/ | Exp Patient admission/<br>Exp Patient readmission/<br>Geriatric nursing/<br>Primary nursing/<br>Hospice and palliative care nursing/<br>Exp Nursing services/<br>Symptom Assessment/<br>Geriatric Assessment/<br>Needs assessment/<br>Hospital volunteers/<br>Nursing process/<br>Exp Patient care planning/<br>Exp Progressive patient care/<br>Exp Caregivers/<br>Exp Home care services/<br>Exp Hospice care/<br>Exp Patient Care Team<br>Exp Continuity of Patient Care/ | Exp Quality of life/<br>Exp Pain/<br>Exp Pain management/<br>Exp Dyspnea/<br>Exp Anxiety/<br>Exp Anxiety disorders/<br>Depression/<br>Exp Depressive disorder/<br>Personal satisfaction/<br>Exp Activities of daily living/<br>Constipation/<br>Accidental Falls/<br>Exp Mental health/<br>Exp Social isolation/<br>Exp Social support/<br>Exp Patient satisfaction/<br>Exp Budgets/<br>Exp Costs and cost analysis/<br>Economics/<br>Exp Economics, hospital/<br>Exp Economics, medical/<br>Economics, nursing/<br>Exp Fees and charges/<br>Exp Resource allocation/<br>Value of life/ |

|  |  |  |  |
|---|---|---|---|
| Key terms | EoL.tw<br>End?of?life.tw<br>Dying.tw<br>Palliative.tw<br>Last adj4 life.tw<br>Hospice.tw<br>Life limit*tw<br>Advanced disease*tw<br>Palliative treatment.tw<br>Palliative medicine.tw<br>Terminal care.tw<br>Terminally ill.tw<br>End-of-life care.tw<br>Hospice care.tw<br>Palliation.tw.<br>Palliative care$.tw.<br>Multi*morbidity.tw<br>Co*morbidity.tw<br>((Frail old*) AND (people OR adult* OR person*)).ti,ab<br>Frail*.tw<br>Frail elder*.ti,ab<br>Frailty syndrome*.ti,ab<br>Advanced illness.tw | Integrated care.tw<br>Model adj4 care.tw<br>Multi?disciplin*tw<br>Multi?disciplinary team.tw<br>Volunteer* tw<br>Volunt*tw<br>Hospital adj3 home.tw<br>Comprehensive assess*tw<br>Holistic assess*<br>(special$ adj2 palliat$).tw.<br>Nurse-led.tw<br>Co?ordination adj3 care.tw<br>Care plans.tw<br>Care?giver*.tw<br>Person?centr*.tw<br>Self?manage*.tw<br>Community health worker*.tw<br>Service delivery.tw<br>Community?based.tw<br>Home visit*.tw<br>Case management.tw<br>Care management.tw | Good death.tw<br>Symptom*.tw<br>Concern*.tw<br>Attainment<br>Dignity.tw<br>Empowerment.tw<br>Transition*.tw<br>Pain.tw<br>Dyspn?ea.tw<br>Breathless*.tw<br>Anxiety.tw<br>Anxious.tw<br>Depress*.tw<br>Quality of life.tw<br>Qol.tw<br>(quality adj2 life).tw.<br>Distress.tw<br>Wellbeing.tw<br>ADL*.tw<br>Activities of daily living.tw<br>Constipat*.tw<br>Fall*.tw<br>Mobil*.tw<br>Symptom management.tw.<br>Psychosocial.tw.<br>(psycho adj social).tw.<br>Psychological distress.tw.<br>Enablement.tw<br>Mastery.tw<br>Resilience.tw<br>Stress.tw<br>Financ*tw<br>(Cost* or economic*).ti<br>(Cost* adj2 (effective* or utilit* or benefit* or minimi*)).ab.<br>Economic model*.tw<br>(Budget* or fee* or financ* or pricing or price* or resource* allocat* or (value adj2 (monetary or money))).ti,ab |
| BOLEAN TERMS | OR | OR | OR |
|  | AND |  |  |
| LIMIT | ((Overview*.ti OR Review.ti OR Synthesis.ti OR Summary.ti OR Cochrane.ti OR Analysis.ti) AND (reviews.ti OR meta-analyses.ti OR articles.ti OR umbrella.ti)) OR ‘‘umbrella review’’.ti,ab OR (meta-review.ti.ab ORMetareview.ti,ab) OR ((overview*.ti OR Reviews.ti) AND (systematic.ti OR Cochrane.ti)) OR (reviews.ti,ab and (meta.ti,ab OR Published.ti,ab OR Quality.ti,ab OR Included.ti,ab OR summar*.ti,ab)) OR (‘‘cochrane reviews’’.ti,ab) OR (evidence.ti AND (reviews.ti OR meta-analyses.ti)) |  |  |

## Appendix 3. Countries included in systematic reviews by WHO region

| Country | Review(s) | Total |
|---|---|---|
| **Region of the Americas** | | |
| USA | [58], [59], [55], [50], [60], [119], [62], [63], [64], [65], [66], [69], [70], [71], [19], [72], [73], [75], [76], [77], [78], [79], [80], [81], [83], [85], [49], [86], [88], [90], [92], [47], [93], [94], [96], [99], [98], [100], [101], [102], [103], [104], [105], [106], [114], [54], [110], [53], [52], [112], [113] | 51 |
| Canada | [59], [50], [60], [65],[69] , [70], [71], [19], [72], [74], [76], [78], [79], [80], [46], [81], [82], [83], [49], [86], [88], [92], [93], [96], [99], [101], [104], [110], [53], [112], [113] | 31 |
| Peru | [73] | 1 |
| Argentina | [46] | 1 |
| Jamaica | [91] | 1 |
| Barbados | [91] | 1 |
| Cuba | [91] | 1 |
| Trinidad and Tobago | [91] | 1 |
| St Lucia | [91] | 1 |
| Grenada | [91] | 1 |
| Antigua | [91] | 1 |
| Barbuda | [91] | 1 |
| Montserrat | [91] | 1 |
| St Kitts and Nevis | [91] | 1 |
| St Vincent and the Grenadines | [91] | 1 |
| Anguilla | [91] | 1 |
| Dominica | [91] | 1 |
| Dominican Republic | [91] | 1 |
| **European Region** | | |
| UK | [119],[63],[64], [69], [19], [75], [76], [79],[80], [46], [81], [49], [88], [90], [93], [99], [57], [48], [105], [114],[54], [110],[53], [52], [112], [113] | 26 |
| Sweden | [50], [60], [70],[72], [73], [76], [80], [46],[81], [85], [49], [93], [95], [99], [98],[100], [104], [112] | 18 |
| Italy | [119], [71],[76], [78], [80],[46], [80], [86], [92], [95], [96], [101], [54], [53], [52] | 15 |
| Norway | [59], [63], [70], [19], [72], [76], [79], [80], [49], [114], [113] | 11 |
| The Netherlands | [64], [69], [70],[82], [83], [86], [92],[93], [99], [110] | 10 |
| Germany | [63], [64], [69], [70], [72], [81], [101], [48], [104] | 9 |
| Spain | [73], [76] , [94], [100], [48] | 5 |
| France | [73], [46] , [93], [103], [54] | 5 |
| Finland | [96], [53], [52] | 3 |
| Ireland | [93], [95, 99] | 3 |
| Denmark | [86], [110] | 2 |
| Poland | [95], [104] | 2 |
| Switzerland | [110] | 1 |
| Malta | [95] | 1 |
| **Western Pacific Region** | | |
| | | |

| | | |
|---|---|---|
| Australia | [59], [55], [50], [63], [65],[69], [72], [73], [75], [76], [78], [79], , [81], [83], [49], [88], [92], [93], [95], [99], [98], [100], [101], [48], [104], [105], [54], [110], [80] | 29 |
| Japan | [59], [55], [119], [83], [86], [100], [104] | 7 |
| Hong Kong | [59], [49], [88], [54], [52, 53] | 6 |
| Tawain | [100] [112] | 2 |
| China | [59], [52] | 2 |
| New Zealand | [64, 93] | 2 |
| Singapore | [88] [100] | 2 |
| **Eastern Mediterranean Region** | | |
| Israel | [55] [53] [52] [54] [119] | 5 |
| **African Region** | | |
| Zambia | [50] | 1 |
| South Africa | [50] | 1 |
| Sub-saharan Africa | [48] | 1 |
| Kenya | [49] | 1 |
| **South-East Asia Region** | | |
| India | [50], [51] | 2 |
| Nepal | [51] | 1 |
| Pakistan | [51] | 1 |

## Appendix 4. AMSTAR quality appraisal by review

| First Author, Year | ' A priori' design provided | Duplicate study selection and data extraction | Comprehensive literature search performed | Status of publication (i.e. grey literature) used as an inclusion criterion? | List of studies (included and excluded) provided | Characteristics of the included studies provided | Scientific quality of the included studies assessed and documented | Scientific quality of the included studies used appropriately in formulating conclusions | Methods used to combine the findings of the studies appropriate | Likelihood of publication bias assessed | Conflict of interest included | Total; |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Alcide 2015[58] | Yes | NR | Yes | Yes | Yes | Yes | Yes | NR | NA | No | No | 6 |
| Bai, 2013 [59] | No | NR | No | NR | No | Yes | Yes | Yes | Yes | No | No | 4 |
| Bainbridge, 2016[55] | Yes | No | No | No | No | No | Yes | Yes | Yes | Yes | Yes | 6 |
| Bakitas 2015[50] | No | NR | No | No | No | Yes | No | Yes | NA | Yes | No | 3 |
| Bakker, 2011[60] | Yes | Yes | No | NR | No | Yes | Yes | Yes | NA | Yes | No | 6 |
| Brereton, 2017[44] | Yes | Yes | Yes | Yes | No | Yes | Yes | Yes | NA | Yes | Yes | 9 |
| Candy 2011[61] | Yes | Yes | No | No | No | Yes | Yes | Yes | Yes | No | Yes | 7 |
| Candy, 2012[62] | Yes | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | No | No | 8 |
| Carpenter, 2017[63] | Yes | No | Yes | No | No | No | No | No | Yes | No | No | 3 |
| Catania, 2015[64] | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | Yes | No | 8 |
| Conroy, 2011[56] | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | Yes | No | 8 |
| De Coninck, 2017[65] | Yes | No | Yes | No | Yes | Yes | Yes | Yes | Yes | No | No | 7 |
| Diop, 2017[66] | Yes | Yes | Yes | Yes | No | Yes | No | Yes | Yes | No | Yes | 8 |
| Dy, 2008[67] | No | No | No | No | No | No | No | No | NR | No | No | 0 |
| Dy, 2013[68] | No | Yes | Yes | NR | No | Yes | Yes | Yes | Yes | No | No | 6 |
| Easton, 2016[69] | No | Yes | Yes | Yes | No | No | Yes | Yes | Yes | No | No | 6 |
| Ekdahl, 2015[70] | No | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | No | 6 |
| Eklund, 2009[71] | No | Yes | No | No | No | Yes | Yes | No | Yes | No | No | 4 |
| El-Jawahri, 2011[19] | No | NR | No | No | No | No | Yes | Yes | Yes | No | No | 3 |
| Ellis, 2011[72] | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | No | No | 8 |
| Fox 2012 [73] | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | Yes | Yes | 9 |

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Frank 2015[74] | No | NA | NA | NA | NA | NA | No | NA | NR | NA | No | 0 |
| Garcia-Perez, 2009[75] | NR | Yes | Yes | No | No | Yes | Yes | Yes | Yes | Yes | No | 7 |
| Gomes, 2013[76] | Yes | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | Yes | 10 |
| Hall, 2011[77] | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | 11 |
| Haun, 2017[78] | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | No | 9 |
| Health Quality Ontario 2014 [79] | Yes | No | Yes | Yes | No | Yes | Yes | Yes | Yes | No | No | 7 |
| Higginson 2010[80] | Yes | No | Yes | No | No | Yes | Yes | Yes | Yes | No | No | 6 |
| Higginson, 2002[46] | Yes | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | No | No | 8 |
| Higginson, 2003[81] | Yes | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | No | 9 |
| Hodgkinson, 2011[82] | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | No | 10 |
| Hopman, 2016[83] | Yes | Yes | No | No | No | No | Yes | Yes | Yes | Yes | No | 6 |
| Joseph, 2016 | No | NR | No | Yes | Yes | NA | NA | NA | NA | No | Yes | 3 |
| Kane, 2015[85] | Yes | No | Yes | No | No | No | Yes | Yes | Yes | Yes | No | 6 |
| Kavalieratos, 2016[49] | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | Yes | No | 8 |
| Kim, 2016[86] | Yes | Yes | No | No | No | Yes | No | No | Yes | No | Yes | 5 |
| Latour, 2007 [87] | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | No | 7 |
| Lorenz, 2008[18] | No | No | No | No | No | Yes | No | NR | Yes | No | Yes | 3 |
| Lowthian, 2015[88] | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | 8 |
| Luckett, 2014 [89] | No | No | No | Yes | No | Yes | Yes | NR | Yes | No | Yes | 5 |
| Lupari, 2011[90] | No | NR | Yes | Yes | No | Yes | No | NR | Yes | No | Yes | 5 |
| Maharaj, 2016[91] | Yes | No | Yes | No | No | No | Yes | Yes | Yes | Yes | No | 6 |
| Martinez, 2014[92] | No | Yes | No | No | No | Yes | Yes | NR | Yes | No | Yes | 5 |
| May, 2014[47] | No | No | Yes | No | No | Yes | No | NR | Yes | No | Yes | 4 |
| McAlister, 2004[93] | Yes | Yes | Yes | No | No | No | No | No | Yes | No | No | 4 |
| Nevis, 2014[94] | No | No | Yes | No | No | Yes | Yes | Yes | Yes | Yes | Yes | 7 |
| Nordly, 2016[95] | Yes | NR | Yes | No | No | Yes | No | Yes | Yes | No | No | 5 |
| Oeseburg, 2009[96] | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | No | 7 |
| Pham, 2014[97] | Yes | No | Yes | No | No | No | No | No | Yes | No | No | 3 |
| Phillips 2004[99] | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | Yes | No | 8 |
| Phillips, 2013[98] | Yes | No | Yes | Yes | No | Yes | Yes | Yes | Yes | No | No | 7 |

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Pillotto, 2017[20] | Yes | No | Yes | Yes | No | No | No | No | Yes | No | No | 4 |
| Procter, 2012[57] | Yes | No | Yes | No | No | No | Yes | Yes | Yes | No | No | 5 |
| Puts, 2017[100] | Yes | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | No | No | 8 |
| Richards, 2003[101] | Yes | NR | Yes | No | No | No | Yes | Yes | No | No | No | 4 |
| Rizzo, 2016[102] | Yes | NR | Yes | No | No | No | No | No | Yes | No | No | 3 |
| Robinson, 2009[48] | Yes | No | Yes | No | No | No | Yes | No | Yes | No | Yes | 5 |
| Roczen, 2016[103] | Yes | No | No | No | No | Yes | No | No | Yes | No | Yes | 4 |
| Ruiz-iniguez, 2017[104] | No | Yes | Yes | Yes | No | Yes | Yes | No | NA | No | Yes | 6 |
| Ryburn, 2009[105] | Yes | No | No | No | No | Yes | No | NA | Yes | No | No | 4 |
| Sampson, 2005[106] | Yes | No | Yes | Yes | Yes | Yes | No | NA | Yes | No | No | 6 |
| Shepperd, 2016[107] | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | No | No | 9 |
| Simoens, 2010[54] | Yes | No | No | No | No | Yes | Yes | Yes | Yes | No | Yes | 6 |
| Singer, 2016[108] | Yes | No | No | No | No | Yes | No | No | Yes | No | No | 3 |
| Singh, 2015[51] | Yes | No | Yes | No | No | No | No | Yes | Yes | Yes | No | 5 |
| Soares, 2012[109] | Yes | No | No | No | No | Yes | No | No | Yes | No | No | 3 |
| Stuck, 2002[110] | Yes | Yes | Yes | No | No | No | Yes | Yes | Yes | No | No | 6 |
| Windham, 2003[111] | No | NR | No | NR | No | No | No | No | Yes | No | No | 1 |
| You, 2012[53] | Yes | No | Yes | No | No | Yes | Yes | Yes | Yes | No | No | 6 |
| You, 2013[52] | Yes | No | Yes | No | No | No | Yes | Yes | Yes | No | No | 5 |
| Young, 2017[112] | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | No | 10 |
| Zimmermann, 2008[113] | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | No | Yes | 9 |

Legend:

NR – not recorded

NA – applicable

# Appendix 5. Service model providers

| **Service model providers** | **Reference** | **Total** |
|---|---|---|
| Nurses | [95] [20] [57] [101] [96] [69] [85] [93] [99] [78] [51] [110] [111] [19] [62] [56] [64] [49] [82] [104] [72] [58] [59] [55] [60] [77] [76] [74] [73] [119] [118] [88] [89] [90] [92] [47] [105] [114] [52] [109] [112] [53] [65] [113] [87] [66] [68] [70] [71] | 49 |
| Physicians | [95] [98] [20] [57] [101] [69] [85] [93] [99] [78] [51] [110] [111] [19] [62] [56] [64] [49] [72] [55] [59] [60] [77] [76] [74] [73] [119] [118] [88] [47] [114] [109] [112] [65] [113] [86] [68] [66] [70] [71] | 40 |
| Social workers | [20] [102] [96] [99] [78] [51] [110] [111] [19] [62] [49] [58] [55] [76] [74] [73] [119] [47] [114] [52] [112] [53] [65] [113] [66] [68] [70] [71] [108] | 29 |
| Physiotherapists | [20] [69] [85] [111] [56] [49] [73] [105] [114] [108] [109] [65] [70] [71] | 14 |
| Volunteers | [51] [110] [62] [55] [50] | 5 |
| Home carers/home health aid | [105] [49] | 2 |
| Formal caregiver | [112] | 1 |
| Other professionals[a] | [20] [98] [69] [78] [51] [110] [111] [62] [56] [49] [82] [59] [60] [77] [74] [73] [119] [88] [89] [92] [47] [114] [108] [109] [112] [65] [113] [68] [70] [71] | 30 |

[a] Other professionals could include one or more of the following: occupational therapists, nutritionists/dieticians, pharmacists, physician assistants, nurse aids/nursing assistants/nursing orderlies, personal care attendants, psychologists, chaplains/spiritual counsellors, counsellors, dentists, audiologists, rehabilitation staff, podiatrists, opticians, health visitor, health educator, care manager, nursing care home staff, art therapist, meditation instructor, programmer and research assistants.

# Appendix 6. Service delivery model key components

| Key components and subcategories | References |
|---|---|
| **1. Care Centred on the Person** | |
| I. Person (physical; psycho-social; spiritual) | [59] [55] [50] [60] [65] [67] [69] [70] [19] [72] [73] [74] [76] [116] [80] [83] [49] [86] [89] [90] [92] [93] [99] [98] [100] [48] [105] [114] [108] [51] [111] [53] [112] [58] [59] [55] [50] [60] [65] [69] [19] [73] [74] [76] [116] [80] [49] [109] [89] [90] [92] [99] [98] [100] [102] [105] [108] [51] [111] [53] [112] |
| II. Person (physical e.g. symptom management) | [1] [41] [42] [2] [4] [6] [8] [9] [11] [12] [43] [13] [44] [16] [17] [19] [22] [23] [45] [46] [47] [27] [29] [48] [31] [33] [35] [49] [50] [36] [37] [51] [39] |
| III. Person (psycho-social) | [52] [1] [41] [42] [2] [4] [8] [11] [43] [13] [44] [16] [17] [22] [24] [45] [46] [47] [29] [48] [31] [32] [35] [50] [36] [37] [51] [39] |
| IV. Person (spiritual) | [1] [41] [72] [17] [22] |
| V. Person (unspecified) | [2] [64] [25] [57] |
| 2. **Education** | |
| I. Education (patients/caregiver; staff) | [34] [1] [3] [8] [9] [10] [13] [16] [17] [35] [21] [22] [70] [27] [28] [29] [31] [51] [3] [64] [15] [45] [17] [35] [21] [70] [36] [28] [30] |
| II. Education (patient/caregiver) | [58] [59] [50] [70] [19] [72] [76] [83] [49] [109] [92] [93] [94] [105] [114] [108] [111] [52] |
| III. Education (staff) | [50] [77] [80] [85] [49] [109] [92] [94] [102] [114] [51] |
| **3. Workforce** | [2] [3] [4] [7] [10] [64] [14] [15] [71] [17] [35] |

## Appendix 7. Experts and teams identified in the scoping review

| Name | Title | Affiliated Centre |
|---|---|---|
| African Region | | |
| Amara Frances Chizoba | Director Mission to Elderlies Project Nigeria Affiliated Centre<br>Nurse | Mission to Elderlies Project Nigeria/ Centre for Clinical Care and Clinical Research Nigeria (CCCRN) |
| Eastern Mediterranean Region | | |
| South East Asia Region | | |
| Taranjit Singh | MSc student, practicing medicine in India | Department of Medical Oncology and Haematology, Artemis Health Sciences Institute, Haryana, India |
| Western Pacific Region | | |
| Jane Phillips | Professor of Palliative Care Nursing | The University of Notre Dame, School of Nursing, Sydney, Australia and the Cunningham centre for palliative care, Sydney, Australia |
| Region of the Americas | | |
| Richard Bennett | Professor of Geriatric Medicine | John Hopkins Geriatric Centre, Baltimore, USA |
| Patricia Davidson | Dean of John Hopkins School of Nursing | John Hopkins School of Nursing, Baltimore, USA |
| Mary T. Fox | Associate Professor | Faculty of Health, School of Nursing, York University, Toronto, Canada |
| Chris Frank | Associate Professor | Division of Geriatric Medicine, Department of Medicine, Queen University, Kingston, Ontario, USA |
| Sydney M Dy | Professor of Health Policy | Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health, Baltimore, USA |
| Dio Kavalieratos | Assistant Professor of Medicine, Palliative Care and Ethics | Division of Internal Medicine, University of Pittsburgh, Pittsburgh, USA |
| Karl A Lorenz | Professor of Medicine | Palo Alto Veterans Affairs Medical Centre, Palo Alto, USA |
| Sandhya Maharaj | Medical doctor | Caura Palliative Care Unit, Caura Hospital, El Dorado, Trinidad and Tobago |
| Finlay A McAlister | Professor | Department of Medicine, University of Alberta Hospital, Alberta, Canada |
| Martine Puts | Associate Professor | University of Toronto, Toronto, Canada |
| Victoria M Rizzo | Associate Professor of Social work | Department of Social Work, Binghamton University, Binghamtom, USA |

| | | |
|---|---|---|
| Jennifer Temel | Clinical Director of Thoracic Oncology, Associate Professor, Harvard Medical School | Massachusetts General Hospital, Boston, USA |
| Kenneth White | Professor of Nursing | University of Virginia Medical Centre, Charlottesville, USA |
| Camilla Zimmermann | Head of the Division of Palliative Care | Princess Margaret Cancer Centre Research Institute, Toronto, Canada |
| Liliana De Lima | Executive Director | International Association for Hospice and Palliative Care, Houston, USA |
| European Region | | |
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