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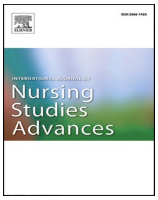

End of life decisions and preference of place of death among geriatric and chronic disease patients: A scoping review

Kennedy Diema Konlan[a,b], Seah Im[c,*], Agani Afaya[d,e]

[a] Mo- Im Kim Nursing Research Institute, Yonsei University College of Nursing, 50-1, Yonsei-ro, Seodaemun-gu, Seoul 03722, Korea
[b] Department of Public Health Nursing, School of Nursing and Midwifery, University of Health and Allied Sciences, Ho, Ghana
[c] Sahmyook University, College of Nursing., 815, Hwarang-ro, Nowon-gu, Seoul, 01795, Korea
[d] Yonsei University College of Nursing., 50-1, Yonsei-ro, Seodaemun-gu, Seoul 03722, Korea
[e] Department Nursing, School of Nursing and Midwifery, University of Health and Allied Sciences, Ho, Ghana

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ABSTRACT

Background: Geriatric and chronic disease patients and families consider the nature, time, and place of death because issues related to the end of life are rarely discussed. This study assessed the end of life decisions and preferences among geriatric and chronic disease patients.

Methods: There was an in-depth search in five electronic databases (PubMed Central, CINAHL, Embase, Web of Science, and Scopus) using the population, concept, and context, framework. A matrix was developed, discussed, accepted, and used for data extraction. Convergent synthesis and thematic data analysis technique were adopted for the analysis. The reporting of findings was done in accordance with the JBI and PRISMA guidelines for reviews.

Results: From the data analysis, home-based end of life care was intuitive and included home visits, telephone follow-up, and patient-initiated services. The key themes that emerged from our analysis that sought to influence end end of life decisions were 1) approach to home-based end of life care, 2) patient and family characteristics, 3) clinical characteristics of the patient, 4) health care provider factors, 5) satisfaction and care rendered to the patient and family, 6) family preference of the place of death, 7) collaboration between multidisciplinary teams of care, and 8) challenges associated with the home-based end of life care. The personal characteristics of the nurse (age, personal and work experience, nursing perspective, and competence) and conducting a home visit influenced patient and family end of life decision. Multidisciplinary care teams (nurses and palliative care specialists) were important in delivering effective end-of-life services.

Conclusion: To support patients in making informed decisions, they must be educated on expected outcomes and implications, adverse impacts of decisions, and the emotional influence on the bereaved family. It is important that divergent technological methods are leveraged to provide essential care to patients nearing the end of life at home. Advancing the quality of end of life care techniques through home visiting will improve the feeling of patients and families about the dying process.

Tweetable abstracts: End-of-life preferences warrants that, divergent technological methods are leveraged to provide care to patients nearing the end of life.

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* Corresponding author.
E-mail address: searinlove@gmail.com (S. Im).

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Contribution of the paper

What is already known

- People nearing the end of life and their relatives ought to consider death's nature, time, and place.
- There are limited scoping studies that have focused on the determinants of preference of place of death and end-of-life care rendered to patients who die at home

What this paper adds

- Home-based end-of-life care was intuitive and included home visits, telephone follow-up, and patient-initiated services.
- The personal characteristics of the family caregivers, such as age, patient and caregiver sex, socioeconomic status, housing situation, patient needs, and preferences, influence end-of-life decisions.
- The likelihood of a home death increased if the family could put pain under control, breathe comfortably, appear to be at peace with dying, keep dignity and self-respect, and be able to spend time with family and friends.

1. Introduction

People nearing the end of life and their relatives ought to consider death's nature, time, and place (Lee et al., 2019). This is important because issues of death are rarely discussed among family members due to the emotions associated with such experiences (Lee et al., 2019; Hall et al., 2011). Regardless of the feelings related to the place of death and the person to stay with during death, it is an inevitable experience that families with older adults and people suffering from chronic disease must go through. The increasing prevalence of older people with chronic disease has necessitated the institutionalization of measures supporting and providing appropriate care to older adults (Hall et al., 2011) and chronic disease patients. Undesirable emotions are associated with the painful experience of death, yet family members must worry about the cost of care and time wasted during hospitalization (Duncan et al., 2019; Garrido et al., 2015). This makes it imperative to consider home-based care as an alternative. Home-based care interventions are useful and cost-effective, especially among older adults and people with chronic diseases (Bi et al., 2022). Another consideration made by families is to have a loved one around during the last moments of the person's life (Bi et al., 2022; Hawking, 2021); this feeling is described as reassuring and promotes healing among bereaved families (Bi et al., 2022; Hawking, 2021; Higginson et al., 1994).

End-of-life patients (70%) prepare to die at home in the company of relatives even though this wish is not always met (Higginson et al., 1994). For the continuous involvement of family members in end-of-life care, home visiting has become cardinal as it allows health providers to discuss, learn, and support caregivers in the provision of end-of-life services (Shepperd et al., 2021). Nurse involvement in end-of-life care for geriatric patients is an important determinant of the nature, choice of place, type of care, and satisfaction that the family achieves during the dying moments (Gomes and Higginson, 2006; Aabom et al., 2005). Health care providers, including nurses, are essential in care rendered to patients, primarily in dying moments (Sousa and Alves, 2015; Becqué et al., 2019). It is imperative that the nurses, while providing care, involve family members to have an apt opportunity to discuss issues related to the death and dying process. There is a rising need for family members to remain near their aging family members and even more pronounced if death results from chronic disease (Hall et al., 2011). People who consider end-of-life decisions are usually in old age or suffering from chronic diseases like cancer and other forms of debilitating illness like heart failure or multiple organ failures.

Several systematic reviews have been conducted regarding end-of-life care of geriatric patients (Koffler et al., 2020), patients with chronic diseases like hematologic disorders (El-Jawahri et al., 2020), family caregivers' perspectives on in-home end of-life-care (Gonella et al., 2019), and the role of relational autonomy in end-of-life care (Hoerger et al., 2018). However, increasingly, many people at the end of life prefer to die at home, which provides bereaved relatives a considerable opportunity to heal appropriately after the death. Several studies have been conducted to determine the influence of home visits and death preference on the care rendered to people at the end of life. Yet there are limited scoping studies that have focused on the determinants of preference of place of death and end-of-life care rendered to patients who die at home. This scoping review comprehensively mapped evidence on end-of-life decisions and preference of place of death among geriatric and chronic disease patients.

2. Methodology

This scoping review was conducted following the JBI guidelines for scoping reviews (Peters et al., 2020). This review was reported in line with the Preferred Reporting Items for Systematic reviews and Meta-Analysis extension for Scoping Reviews (PRISMA-ScR) (Tricco et al., 2018). The protocol for this study was not registered.

2.1. Search strategy

We conducted a comprehensive search in five electronic databases, which included PubMed Central, Cumulative Index for Nursing and Allied Health Literature (CINAHL), Embase, Web of Science, and Scopus. The Population, Concept, and Context framework recommended by the JBI for scoping reviews was adopted in the design and conduct of the search strategies. The population for this study included geriatric patients or those with chronic diseases, the concept was the end-of-life home-based care and the patient's preferences of the place of death, and the context was nursing home facilities. An initial limited search was conducted in PubMed and

CINAHL, then adjusted to specific database requirements for each database. Subject terms (identified from relevant study titles and abstracts) and free-text terms (identified from study descriptions of articles) were used to develop the preliminary search strategy. The search strategies were then tailored to the various databases considering the differences in thesaurus terminologies and indexing. The search was conducted in these databases and was limited to the range January 2000 to December 2021. The keywords that were searched were ("chronic disease" OR patient OR "chronic patients" OR "older patients") AND ("home visit*" OR "home care*" OR "home support") AND ("palliative care" OR "end of life care" OR "supportive care" OR "geriatric care"). These used the appropriate Boolean operators, truncation, wildcards, and appropriate synonyms, as well as Medical Subject Headings (MeSH) terms.

2.2. Screening of studies

The various citations from the electronic database search were reviewed to remove duplicates. The remaining titles and abstracts were screened by two review authors (KDK & SI). Identified full-text articles were assessed independently for eligibility based on the inclusion criteria by two review authors (KDK & SI). Full-text articles that met the inclusion criteria were included for data synthesis.

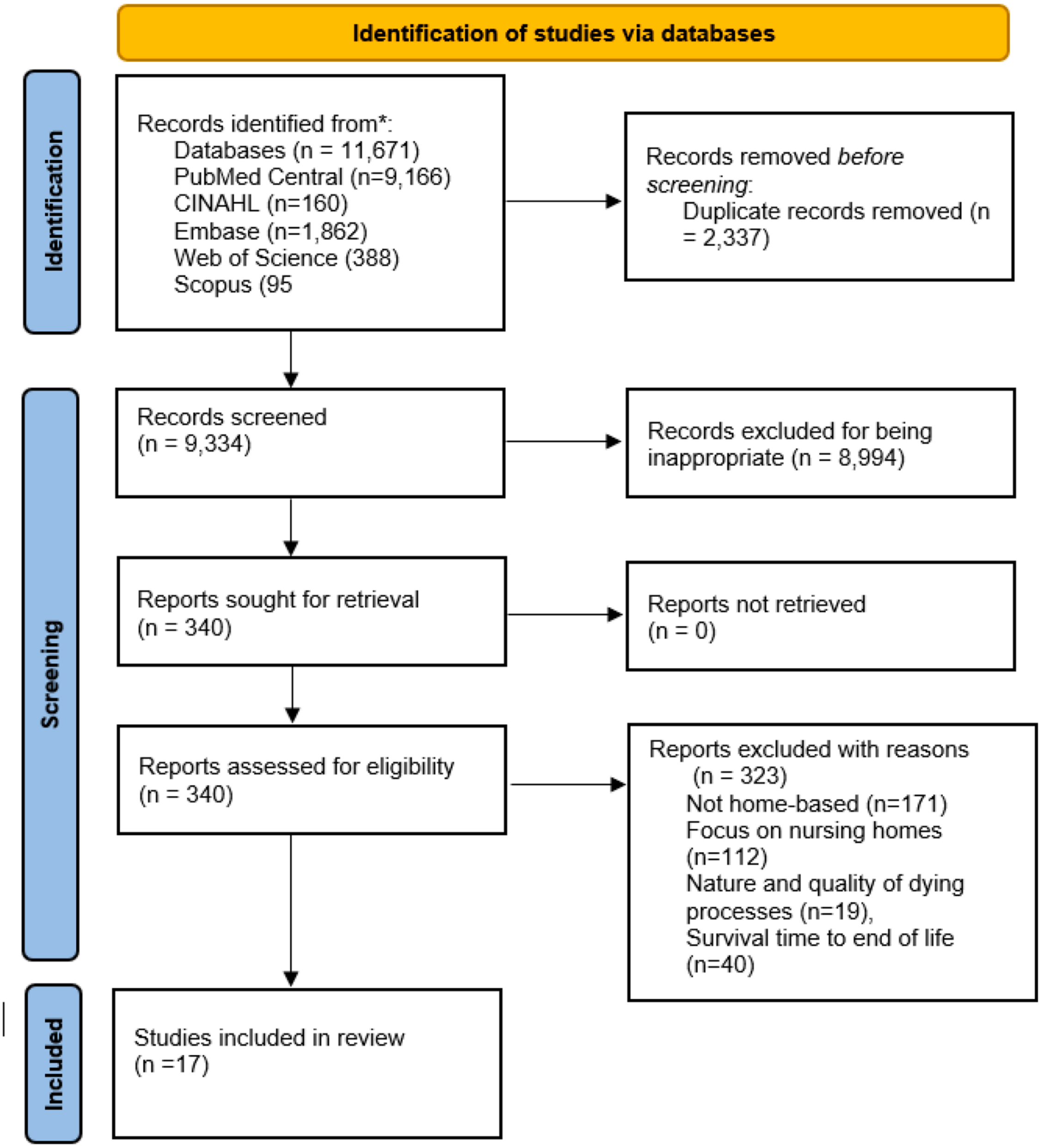

Fig. 1. PRISMA flow diagram for study selection.

Table 1
Study characteristics.

	Authors	Purpose	Population	Data collection	Settings	Design	Data analysis
1	Pivodic et al., 2016(21)	Degree and factors associated with bereaved relatives' satisfaction with home end-of-life care delivered by general practitioners	Bereaved relatives of cancer patients	Postal survey (4–10months). 548 questionnaires	London, United Kingdom	Population-based mortality follow-back survey	Weighted percentages and bivariate analyses.
2	Danielsen et al., 2018 (25)	Conditions that facilitate or hamper more time at home and home deaths for patients with a terminal disease and short life expectancy	Home care nurses or general practitioners	4 focus group discussion. 19 participants	Norway	Qualitative research design	Systematic text condensation through thematic and content analysis
3	Lai et al., 2019(26)	Home-based end-of-life care and difficulties in community health service centers	Health care providers	Interviews. 19 health care providers	Shangai	Qualitative	Qualitative content analysis
4	Bacque et al., 2021(27)	Approach, influencing factors, and support of family caregivers in end-of-life home care	Nurses from home care organizations	Semi-structured interviews. 14 nurses	Netherlands	Qualitative	Thematic analysis
5	Scheereens et al., 2015 (28)	The development of a phase 2 intervention on early integration of primary health care for end-stage Chronic obstructive pulmonary disease	General practitioners and Nurses	3 focus group discussion with general practitioners (*n*= 28) and 4 community nurses (*n*= 28)	Flanders, Belgium,	Qualitative	Thematic data analysis
6	Brink & Smith 2008 (29)	Determinants of home death among patients receiving palliative home care	Health information	Health information of 536 patients	Ontario, Canada	Retrospective review	Simple descriptive and Chi-square analysis
7	Brumley et al., 2003 (30)	Effectiveness of a palliative program for end-of-life care	558 patients were enrolled for two years follow up	Telephone interview of 300 patients (161 Palliative Care Program and 139 comparison group)	Southern California	Randomized control Trial	Mantel-Haenszel $x2$ tests, Mann-Whitney U test, and independent samples t-test
8	Mitchell et al., 2015 (22)	Experience of general practitioners providing end-of-life care in the community, particularly the facilitators and barriers to good-quality care.	General practitioners in end-of-life care	Online Questionnaire. 516 general practitioners	England	Questionnaire survey	Descriptive statistics and an inductive thematic analysis
9	Poulous et al., 2018 (32)	End-of-life care in the home is provided by existing multidisciplinary community palliative care teams, with specialist supportive community care workers	Family caregivers, community palliative care teams, and community care workers	Survey and/or telephone interview with family caregivers, community palliative care teams and community care workers	New South Wales, Australia	Mixed methods	Descriptive analysis and thematic analysis
10	Devlin & McIlfatrick, 2015(23)	Role of home-care workers in palliative and end-of-life care in the community	Home-care workers and community nurses	Survey (236 questionnaires) and focus group discussion	United Kingdom	A mixed methods approach	descriptive statistical and cross tabulations, and thematic data analysis
11	Baik et al., 2021(31)	Educational needs and priorities of home care workers caring for community-dwelling adults with heart failure at the end-of-life	Home care workers	Focus group discussion (41 home care workers)	New York City	Semi-quantitative using point rating	Directed content analysis methods
12	Smith & Porrock 2009 (35)	Attitudes and influencing factors of community nurses to the care of the dying patient.	Community nurses working across all National Health Service primary care	Questionnaire 667 registered community nurses	Two English countries	Cross-sectional	Descriptive, correlational, and inferential statistics

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Table 1 (*continued*)

	Authors	Purpose	Population	Data collection	Settings	Design	Data analysis
13	Aabom et al., 2006(10)	Effect of general practitioners' home visits on terminal declaration and on the place of death	Patients with cancer	Mortality follow-back design of 2025 on a mortality register	Island of Funen/ Denmark	Matched case-control study	Multivariate logistic models
14	Jack et al., 2012(24)	Health care professionals' perspective of hospice at home service	Health care workers and Nurses	75 health care professionals	United Kingdom	An evaluation study	Thematic analysis approach
15	Murakame et al., 2018 (33)	Clinical outcomes of a project to enhance the awareness of community-based palliative care, focusing on home death and care rates in communities	Palliative care physicians, nurses and medical social workers	Cancer patients who received treatment at a single community cancer center	Toyama Prefecture Saiseikai Takaoka Hospital	Single-center community-based intervention	*t*-test, Mann-Whitney U test, chi-square test, Fisher's exact test, and generalized estimating equation
16	Angwenyi et al., 2021 (34)	Impact of community home-based care on self-management outcomes for chronically ill patients	Patients with Human Immuno-deficiency Virus and non-communicable diseases	Survey 140 patients with Human Immuno-deficiency Virus and non-communicable diseases	Rural Malawi	Pre- and post-evaluation survey	Descriptive statistics, correlations, and pairwise comparison
17	Ikezaki & Ikegami 2011(36)	Combined effects of patient's and family's preferences for death at home in determining the actual site of death	4175(1664 cancer and 2511 non-cancers	Mailed questionnaires to the Visiting Nurse Stations	Japan	Retrospective case-control study	*t*-test, univariate, bivariate, and multiple logistics analysis

Disagreements between the two review authors were fully discussed and resolved to ensure consensus. A detailed article selection process at the various stages has been clearly shown in the PRISMA flowchart diagram (see Fig. 1)

2.3. Inclusion and exclusion criteria

The inclusion criteria included studies of all designs; i.e., quantitative and qualitative studies and those that included all forms of chronic diseases in older adults. Studies that indicated that they considered the factors that were associated with end-of-life decision-making or the preferences regarding this were included. The exclusion criteria involved studies that were conducted within nursing home facilities. Other exclusion criteria were studies focusing on the nature and quality of dying processes, home hospice care, facilitators and end-of-life care for hospice care facilities, and survival time to end of life.

2.4. Data charting

A matrix was developed, discussed, and accepted by the authors to be used for data extraction. The matrix ensured the extraction of comprehensive information regarding home-based care, preference of the patient's death place, and the issues that influenced the care. The data extraction parameters included: the first author's name and year of publication, study population, sample and sampling technique, study design, age of respondents, data analysis technique, and factors that influenced nurse-led home-based care at the end of life, as well as the key findings.

2.5. Data synthesis and analysis

The thematic data analysis technique was adopted to analyze the extracted information from the included studies. A convergent qualitative synthesis design was employed where findings from qualitative, quantitative, and mixed method studies were transformed into qualitative descriptive statements (Hong et al., 2017; Pluye and Hong, 2014). The descriptive qualitative outcomes were then read several times and generated codes. Related codes coalesced into subthemes, and the related subthemes formed the main themes. The main themes comprehensively gave an overarching framework for the presentation of the study findings.

3. Results

Through an in-depth search of five electronic databases (PubMed Central=9166, CINAHL =160, Embase=1862, Web of Science= 388, and Scopus =95), 11,671 titles were retrieved, and 2337 duplicates were identified and removed. In total, 9334 were screened by title, abstract, and full text, and 17 studies were selected based on predetermined inclusion and exclusion criteria. The article selection process is illustrated in Fig. 1.

Table 2
Distribution of factors that influence the end of life and care of the dying.

	Author	Outcome	Measurement	Factors that influence end-of-life care	Key findings
1	Pivodic et al., 2016(21)	Satisfaction and service factors with home care	Adapted questionnaire from previous studies	The odds of high satisfaction (excellent/ very good) with end-of-life care by a general practitioners doubled if general practitioners made three or more visits (adjusted OR: 2.54,95% CI: 1.52–4.24)) and halved if the patient died at the hospital (adjusted OR: 0.55 (95% CI: 0.31–0.998)	● Patients that stayed home at end-of-life, 55% (95% CI: 51%–59%) had excellent/very good home care by general practitioners, compared with 78% (95% CI: 74%–82%) for specialist palliative care providers and 68% (95% CI: 64%–73%) for district/community/private nurses.
2	Danielsen et al., 2018(25)	Conditions that facilitate or hamper deaths for patients with a terminal disease and short life expectancy.	Semi-structured interview guide	● Achieving a close and trusting collaboration with the patient and next of kin. ● Initial palliative care planning in the patient's home following discharge from the hospital.	● Palliative care at home depends on close collaboration and dialog between the patient, family, home care nurses, and general practitioners. ● Initial interdisciplinary collaboration meeting in the patient's home is crucial for a good result. ● The family is fundamental in supporting the patient to die at home.
3	Lai et al., 2019 (26)	End-of-life care for cancer patients	A self-developed semi-structured interview guide	● Monitoring the patient's condition, managing the symptoms, giving care instructions, performing nursing procedures, and providing psychological support.	● Service was delivered regularly by the physicians and nurses using the approaches of home visits and/or telephone follow-ups.
4	Becque et al., 2021(27)	Approach, influencing factors, and support of family caregivers	Qualitative interviews	● Nurses paying attention to family caregivers' needs. ● Nursing activities include support needs, practical education, support in decision-making, emotional support, and organizing respite care.	● Provision of support to family caregivers is usually based on intuition and experience rather than on a systematic approach. ● Different factors at the individual, organizational and societal levels influenced the support of family caregivers, knowledge, and experience
5	Scheereens et al., 2015(28)	Clinical practice at the end-stage chronic obstructive pulmonary disease	Semi-structured topic guide (focus group discussion guide)	● Barriers were related to the unpredictability of chronic obstructive pulmonary disease ● Lack of cooperation and experience with primary health care, lack of education, insufficient hospital care continuity, and lack of communication between professional caregivers.	● Facilitators were used of trigger moments for early integration of primary health care, such as after hospital admission or when an end-stage chronic obstructive pulmonary disease patient becomes oxygen-dependent or housebound, positive attitudes towards primary health care in informal caregivers, more focus on early integration of primary health care in professional caregivers' education, implementing advance care planning in health care and primary health care systems and enhancing communication about care and primary health care.
6	Brink & Smith 2008(29)	Home death in palliative home care	InterRAI the palliative care assessment tool	● Functional and cognitive impairment, weight loss, incontinence, and delirium. ● The patient's wish to die at home and the family's ability to cope were strong determinants of home death	● Patients who died at home were more likely to be functionally impaired and less likely to live alone. ● Patients who lived alone died at home (41%). Home death was common among patients who preferred to die at home (59%).
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Table 2 (*continued*)

	Author	Outcome	Measurement	Factors that influence end-of-life care	Key findings
	Brumley et al., 2003(30)	Medical service use and satisfaction with services	Palliative Performance Scale. The Reid-Gundlach Satisfaction with Services instrument	● Palliative care patients had increased satisfaction with services 60 days after enrollment and significantly fewer emergency department visits, hospital days, skilled nursing facility days, and physician visits than the comparison group.	● At 60 days following enrollment, the palliative care group had significantly higher satisfaction than at baseline ($t = -2.57$, $p = 0.01$). ● Comparison group members had twice as many emergency department visits and four times as many hospital days as the palliative care group.
8	Mitchelle et al., 2015(22)	Experiences of end-of-life care	Online questionnaire survey was developed as part of the clinical priority workstream of the Royal College of General Practitioners Clinical Innovation and Research centre	● Lack of resources inhibited continuity of care (time, staff numbers, increasing workload, and funding). ● An effective multidisciplinary team was important in effective end of life care.	● General practice plays a key role in the delivery of care to people approaching the end-of-life and families. ● Sudden deteriorations in a patient's condition and inadequate symptom-control were associated with avoidable delays in clinical assessment, accessing or administering medication
9	Poulous et al., 2018(32)	Quality of death and dying	Ten items from the Quality of Death and Dying Questionnaire.	● Hospital care might be adequate, but it was not an environment in which loved ones wished to pass the last days. ● Being at home allowed the patient and family caregivers to feel "a little bit more in control," and family and friends could visit whenever they wanted.	● Family caregivers value support provided by clinical care workers for enabling choice, providing practical assistance, and emotional support and reassurance. ● Satisfactory outcomes for patients and their families who wish to have end of life care in the home can be enabled with the additional support of specially trained clinical care workers.
10	Devlin & McIlfatrick, 2015(23)	Role of home care worker in providing community care	Questionnaire, adapted from the study by Fleming and Taylor (2007)	● Lack of time was consistently reported as a restricting factor of the home-care workers' role.	● It was found that home-care workers considered palliative and end-of-life care as an important part of their role. ● The community health nurse's role incorporated a genuine caring dimension with a need for additional support in the provision of end-of-life care. ● Various restricting factors such as training deficits, need for support and supervision, and communication issues were also identified.
11	Baik et al., 2021 (31)	end of life care for heart failure patients	Self-develop focus group discussion interview guide	● Lack of supportive home care groups ● Challenges in expressing empathy towards the dying	● Respondents experienced difficulties maintaining a positive attitude and demeanor with patients nearing the end-of-life, including sadness or hopelessness associated with not being able to heal the patient.
12	Smith and Porrock et al., 2009(35)	Attitudes of community nurses to care of the dying	The questionnaire was based on Frommelt's Attitudes to Care of the Dying Scale	● Achieving a home death appears to be very fragile ● Multidisciplinary working and the value of a good team environment and close relationships with general practitioners' practices	● Almost 40% of community nurses held negative attitudes toward caring for the dying. ● Attitudes of community health nurses were also influenced by levels of support, workload, and time constraints.

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Table 2 (*continued*)

	Author	Outcome	Measurement	Factors that influence end-of-life care	Key findings
13	Aabom et al., 2005(10)	Hospital death	Mortality registry	● A strong association between terminal declaration and general practitioners home visits in the week preceding the declaration (OR: 11.5, 95% CI: 6.0_24.6). ● terminal declaration that general practitioners home visit was inversely associated with hospital death (OR: 0.18 (0.11_0.29)).	● Patients (38.0%) received a terminal declaration, and 56% died in the hospital. ● General practitioners' home visits in the week before terminal declaration (OR: 16.8; 95% CI: 8.2_34.4), and 4weeks before terminal declaration (OR: 6.4; 95% CI: 4.5_9.2) were associated with an increased likelihood of receiving a terminal declaration. ● General practitioners home visits in the group with terminal declaration (OR: 0.18; 95% CI: 0.11_0.29) and the group without terminal declaration (OR: 0.08; 95% CI: 0.05_ 0.13) were inversely associated with hospital death.
14	Jack et al., 2013 (24)	Home care for the dying	Interviews, focus group discussion, open-ended electronic surveys	● Input from a multi-professional specialist palliative care service ● The crisis intervention service was helping patients remain in their own home.	● Support for family careers appeared to enable them to continue coping, rapid access to the service was suggested to contribute to faster hospital discharges.
15	Murakame et al., 2018(33)	Changes in the home death rate	Adopted the regional referral clinical pathway for home-based palliative care as an information sharing tool	● Participation of home care physicians and visiting nurses in the Palliative Care Emphasis Program on Symptom Management and Assessment for Continuous Medical Education (PEACE-based education) and patient palliative prognostic index values significantly influence the home death rate	● In 2012–2013, home deaths were as high as 19.9% and greater than the previous 5.9% (p= 0.001). ● Participation of home care physicians and visiting nurses in a palliative care education program and patients' Palliative Prognostic Index values were factors significantly influencing the home death rate.
16	Angwenyi et al., 2019(34)	Self-management outcomes for chronically ill patients	Adapted scales from the Stanford Chronic Disease Self-Management Program	● Illness intrusiveness negatively correlated with self-efficacy ● Self-efficacy increased with an increment in quality of life (r= 0.457, $p < 0.000$) and was positively associated with improved general health status.	● The odds for self-efficacy improvement were lower for patients with longer diagnosed conditions. ● Programs maintaining regular home visits had higher patient satisfaction levels. ● There were differential changes in self-management outcomes following community home-based care interventions.
17	Ikezaki & Ikegami 2011 (36)	Preference of place of death	Activities of daily living and cognitive function	● Both the patient and the family expressed such preferences [cancer: OR (95% CI) = 57.00 (38.79–83.76); non-cancer: OR (95% CI) = 12.33(9.51–15.99)].	● Patients served by physician-based clinics were likelier to die at home, and the probability was greater for cancer patients.

Legend: CI: Confidence interval, interRAI: the 'interRAI palliative health care assessment tool' is comprehensive, standardized system for evaluating the needs, strengths, and preferences of those in palliative care or hospice settings*,* OR: Odds Ratio, p: *p-value, t*: student *t*-test.

3.1. Study characteristics

Table 1 displays the characteristics of the included studies. The parameters under this category include the study's purpose, population, data collection, setting, design, and data analysis method. The studies were conducted in the United Kingdom (UK) (Aabom et al., 2005; Pivodic et al., 2016; Mitchell et al., 2016; Devlin and McIlfatrick, 2010; Jack et al., 2013), Norway (Danielsen et al., 2018) Shangai (Lai et al., 2019), Netherlands (Becqué et al., 2021), Belgium (Scheerens et al., 2018), Canada (Brink and Frise Smith, 2008), US (Brumley et al., 2003; Baik et al., 2021), Australia (Poulos et al., 2018), Japan (Murakami et al., 2018), rural Malawi (Angwenyi et al., 2021). The study designs that were adopted were population-based mortality follow-up (Pivodic et al., 2016), qualitative research design (Danielsen et al., 2018; Lai et al., 2019; Becqué et al., 2021; Scheerens et al., 2018), retrospective review (Brink and Frise Smith, 2008), randomized control trial (Brumley et al., 2003), cross-sectional survey (Mitchell et al., 2016; Poulos et al., 2018; Smith and Porock, 2009), a mixed-methods approach (Devlin and McIlfatrick, 2010), semi-quantitative and endpoint rating (Baik et al., 2021), matched case-control (Aabom et al., 2005), an evaluation study (Jack et al., 2013), single-center community-based intervention (Murakami et al., 2018), and pre-and post-evaluation (Angwenyi et al., 2021).

3.2. Factors that influence end of life care of chronic disease and geriatric patients

The key themes that emerged were 1) approach to home-based end-of-life care, 2) patient and family characteristics, 3) clinical characteristics of the patient, 4) health care provider factors, 5) satisfaction and care rendered to the patient and family, 6) family preference of the place of death, 7) collaboration between multidisciplinary teams of care, and 8) challenges associated with the home-based end-of-life care. Table 2 presents the factors that influence the end of life and care of the dying among geriatric patients.

3.3. Approach to home-based end-of-life care

Multiple approaches were incorporated in conducting home-based end-of-life care, including home visits, telephone follow-ups, and patient-initiated telephone services (Lai et al., 2019; Becqué et al., 2021; Ikezaki and Ikegami, 2011). Home-based end-of-life care was based on intuition and experience instead of any systematized scientific approach (Becqué et al., 2021). Another factor that influenced the approaches of home-based care was the role to be played by practitioners towards the end-of-life (Devlin and McIlfatrick, 2010). The duties of health care providers during a home visit for end-of-life care were varied and included carrying out additional duties not specified by managers (Devlin and McIlfatrick, 2010; Angwenyi et al., 2021). These additional duties included shopping, posting letters, or looking after pets (Devlin and McIlfatrick, 2010). The likelihood of support from a palliative care center or a nurse's phone call increased patients' choice to have a home death (Danielsen et al., 2018; Lai et al., 2019). Other forms of home care included the palliative care teams performing monitoring (outreach) weekly and caring on a 24-hour basis for 365 days as necessary (Murakami et al., 2018; Ikezaki and Ikegami, 2011). Home-based care also involves transferring the patient to a hospital using an ambulance, and sometimes death did occur (Jack et al., 2013; Angwenyi et al., 2021).

3.4. Patient and family characteristics related to end-of-life care

Various demographic, family, and individual characteristics influenced the tendency of a person to die at home (Brink and Frise Smith, 2008). The factors that influence nurse support were demographic and personal characteristics of the family caregivers, such as age, socioeconomic status, housing situation, needs, and preferences (Becqué et al., 2021). The patient's sex was related to the likelihood of a home death, as men were more likely to die at home (Brink and Frise Smith, 2008; Poulos et al., 2018). Caregivers indicated that patients' choice of place of death was the primary determinant and shaped by a range of factors, such as level of income, family relationship, duration of sickness, number of home visits from a health professional, and individual preferences (Brink and Frise Smith, 2008; Poulos et al., 2018; Angwenyi et al., 2021). The sense of self-efficacy was an important determinant of home death, even though the odds of improvement were lower among patients with illnesses longer than ten years, those not enrolled in a support group, and those receiving over three home visits (Angwenyi et al., 2021).

3.5. Clinical characteristics of the patient

Various clinical characteristics influenced the likelihood of home death. The likelihood of a home death increased if the patient had pain relief, could breathe comfortably, appeared to be at peace with dying, kept dignity and self-respect, and spent time with family and friends (Poulos et al., 2018). A higher level of functional impairment, cognitive impairment, weight loss, daily incontinence, and an indication that delirium may be present were related to home death (Brink and Frise Smith, 2008). Other clinical factors associated with a home death were immediate deterioration in a patient's condition, inadequate symptom control, avoidable delays in clinical assessment, and delay in accessing care or administering medication (Mitchell et al., 2016; Scheerens et al., 2018; Ikezaki and Ikegami, 2011). The relatives' inability to manage the patient's serious and complex symptoms at home influenced the decision to seek health care services, especially in the dying moments (Lai et al., 2019). The nurses explained that changing support needs of family caregivers, long-term burden, a rapid and unpredictable disease process, and late identification of the seriousness of the palliative situation by other nurses might lead to late referrals for nursing support and result in a home death (Becqué et al., 2021). As well as meeting their practical needs, the emotional support and reassurance received from clinical care workers were crucial in enabling family caregivers to provide end-of-life care (Poulos et al., 2018).

3.6. Health care provider factors that influenced end-of-life care

The nature of the caregiver influenced the likelihood of a home death as it was shown that general practice played a crucial role in delivering care to people approaching the end of life (Pivodic et al., 2016; Mitchell et al., 2016; Lai et al., 2019; Becqué et al., 2021). The personal characteristics of the nurse (age, personal and work experience, nursing perspective, and competence) conducting a home visit influenced the care rendered to the patient and the family (Aabom et al., 2005; Becqué et al., 2021). The level of knowledge, training and awareness of the care providers' role increased the acceptability of a home death (Mitchell et al., 2016; Smith and Porock, 2009). A significant number of home-care workers had fulfilled a previous caring role, both personally and professionally, which influenced their choice as they found this role rewarding (Devlin and McIlfatrick, 2010). The person that discussed the process of dying, preferences, and patients' needs was also instrumental in determining the place of death (Smith and Porock, 2009). Being unable to tell the patient the truth about the state of health influenced the place of death (Mitchell et al., 2016; Lai et al., 2019).

3.7. The level of satisfaction and care rendered to the patient and family

The level of patient and family satisfaction and care rendered, especially during the last aspect of life, was associated with likelihood of a home death (Danielsen et al., 2018; Becqué et al., 2021). Bereaved relatives of patients who had received at least one home visit by a general practitioner rated the home care provided as very good or excellent (Pivodic et al., 2016; Becqué et al., 2021; Brumley et al., 2003). Nurses' and patients' level of satisfaction from caring for the dying and achieving a 'good death' was also noted (Becqué et al., 2021; Smith and Porock, 2009). The factors that influenced the satisfaction of the general practitioner with home care of the dying were specific patient-associated characteristics. These patient characteristics were older age, lower financial burden, preference for home death, higher number of days spent at home, less pain or discomfort, and respondents' lower grief intensity (Pivodic et al., 2016). When home care providers had adequate trust in the practitioner who visited their home, they were more likely to report satisfaction to care before death (Danielsen et al., 2018). The nurses highlighted that home-care workers sometimes miscommunicated with patients by providing inaccurate information concerning services (Devlin and McIlfatrick, 2010). The perception of death and the fact that participants could feel death approach influenced the nature of care that the practitioner implemented (Scheerens et al., 2018; Murakami et al., 2018).

3.8. Patient and family preference at the place of death

Patient and family preference for the place of death of loved ones was an important factor (Danielsen et al., 2018; Lai et al., 2019; Ikezaki and Ikegami, 2011). Patients who died at home had their relatives perform basic chores for them before death, which increased their preference for a home death (Danielsen et al., 2018; Scheerens et al., 2018). Family members' presence at the point of death, coping with the dying process, previous experience with providing end-of-life care, limited networks of support, individual health issues, and patient's personal wishes influenced the decision for home death (Lai et al., 2019; Brink and Frise Smith, 2008; Poulos et al., 2018; Ikezaki and Ikegami, 2011). When home care was comparable to hospital care, patients felt more confident about dying at home (Lai et al., 2019). Family members' ability to cope with death and their feelings of sadness and hopelessness influenced the decision to have a home death (Baik et al., 2021).

3.9. Collaboration between multidisciplinary teams of care

When home-based care for the dying was coordinated among various and diverse health care professionals, the likelihood of a home death increased (Aabom et al., 2005; Mitchell et al., 2016; Danielsen et al., 2018; Becqué et al., 2021). Effective multidisciplinary teamwork, including the district nurses and specialist palliative care teams, was necessary to deliver effective end-of-life care (Aabom et al., 2005; Mitchell et al., 2016). Also, establishing effective support with the primary health care provider and collaborating in the initial stages after discharge influenced the decision not to have rehospitalization (Danielsen et al., 2018). Having the patient's family as collaborators in the care and support was essential in deciding to die (Becqué et al., 2021; Poulos et al., 2018). Diverse professional care teams consisting of physicians, nurses, pharmacists, medical social workers, and other professionals provided palliative care to improve home care (Devlin and McIlfatrick, 2010; Danielsen et al., 2018; Becqué et al., 2021; Murakami et al., 2018). The added input from a multi-professional specialist or palliative care service was fundamental to enabling some patients to remain at home (Mitchell et al., 2016; Jack et al., 2013). However, conflicting therapies and poor communication between professional caregivers were said to prevent the early integration of primary health care teams (Scheerens et al., 2018).

3.10. Challenges associated with home-based end-of-life care

Several interrelated and interdependent factors impeded the care and likelihood of a home death (Lai et al., 2019; Becqué et al., 2021; Scheerens et al., 2018). Being unable to provide the service and feeling powerless when facing psycho-spiritual problems were significant difficulties associated with a patient dying at home (Lai et al., 2019). One important reason for the inability to provide adequate services to the dying was a wide gap between what the service could offer and what the patients and their families needed (Lai et al., 2019; Becqué et al., 2021). The inability to perform critical services like urinary catheterization and venipuncture, closely monitor the effects of drugs, and find a suitable time to make home visits influenced the place of death (Brink and Frise Smith, 2008). Lack of resources, time, staff, high workload, and funding inhibited continuity of care and engagement in effective care planning and discussion (Mitchell et al., 2016; Devlin and McIlfatrick, 2010; Smith and Porock, 2009; Ikezaki and Ikegami, 2011). Some of the people that lived alone died at home (Brink and Frise Smith, 2008). Some other challenges were the absence of support care groups and the caregiver not having empathy towards the patient and family influenced the nature of care and the place of death (Baik et al., 2021). Other important factors that influenced the place of death and care rendered to the patient and his family at the time of death were laws and regulations that govern caregiving and the practice of nursing as a profession (Becqué et al., 2021). The lack of a coherent, comprehensive care plan for the dying patient was identified as influencing how care was rendered to a dying patient (Scheerens et al., 2018).

4. Discussion

We mapped evidence on end-of-life decisions and preference of place of death among geriatric and chronic disease patients. End-of-life care is particularly important as it influenced bereaved relatives' recovery and psychological well-being (Weaver et al., 2019). Given that families can reflect on the dying moments of their relatives during the recuperation period, health care professionals must prioritize the measures they incorporate in providing end-of-life care (Anderson and Ewen, 2011). In many other systematic reviews, the level of communication and the empathetic care rendered by professional health workers, especially at the end of life, was critical in a satisfactory death and proper recuperation of bereaved relatives (Gonella et al., 2019; Weaver et al., 2019; Anderson and Ewen, 2011). Therefore, end-of-life care is essential to the care rendered to geriatric and chronic disease patients. It is key that their wishes in this very vulnerable period are identified and respected. Studying the factors that influence preferences of the place of death and the decision-making process for this cadre of patients is therefore essential to institute appropriate care procedures.

We identified diverse end-of-life care approaches, including home visiting, telephone interviews and instruction, and patient-initiated care. Health professionals, including those conducting home visits, must understand and institute measures promoting satisfaction among patients and bereaved relatives. The home visiting approaches used by health care professionals were mainly through telephone follow-up and patient-initiated services by leveraging modern technology that allows for direct communication and the delivery of instructions. Incorporating cost-effective modern technological methods to care for patients with a terminal illness is imperative in supporting relatives to give optimum care. Some systematic reviews have advocated the use of telephones and modern care methods (van Loon-van Gaalen et al., 2021; Straßner et al., 2019). For client-centered care, end-of-life decisions and preferences must be understood among professionals who provide home-based care. Home-based care is cost-effective, culturally appropriate, and an acceptable method incorporated in primary health care systems to provide care to people, including those who have no preference for place of death (van Loon-van Gaalen et al., 2021; Diema Konlan et al., 2021). Unless the care must be done using complicated and sophisticated medical equipment, home-based care can be a good substitute for hospital care as patient education can be done using local and indigenous resources of the patient and community (Diema Konlan et al., 2021). As a result, health care practitioners are devising multiple and scientifically appropriate means to care for patients in their homes. This home-based care/ home visiting was reported to be acceptable among people living in rural communities in Ghana (Diema Konlan et al., 2021).

We observed that multiple approaches were adopted to promote end-of-life care at home. These approaches incorporated self-teaching, group teaching, use of local resources, or promotion of community-wide acceptance of care. Similar findings were also reported to be adopted by health care professionals to provide care to people nearing the end of life (Sallnow et al., 2016; Smith-Stoner, 2009). These education methods must focus on improving community and individual knowledge on care procedures (Diema Konlan et al., 2021; Sallnow et al., 2016). These approaches to teaching care are also essential in decreasing family fatigue, isolation, and the magnitude of concern regarding the patient's status and eventual health outcome (Sallnow et al., 2016). The aggregation of these approaches warrants the adoption of public health approaches that use health promotion principles to ensure successful end-of-life care (El-Jawahri et al., 2020; Grindrod and Rumbold, 2018; Bone et al., 2018; Fond et al., 2019). As the population ages and the end of life become imminent for almost every family, new innovative, culturally appropriate approaches should be identified and tested. This will ensure that all community members accept end-of-life care, especially when it occurs at home (Hoerger et al., 2018; Bone et al., 2018). This highlights the essence of health care professionals incorporating divergent methods of providing care to patients and informal caregivers.

Furthermore, we identified that family and patient characteristics were essential factors influencing care, the decision, and the preference for the place of death. These family dynamics emphasize the intensity of family cohesion and support that can be critical in the level of resilience and cognitive decisions made. The end-of-life experience among patients and families is usually associated with increasing the already fragile psychological tension, spiritual instability, and the volatile risk of breaking family resilience systems (Palacio et al., 2020; Zanatta et al., 2020). Family caregivers have some expectations that include offering environmental, emotional, and psychosocial support; keeping the family informed; promoting family understanding; and establishing a partnership with family careers by involving and guiding them in shared decision-making (Gonella et al., 2019; Colenda and Blazer, 2021). Therefore, health care providers must be wary of these individualized needs that exist within families and provide home care services that are specific and tailored to address these needs. Meeting family needs, understanding family characteristics, and providing individual or family-centered end-of-life care should focus on home-based care services (Gonella et al., 2019; Grindrod and Rumbold, 2018; Fond et al., 2019). Home-based care must be leveraged to ensure that care is rendered and accepted culturally by the family (Zadeh et al., 2018). Therefore, to provide successful end-of-life care to patients and families, care providers must evaluate cultural antecedents, family values, knowledge, nature of the relationship, and family resilience systems.

The clinical status of patients was identified to be cardinal in care expectations and preferences of the place of death of patients and their families. Patients' specific clinical needs must be addressed earnestly to improve their living conditions and limit the likelihood of related complications before death (Hoerger et al., 2018; Etkind Simon et al., 2020). The need for end-of-life care and support from caregivers was emphasized when patients with a higher proportion of visits that addressed coping experienced improved quality of life and depression symptoms (Hoerger et al., 2018). Patients in the latter moments of their illness can have depressing and undesirable consequences on the family and the care provider. It is also important that health care providers are wary of their personal emotional antecedents that may influence patient care. It is difficult for providers to be able to separate their personal biases from the care experience. Providers' role is essential in the patients' support (Etkind Simon et al., 2020). These personal characteristics of the service provider in this review were identified to include training, work experience, personal skills, work experience, age, professional perspective, and professional viewpoint. The training of home care and end-of-life care service providers must be focused on improving patients' and families' lives and living conditions. When health care providers are appropriately trained and oriented to enhance these conditions, patients' end-of-life care experience will be described as satisfactory.

We identified that the choice of place of death and the nature of death were personal. In contrast, other researchers identified family and other relationships that contributed to the end-of-life care and decision on death (Gomes and Higginson, 2006; Etkind Simon et al., 2020; González-González et al., 2020). In another review, about half of the participants wished to have end-of-life care in the home (González-González et al., 2020). End-of-life care is a decision that is mostly dependent on the patient. The nature of services received during these late moments, including palliative care, cardiopulmonary resuscitation, and drug or other therapy, is imperative to the patient's satisfaction before death (Gomes and Higginson, 2006; González-González et al., 2020). The care rendered to the patient must be seen to support and guarantee the patient's right to autonomy, especially at the very last moment of death. Palliative and home-based care of the patient and family must consider these personal choices of the patient and the family. End-of-life preferences ought to be evaluated and understood in the context of patient-level knowledge, socio-cultural circumstances, nature of care, and the approach practitioners adopt in providing end-of-life care.

4.1. Strengths and limitations

We highlighted thematically the factors associated with end-of-life home-based care rendered by health care providers and patient relatives. The themes were diverse and showed important factors to consider when making plans towards improving the experiences of patients and relatives regarding the end of life. One important limitation of this review was that the literature search was mainly limited to electronic databases. This might have omitted the possibility of the benefits associated with non-indexed studies that assessed the experience of end-of-life home-based care.

5. Conclusion

The focus of our study was to assess and determine the state of the literature on end-of-life care and choices related to the place of death among geriatric and chronic disease patients. We identified that the preference for home-based end-of-life care was highly favored among most of the studies. Divergent technological methods must be leveraged to provide essential care to patients nearing the end of life at home. This form of care was key to patients' satisfaction with care and the dying process for the patient, caregiver, and family. To support patients in making informed decisions, they must be educated on expected outcomes and implications, adverse impacts of decisions, and the emotional influence of outcomes on the bereaved family. Advancing the quality of end-of-life care techniques through home visiting will improve the feeling of patients and family members about the dying process. It is important to improve the knowledge of end-of-life caregivers on the best approaches to cope and give the appropriate care to the dying. This will make patients and their families carefully consider the consequences of their decisions for themselves and their families should the patient die. In making this education imperative, patients' end-of-life care preferences can guide health care providers on the appropriate and desired care. This will also improve the emotional well-being of providers as they become confident that the patient-desired care was provided. It is also imperative that health care providers provide empathetic care to families and patients nearing the end of life. Also, future end-of-life care rendered to patients should focus on strategies that aid patients and families in accepting their situations and being informed on decision-making. This study necessitates the development of interventions that aim at promoting and improving family and caregivers' resilience. Intervention studies must focus on identifying and testing active coping strategies that improve adaptation to illness by increasing awareness of positive aspects of coping, caregiving, personal meaning, and family support.

CRediT authorship contribution statement

Conceptualization (KDK, SI), data acquisition (KDK, SI), formal analysis (KDK), funding acquisation (KDK, SI, AA), investigation and quality appraisal (KDK, SI), project adminstration (KDK), drafting of manuscript (KDK), reviewing, and editing for critical intellectual content (KDK, SI, AA)

Declarations

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Not applicable.

Consent for publication

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Availability of data and materials

All data generated or analyzed during this study are included in this published article.

Declaration of interests

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Supplementary materials

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