Impact of Home Healthcare on End-of-life Outcomes for People With Dementia: a Systematic Review

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Abstract

Background: Home healthcare (HHC) may reduce acute hospital utilization, but its effect on homebound people living with dementia (PLWD) at end-of-life remains unclear. We aim to describe the impact of HHC on acute healthcare utilization and end-of-life outcomes in PLWD.

Methods: Design: A systematic review of quantitative and qualitative studies regarding the association between HHC (exposure) and targeted outcomes. Interventions: HHC provided by health care professionals, including physicians or nurses. Participants: At least 80% of study participants had dementia and lived at home. Measurements: Primary outcome was acute healthcare utilization in the last year of life. Secondary outcomes included palliative care use, advance care planning (ACP), continuity of care in the last year of life, and place of death. We identified contextual information about policy changes in HHC for these outcomes.

Results: We included five studies from USA, Japan, and Italy, none of which received a high-quality rating. At micro-level, HHC may be associated with a lower risk of acute healthcare utilization in the early period (e.g., last 90 days before death) and a higher risk in the late period (e.g., last 15 days) of the disease trajectory toward end-of-life in PLWD. ACP with written decisions may be an important mediator of this. HHC increases referrals to palliative care. At meso-level, HHC providers’ difficulty in making treatment decisions for PLWD at the end-of-life may require further training and external support. Coordination between HHC and social care is mentioned but not well examined in the existing literature.

Conclusions: The review highlights the dearth of dementia-specific research regarding the impact of HHC on end-of-life outcomes. In PLWD, the core components of HHC for achieving better quality end-of-life, the integration between health and social care, and coordination between primary HHC and palliative care should be further investigated in future studies.

Impact Statement

The differential effect of HHC on acute healthcare utilization in the early or late periods of the disease trajectory implies disparate care needs at different stages for people with dementia. Distinct components and models of HHC services which better meet needs in different periods should be investigated in future longitudinal studies with a longer follow-up period. Integration of HHC and social care, and seamless support from external specialists to HHC may contribute to people living and dying well with dementia in place.

Introduction

Dementia is a life-limiting, progressive neurodegenerative syndrome affecting multiple cognitive and physical functions.\(^1\) It is currently one of the commonest causes of death in Western countries, and globally, leading to an escalating need for end-of-life care.\(^2\)–\(^4\) People living with dementia (PLWD) are at a high risk of experiencing care transitions and acute healthcare utilization,\(^5\) particularly towards the end-of-life.\(^6\)–\(^8\) Research in the US and Taiwan has shown that potentially non-beneficial life-sustaining treatments such as tube feeding or mechanical ventilation are associated with care transitions\(^9\)–\(^11\) which may not improve the quality or length of life and are burdensome for the PLWD and their carers.\(^7\),\(^8\),\(^10\),\(^12\) Strategies to support this population with complex care needs and high care costs living and dying well in the community are vital.\(^13\),\(^14\)

Palliative care is an approach which involves the identification and management of problems associated with a life-threatening illness, including dementia, for patients and their families.\(^15\),\(^16\) Its impact on reducing transitions for PLWD in care homes has been investigated,\(^17\)–\(^19\) however, the evidence on effective palliative care for PLWD living at home remains inconclusive.\(^20\),\(^21\) Given the higher risk of end-of-life transitions in PLWD living at home than those in nursing homes,\(^6\),\(^22\) it is important we better understand the effect of home healthcare (HHC) approaches towards end-of-life.\(^16\),\(^23\)

HHC comprises a spectrum of clinical care for people living at home with various levels of care needs and health conditions throughout different stages in the life course,\(^24\) and is increasingly recognized as an integrated and value-based service for the aging population.\(^14\) Different types of HHC vary in terms of acuity, type of care provided, and degree of physician involvement, including patient-centered medical home, skilled home health care, home-based primary care, physician house calls, hospital at home.\(^24\),\(^25\) To date, there is no review regarding the impact of HHC on acute healthcare utilization and outcomes at the end-of-life among PLWD. We aimed to synthesize the evidence identified from this systematic review.
Methods

We adhered to PRISMA guidelines and registered the protocol with the International prospective register of systematic reviews (PROSPERO, https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42019151250).

Eligibility criteria

We included peer-reviewed original articles of quantitative and qualitative studies. Inclusion criteria on study design, the definition of PLWD and HHC, and details of the outcomes we targeted are summarized in Table 1. Hospice palliative care, defined by the World Health Organization’s definition, is not included in the HHC (exposure) but as an outcome in our study. We identified information on policy changes in HHC that may influence its impact on targeted outcomes.

| Population | Exposure | Outcome |
|------------|----------|---------|
| • At least 80% of study participants had a clinical diagnosis of dementia and lived at home | Primary home healthcare | Primary |
| • Data of people with dementia (if < 80% of study participants) were analyzed separately | • Provided by health care professionals | • Acute healthcare utilization in the last year of life |
| | • At least include physicians or nurses | • Hospitalization or intensive care unit admission |
| | • Examples | • Length of hospital or intensive care unit stay |
| | - Home-based primary care | • Emergency department visits |
| | - Skilled home health care | • Transition of care |
| | - Patient-centered medical home | • Life-sustaining treatments |
| | - Physician or nurses house calls | • Aggressive procedures |
| | - Hospital at home | • Drug prescriptions |
| | - Medication management | Secondary |
| | - Rehabilitation | • ‘Continuity of care’ in the last year of life |
| | • Exclude | • Use of hospice palliative care including advance care planning at any time after the start of home healthcare |
| | - Home-based palliative care | • Place of death |
| | - Routine dialysis or respiratory care | |
| | - Hygiene care | |
| | - Nutrition consultation | |
| | - Exercise coaching | |
| | - Other social care services | |
| | - Self-management | |
| | - Case management | |

Search strategy and study selection

We applied a three-step search strategy: We undertook an initial limited search of Medline followed by the analysis of the terms used in titles and abstracts, and of the index terms used to describe articles. A second search using all identified keywords and index terms for “dementia”, “home healthcare”, and a series of outcomes such as “acute healthcare utilization”, “continuity of care”, “palliative care” or “place of death” were then undertaken across five electronic databases, including OVID Medline, EMBASE, PsycINFO, Cochrane Library, CINAHL, from inception to September 2020. Thirdly, the reference list of all identified articles was searched for additional studies.
Search terms were used in combination with MESH headings, controlled vocabulary, and free-text terms to cover the topics and detail (see Supplementary file).

Two authors (PJC, LS) each read the abstracts of half of the retrieved records to identify potentially relevant publications. These publications were marked as ‘include’ or ‘uncertain’ after the exclusion of irrelevant studies. A random 15% of selected records were independently checked by a second reviewer. The two authors then retrieved the full texts of identified studies and screened them according to the eligibility criteria. The final list of articles was checked by the two authors and any disagreements were discussed with the third reviewer (ELS) to reach consensus. We constructed a PRISMA flowchart to describe the selection process and a table containing excluded studies with the rationale for exclusion. References were managed and deduplicated by citation management software.

Data extraction

We extracted relevant data into a standardized table using Microsoft Excel. The table format was pilot-tested on three articles to ensure consistency and was approved by the research team. Extracted data included country, time, study design, data source and collection, research questions (aims), participants, content of interventions, comparison, outcomes. Information from included studies was extracted by PJC and JYL independently and checked for accuracy by RM. Discrepancies were discussed with ELS to reach consensus.

Quality assessment

The Critical Appraisal Skills Programme (CASP) toolkit was used by PJC and LS to appraise the quality of the included studies.26 Studies were rated as strong, moderate, or weak based on the following components: study design, data collection method, bias of selection and outcome measurements, intervention integrity, confounding factors, appropriate analysis, and implication for practice. Discrepancies were discussed with RM to reach a consensus.

Data synthesis

We narratively described the effectiveness of HHC-related outcomes. We used an adapted classification of implementation evaluation based on the framework of Ferlie and Shortell27 to synthesize core properties of HHC. We focus on three levels of implementing HHC for PLWD in different country contexts: macro- such as national policy or financial provision; meso- training or service model; micro- key components delivered to individuals in a specific program.28 We were unable to conduct a meta-analysis due to clinical and statistical heterogeneity across studies. Results were set out in a table with data reported from the included study (e.g. p-values).

Results

Of all retrieved studies, five met the inclusion criteria. The selection process is illustrated in the PRISMA flow chart (Fig. 1).

Studies’ characteristics

We identified five studies; one prospective cohort study,29 two retrospective cohort studies,30,31 and two case-control studies (Table 2).32,33 No clinical trials or qualitative studies were included. In total, 4,493 participants with dementia were included in these quantitative papers. Three studies (3,936 participants, 87.6%) were conducted in the USA,30,31,33 and one each from Italy29 and Japan.32 All studies included both males and females and most participants were aged over 80. The HHC provided in these five studies were all forms of home-based primary care.
| Study       | Design                              | Aim                                                                 | Data source                                                                 | Participants | HHC intervention                                                                 | Comparison                                                                 | Quality  |
|------------|-------------------------------------|----------------------------------------------------------------------|----------------------------------------------------------------------------|--------------|----------------------------------------------------------------------------------|----------------------------------------------------------------------------|----------|
| Toscani    | Observational, multicenter prospective cohort. Quantitative. | To describe and compare critical decisions made by health care professionals for people with dementia in nursing homes and home care. | The End-Of-Life Observatory: Prospective Study on Dementia patients Care study. June 2007 to May 2009. | 496 people with advanced dementia (FAST ≥ 7); 181 in the HHC group, 315 in the nursing home group. | Multidisciplinary team consists of visiting nurses, general practitioners who provide disabled older people with assistance at home in the Emilia Romagna area. HHC may also include visits by psycho-geriatricians, palliative care consultants, social workers, and volunteers. | Nursing home staff comprise physicians, nurses, physiotherapists, psychologists, and health aides. Nursing homes differ widely in the numbers of inpatients and services offered (ie, occupational therapy, dementia day care, cognitive therapy, music therapy, etc.). | Moderate |
| Mitchell   | Observational, retrospective cohort. Quantitative. | To examine and compare the EOL experience of people with severe dementia who died within one year of admission to a nursing home or a home care service. | State of Michigan (1) MDS-Nursing Home Version 2.0 (n = 121,129 people in 458 facilities). 1st July 1998 to 31st December 2000. (2) MDS-Home Care (n = 23,095 people). 1st October 1998 to 31st December 2001. | 3020 people aged ≥ 65 with advanced dementia (CPS = 5/6); 290 in the HHC group, 2730 in the nursing home group. | Michigan Choice Waiver for the Elderly and Disabled program. The waiver program provides a wide range of home care agency-based services, including nursing care, personal emergency response systems, and other social care support. | Nursing home care in all facilities in Michigan | Weak     |

CPS = Cognitive Performance Scale, DILE-dementia = Degree of Independent Living for the Elderly with Dementia, EOL = end-of-life, FAST = Functional Assessment Staging Tool, HHC = home healthcare, MDS = Minimum Data Set. POLST = physician orders for life-sustaining treatment.
| Study               | Design                          | Aim                                                                 | Data source                                                                 | Participants           | HHC intervention                                                                 | Comparison                                                                 | Quality |
|---------------------|---------------------------------|----------------------------------------------------------------------|------------------------------------------------------------------------------|------------------------|-----------------------------------------------------------------------------------|--------------------------------------------------------------------------------|---------|
| Jennings 2019       | Observational, retrospective cohort. | To examine the impact of a coordinated care program that specifically focused advance care planning on EOL care in homebound people with dementia | Epic-based electronic health records in the University of California, Los Angeles (UCLA) and the other two hospital systems in West Los Angeles. | 332 people with dementia; 184 in HHC with POLST group, 138 in HHC without POLST group. | Alzheimer’s and Dementia Care (ADC) program, a longitudinal comprehensive nurse practitioner dementia management program, with the completion of POLST. POLST, a document on physician orders for a series of life-sustaining treatments that a patient wishes to receive or refuse towards the EOL. | ADC program without the completion of POLST | Weak    |
| United States of America | Quantitative.                  |                                                                      |                                                                              |                        |                                                                                   |                                                                              |         |
| Arai 2020           | Observational, retrospective case-control. | To examine and compare the outcomes of fever treatment between home care patients who received home treatment and those who were hospitalized for treatment. | Medical records from Iki-iki Clinic, Japan. | 61 people aged ≥ 65 develop a fever of ≥ 38.0°C during home care. (98% DILE-dementia ≥ 1); 40 in the HHC group, 21 in the hospitalized group. | Home care on a 24-h, 365 days a year basis was provided by doctors’ and nurses’ visits regularly. The treatment for the fever episode was kept at home. | Transfer and admission to nearby hospitals after the fever episode. | Weak    |
| Japan               | Quantitative.                  |                                                                      |                                                                              |                        |                                                                                   |                                                                              |         |
| Wilson 2015         | Observational, retrospective case-control (propensity score matching). | To describe the differences in health care utilization and costs between elder people who received home-based care and the control group. | Medicare utilization records from JEN data management and consulting associates. | 584 people with dementia; 144 in the House Calls program, 440 in the control group. | The House Calls program - Developed to provide medical care to frail older people, including those with dementia - Focused on continuity of care, integrated care based on patients’ needs, coordinated team-based approaches. - Delivered by a team of physicians, nurse practitioners, non-clinical care managers, and social workers. | Patients enrolled in Medicare but not participating in the House Calls program. | Weak    |
| United States of America | Quantitative.                  |                                                                      |                                                                              |                        |                                                                                   |                                                                              |         |

CPS = Cognitive Performance Scale, DILE-dementia = Degree of Independent Living for the Elderly with Dementia, EOL = end-of-life, FAST = Functional Assessment Staging Tool, HHC = home healthcare, MDS = Minimum Data Set. POLST = physician orders for life-sustaining treatment.
Four studies mentioned that the HHC was provided by the multidisciplinary team.\textsuperscript{29,31–33} HHC in the other study emphasized advance care planning (ACP) in a nurse-led program.\textsuperscript{30} Only one study mentioned the duration of the HHC intervention,\textsuperscript{31} and no study reported the time between dementia diagnosis and the first HHC.

Two studies contrasted outcomes in people receiving HHC to those in nursing home care,\textsuperscript{29,31} and another study compared outcomes of treatments for acute events between the HHC group and the hospitalized group.\textsuperscript{32} Four studies investigated outcomes related to end-of-life issues or palliative care,\textsuperscript{29–31,33} whereas survival and mortality rate was the main outcome outcomes in the other study.\textsuperscript{32}

\textit{Meso-level}

Three studies mentioned coordination with social workers, non-clinical social care support, and external specialists such as palliative care consultants or geriatricians in HHC\textsuperscript{29,31,33}

\textit{Macro-level}

We did not find information on national policy or financial schemes that influence HHC for PLWD in the selected articles.

\textbf{Quality of the evidence}

No study received a high-quality rating (Table 2). The main reasons for low scores were authors not taking account of confounding factors appropriately in the analysis and the absence or insufficiency of follow-up period due to study design.

\textbf{Impact of HHC on end-of-life outcomes for PLWD}

Results identified from included papers were summarized in Table 3. All the observed impacts were at the micro-level.
Table 3
End-of-life outcomes in people with dementia who receive home healthcare

| A. Primary outcome measure |
|----------------------------|
| Acute healthcare utilization in the last year of life |
| Toscani 2015 | Physicians feel it difficult to decide for patients' hospitalization (when patients’ prognosis of survival ≤ 15 days) | HHC group vs. Nursing home care group | 25.5% vs. 3.1%, $p < 0.001$ |
| Mitchell 2004 | Hospitalization within 90 days prior to the last MDS assessment | HHC group vs. Nursing home care group | 31.5% vs. 43.7%, $p < 0.001$ |
| ED visit within 90 days prior to their last MDS assessment | 13.1% vs. 11.4%, $p = 0.41$ |
| Procedures use |
| 1. Oxygen therapy within 14 days prior to their last MDS assessment | 12.5% vs. 24.4%, $p < 0.001$ |
| 2. Feeding tube (time frame not mentioned) | 11.9% vs. 27.2%, $p < 0.001$ |
| 3. Intravenous therapy | 2.8% vs. 3.6%, $p = 0.52$ |
| 4. Foley catheter | 15.8% vs. 29.4%, $p < 0.001$ |
| Medication use within 7 days prior to their last MDS assessment |
| 1. Antipsychotic | 19.7% vs. 22.7%, $p = 0.35$ |
| 2. Antianxiety | 20.7% vs. 15.9%, $p = 0.05$ |
| 3. Antidepressant | 24.7% vs. 21.5%, $p = 0.21$ |
| Jennings 2019 | Hospitalization in the last 6 months | HHC with POLST vs. HHC without POLST group |
| 1. Any hospitalization | 43% vs. 31%, $p = 0.04$ |
| 2. > 1 Hospitalization | 22% vs. 12%, $p = 0.02$ |
| 3. Length of stay in hospital, median (IQR) | 5.8 (3.7–8.3) days vs. 4.1 (3.1–8.9) days, $p = 0.22$ |
| ED visit in the last 6 months |
| 1. Any ED visit | 29% vs. 23%, $p = 0.27$ |
| ICU admission in the last 6 months |
| 1. Any ICU admission | 6% vs. 4%, $p = 0.62$ |
| 2. Length of stay in ICU, median (IQR) | 2.0 (1.0–3.4) days vs. 5.8 (0.4–11.7) days, $p = 0.41$ |

| B. Secondary outcome measures |
| Hospice and palliative care use |
| Toscani 2015 | Physicians feel it difficult to decide for deep or terminal sedation | HHC group vs. Nursing home care group | 0.7% vs. 1.41%, $p = 0.49$ |

ED = emergency department, HHC = home healthcare, ICU = intensive care unit, IQR = interquartile range, MDS = Minimum Data Set, POLST = Physician Orders for Life-Sustaining Treatment.
### A. Primary outcome measure

| Purpose of all the decisions made for | 57% vs. 81.1% | 13.1% vs. 5.7%, p < 0.001 |
|--------------------------------------|----------------|---------------------------|
| Reduce symptoms/suffering           |                | HHC group vs. Nursing home care group |
| Avoid/stop futile treatments        | 10.3% vs. 8%   | 78% vs. 64%, p = 0.01     |
| Improving the quality of death by minimizing suffering | 0% vs. 1.6% | 74% vs. 62%, p = 0.03     |

**Mitchell 2004**  
**Hospice care referral any time prior to death**

**Jennings 2019**  
**Hospice care discussion or consultation in the last 6 months of life**

**Wilson 2015**  
**Hospice use**

**Advance care planning**

**Mitchell 2004**  
**Advance directive any time prior to death**

**Place of death**

**Jennings 2019**  
**Home death**

**Arai 2020**  
**Place of death (within 90 days after fever onset)**

ED = emergency department, HHC = home healthcare, ICU = intensive care unit, IQR = interquartile range, MDS = Minimum Data Set, POLST = Physician Orders for Life-Sustaining Treatment.

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**Acute healthcare utilization in the last year of life**

Three studies reported results regarding our primary outcomes of interest. In the Italian cohort study, Toscani et al. found that physicians providing HHC were more likely to find the decision of whether PLWD should be hospitalized or not when patients’ survival prognosis was estimated at fewer than 15 days difficult than physicians practicing in nursing homes (25.5% vs. 3.1%, p < 0.001). In the USA, however, Mitchell et al. reported that fewer people with advanced dementia receiving HHC were hospitalized within 90 days before the last Minimum Data Set (MDS) assessment compared to those cared for in nursing homes (31.5% vs. 43.7%, p < 0.001). In terms of specific procedures, fewer people in the HHC group were given life-supporting therapies such as oxygenation or feeding tube compared to those in the nursing home group at the end-of-life.

Jennings et al. described the impact of an HHC program in California, which specifically focused on ACP including Physician Orders for Life-Sustaining Treatment (POLST), on end-of-life care in PLWD. A higher proportion of PLWD who received HHC with the completion of POLST experienced hospitalizations in the last 6 months of life compared to those receiving HHC but without a POLST. There was no significant difference between the length of hospital stay, ICU admission, or frequency of ED visits between the two groups.

**Hospice palliative care use**
In Toscani’s study, physicians in the nursing home group were more likely to consider/make decisions that focused on reducing suffering or on improving quality of death for PLWD than physicians providing HHC. Two studies in the USA reported a higher percentage of HHC recipients used hospice or were referred to hospice care before their death compared with nursing home residents or the control group. In California, Jennings et al. demonstrated that PLWD who received HHC with a completed POLST were more likely to have hospice care discussion or consultations, use hospice care when they died, and died at home, compared to HHC recipients who did not have a completed POLST.

**Advance care planning**

Only Mitchell’s study indicated that fewer HHC recipients had advance directives before death compared to nursing home residents, despite a higher proportion of HHC recipients having a life expectancy of less than 6 months.

**Place of death**

Each study in the USA and Japan reported this outcome. A higher proportion of PLWD in HHC with POLST group died at home than those in HHC without POLST group.

**Discussion**

We identified five studies in this first systematic review to examine the association between primary HHC and end-of-life outcomes among homebound PLWD who are at high risk of mortality. The groups for comparison and outcomes measured in the included studies vary, and we found the results were heterogeneous and too limited to conclusively examine the effects of HHC on end-of-life outcomes. At the micro-level, HHC may be associated with a lower risk of acute healthcare utilization in the early period (e.g., last 90 days before death) and a higher risk in the late period (e.g. last 15 days) of the disease trajectory toward end-of-life in PLWD. HHC seems to increase referrals to palliative care or hospice use, whilst ACP with written decisions regarding life-sustaining treatments may play an important mediator in the effect of HHC on end-of-life outcomes. At the meso-level, HHC providers’ difficulty in making treatment decisions for PLWD at the end-of-life may require further training and external support. The coordination between HHC and social care is mentioned but not well investigated in the existing literature.

**Micro-level**

The differential effect of HHC on acute healthcare utilization among PLWD in the early or late period implies different care needs at various stages in the disease trajectory among PLWD, for which distinct components and models of HHC service may meet their needs better. A systematic review showed that home-based primary care mostly reduces the events and length of stay of hospitalization, however, this effect was observed within one year after HHC but not followed up to the recipients’ death. In addition, we have not been able to clarify the influence of the duration, continuity, or intensity of HHC from current literature. Among homebound PLWD towards end-of-life, identifying care needs and treatment decisions are complicated because the person may not be able to express their care preferences. Components of multidisciplinary approaches in HHC may be beneficial to PLWD toward end-of-life, but none of the selected studies examined the effectiveness of skill mix across various professions or quantified the contribution of each discipline.

Given that people with dementia may lose the capacity to make decisions for themselves, ACP in HHC may substantially influence end-of-life outcomes. For example, PLWD who received ACP-focused HHC and had advanced decisions such as POLST were slightly more likely to have acute healthcare utilization in the last 6 months of life but also had more hospice care consultations, died with hospice care, and died at home. This divergent phenomenon may be because those who engaged in care planning might pay more attention to their health and seek more chances for treatments for acute and reversible health care needs, but also choose less burdensome management when death is inevitable. The other reason is that more acute healthcare utilization may promote consideration of future care wishes and completion of advanced directives.

**Meso-level**

Providing training programs and seamless palliative care support from external specialists to HHC practitioners may improve the capability of primary end-of-life care in the home setting. Even though palliative care referral or hospice use is higher for people in the HHC group than those in nursing homes or the control group, Toscani et al. found that HHC physicians were less likely to initiate palliative care for PLWD. This finding may reflect that timely palliative care approaches provided by HHC professionals, such as
symptom control, can be further promoted through knowledge and skills training. Further service commissioning and integration between HHC teams and external specialists such as geriatricians or palliative care may contribute to PLWD living and dying well at home.

Good quality HHC requires strong coordination between health and social care services to achieve better end-of-life outcomes. A UK cohort study found that the need for social care services increased among PLWD toward the end-of-life, and the lack of social care support at home may lead to a higher risk of acute healthcare use. In the selected studies, only one American study assessed the use of social services in the HHC setting and found it was not being used to its full potential, showing that the coordination between health and social care may also be an area for improvement. Reform of national policy and payment schemes would be vital in promoting better care for individuals, and to build up interdisciplinary collaborations and delivery systems between health and social care services. Contextual information, including descriptions of the related policy and payment schemes in each country, however, was not mentioned in the selected papers.

Macro-level

To understand this context better, we summarize some international examples through a brief policy review and discussion in our research network (Table 4), including those from where the five papers of this review originated (USA, Italy, Japan) and the top-ranked countries in related regions in the Quality of Death Index Report, such as the UK in Europe and Taiwan in Asia. We found the key lessons from the policy comparison are the continuity of care, with a seamless connection between primary care and palliative care throughout the disease trajectory, as well as comprehensive care with coordination between health and social care sectors.
### Table 4
International comparison of the policy and payment scheme that support better home healthcare for the people with dementia

| Country* | National policy                                                                 | Payment scheme or financial resource | Descriptions                                                                                                                                                                                                 |
|----------|---------------------------------------------------------------------------------|--------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| USA      | Accountable Care Organizations (2010)25, Bundled Payments for Care Improvement (2013)43 | National health insurance (Medicare, Medicaid) | Switch fee-for-service payments to quality- and value-based purchasing program that promotes home health use and the coordination of home-based social care services                                                                                           |
| Japan    | Community-based Integrated Care System (2012)41, 44                             | Mandatory health and long-term care insurance; and social security system | The aim is to improve coordination between medical care and welfare services at home or in the community. Incentives for both health and long-term care insurance have been increased and integrated for encouraging care managers’ coordination of early discharge support, physicians who advise care managers in home-based care, and home-based medical care |
| Italy    | Dementia National Plan (2014)45                                                  | National Insurance and general taxation | Improve the quality of care delivered at home by promoting the training of health- and social care professionals and developing shared activities involving general practitioners and carers                                                                                 |
| Taiwan   | Integrated Home Care Project (2016)42                                            | Mandatory national health insurance  | Universal payment scheme aims to enhance the continuity and integration of series of home-based healthcare. Multidisciplinary team services including dentists, traditional Chinese medicine physicians, psychologists are reimbursed                                      |
|          | Long-term Care Plan 2.0 (2016)46                                                 | Taxes on inheritance, tobacco, gift, and house or land transactions income | The aim is to allocate more resources on community and home-based social care in coordination with home-based medical care                                                                                      |
| UK       | The NHS Long Term Plan, NHS England (2019)47                                     | National Insurance and general taxation | The aim is for patients to receive more options, better support, and properly joined-up care at the right time in the optimal care setting. NHS England will provide “Comprehensive Model for Personalised Care” for up to 2.5 million people by 2023/24. Promotes funding of care in place of person's choice |

*Country is sorted by the year of policy formulation. QODI = Quality of Death Index.

### Strengths and limitations

We comprehensively and systematically searched the literature by applying a wide range of search terms including synonyms of HHC and different types of HHC programs. The identified studies were rigorously checked by quality assessment tools. The international members of our research team provided insights and interpretation.

This study has several limitations. Firstly, the majority of studies evaluating the effect of HHC had short follow-up periods, often less than 12 months after the HHC started. Data about end-of-life outcomes that occurred within the final year before death were neither investigated nor analyzed separately, leading to fewer papers meeting our selection criteria. Secondly, none of the included studies were rated as high quality in critical appraisal. Outcomes were heterogeneous and it was not possible to pool data and meta-analyze findings. In addition, the lack of information about the duration, intensity, or components of HHC interventions meant we could...
not explore the “dose-response” relationship between characteristics of HHC and outcomes.\textsuperscript{53} Finally, the small sample size in the HHC group and lack of random sample selection may lead to poor external validity.\textsuperscript{54}

**Implications for research and practice**

The sparse evidence in our review suggests that the role of primary HHC may have been overlooked as a key service that could deliver better quality end-of-life care for PLWD. HHC services may vary widely across countries, and details of the components and contextual factors of HHC and how they are implemented are important to evaluate the effect of complex interventions, which were not reported in the included studies.\textsuperscript{55} For future studies, it is essential to better understand the effective components of HHC and the mechanism of how they influence end-of-life outcomes for PLWD.

Conducting a randomized trial or a prospective cohort study with a longer follow-up period of HHC would be challenging in practice.\textsuperscript{23, 35} A more pragmatic, hybrid paradigm incorporating quality improvement or service evaluation may be more useful and realistic to conduct.\textsuperscript{56} Large real-world datasets containing whole population samples, with complete follow-up are also good sources to evaluate HHC programs throughout the disease trajectory; though appropriate and robust methodologies should be applied.\textsuperscript{54, 57–59} This would reduce selection bias and prevent missing data due to the attenuation of study cohorts. Current metrics of care quality which were developed for individual diseases are not holistic and do not capture more value-based dimensions such as continuity of care or level of care integration.\textsuperscript{60}

At the micro-level, advance care planning, comprehensive geriatric assessment, and a palliative approach which focuses on patients’ care preferences and improving quality of life should be emphasized in HHC for PLWD.\textsuperscript{61–63} It has been suggested that, at the meso-level, stakeholders should enhance education for HHC users and providers, strengthen the training of the interdisciplinary workforce, and promote a service model supported by external professionals including social care or even telemedicine during the pandemic to meet complex end-of-life care needs in PLWD\textsuperscript{24, 37, 61, 64}. At the macro level, policymakers are encouraged by the experience of national policy and payment schemes reform in some countries to build up the continuously integrated care framework that improves the synergy of various services.\textsuperscript{24, 25, 61}

**Conclusion**

For PLWD, primary HHC may increase use of hospice palliative care and is associated with a differential effect on acute healthcare utilization in early or late periods of disease trajectory toward the end-of-life. Core components in HHC, such as ACP or its multidisciplinary approach should be further investigated to understand their individual effects. Population-based large databases may provide opportunities to examine more clearly the long-term effect of HHC on end-of-life outcomes, association with other services such as palliative care, and the overall impact on the healthcare system in a longitudinal study design. Integration between health and social care and seamlessly merging various home-based services for better continuity of care have been emphasized in national policy in some countries and can be adapted by other nations to promote better end-of-life care for homebound PLWD.

**Declarations**

**Availability of data and materials**

All data generated or analyzed during this study are included in this published article and its supplementary files.

**Ethics declarations**

**Ethics approval and consent to participate**

No ethical approval was required for this systematic review of existing published literature.

**Consent for publication**

Not applicable.

**Competing interests**
The authors declare that they have no conflict of interest.

**Authors’ contributions**

Study concept and design: PJC, RM, LVdB, ELS. Acquisition of data: PJC, LS. Analysis and interpretation of data: PJC, LS, RM, JYL. Drafting of the manuscript: PJC, LS. Critical revision of the manuscript for important intellectual content: all authors. All authors have read and approved the manuscript.

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**Figures**

![PRISMA flowchart of the selection process.](image-url)
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