

# Co-designing Community Out-of-hours Palliative Care Services: A systematic literature search and review

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## Abstract

**Background:** In order to provide responsive, individualised and personalised care, there is now greater engagement with patients, families and carers in designing health services. Out-of-hours care is an essential component of community palliative care. However, little is known about how patients, families and carers have been involved in the planning and design of these services.

**Aim:** To systematically search and review the research literature that reports on how out-of-hours palliative care services are provided in the community and to identify the extent to which the principles of co-design have been used to inform the planning and design of these services.

**Design:** Systematic literature search and review.

**Data sources:** A systematic search for published research papers from seven databases was conducted in MEDLINE, PsycINFO, Embase, Emcare, PubMed, CINAHL and Web of Science, from January 2010 and December 2021. Reference list searches of included papers were undertaken to source additional relevant literature. A manifest content analysis was used to analyse the data.

**Results:** A total of 77 papers were included. The majority of out-of-hours services in the community were provided by primary care services. The review found little evidence that patients, families or carers were involved in the planning or development of out-of-hours services.

**Conclusion:** Incorporating patients, families and carers priorities and preferences in the planning and designing of out-of-hours palliative care service is needed for service providers to deliver care that is more patient-centred. Adopting the principles of co-design may improve how out-of-hours care can be delivered.

## Keywords

Palliative care, co-design, out-of-hours, terminal care, community, health services

### What is already known about this topic?

- Out-of-hours palliative care services vary across organisations, jurisdictions and countries based on availability of resources, workforce, and geographical area.
- There is no one best fit model of out-of-hours palliative care service that can provide all the needed care and resources to patients with palliative care needs, their families and carers.
- The involvement of patients, families and carers in planning and designing out-of-hours palliative care service continues to prove difficult to achieve in practice.

### What this paper adds?

- This review identified the extent to which the principles of co-design have been reported by the research literature to inform the planning and design of out-of-hours palliative care services in the community.

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- Palliative care patients, families or carers appear to be under-represented in research that reports on the planning and developing of out-of-hours palliative care services in the community.
- Findings suggests that there may be significant impediments to end-user engagement in the co-design of services and highlights the need to involve patients, families and carers in developing out-of-hours care models to provide more individualised and personalised service.

#### Implications for practice, theory or policy

- A greater role for patients, families and carers as end-users in out-of-hours service planning and design is needed for out-of-hours palliative care services in the community.
- The GP plays a critical role in caring for individuals who want to be cared for in the community. The delivery of effective patient-centred out-of-hours palliative care requires services to be coordinated and well-integrated.
- Further work is required to support the co-design of out-of-hours palliative care services in ways that engage and build patient, family, carer, neighbourhood and community capacity.

## Introduction

Out-of-hours service is a fundamental component in community palliative care. It is defined as care delivered during out of usual working hours, weekends and public holidays.<sup>1</sup> Providing such care, especially in a person's home can be physically and emotionally challenging.<sup>2</sup> During out-of-hours, when less help and support is available, escalation of physical symptoms, emotional and psychological distress can increase the stress and anxiety experienced by families and carers.<sup>2-4</sup> Increased care-related burden is often reported as patients near end-of-life.<sup>5</sup>

In 2018, the World Health Organisation (WHO) emphasised the need for round-the-clock palliative care services to support patients, their families and carers in the community.<sup>6</sup> Patients, families and their carers often face issues such as unsatisfactory symptom management, insufficient consideration of personal preferences, culturally inappropriate care, unnecessary ambulance call outs and hospital admissions.<sup>7-11</sup>

To address these challenges, various models of out-of-hours palliative care services have been developed. However, health service design and planning has often been dominated by healthcare planners and professionals, a practice that may skew services away from delivering responsive care that prioritises the needs of patients, families and carers.<sup>12,13</sup> Viewing patients, families and carers as the 'expert of their experiences', involving them as partners and collaborators in planning and designing out-of-hours palliative care services could be part of the solution. Whilst challenging, such an approach is consistent with the philosophy of palliative care which emphasises person and family-centred care. Patients, families and carers input can assist service providers to prioritise what services are needed and how they should be provided to achieve the best outcomes.<sup>14,15</sup> Applying an approach to service planning that values end-user input, can enable the needs of different population groups to be better

understood and optimise patient-centric, holistic, and a stronger relational approach to care.<sup>16-19</sup>

Despite this imperative, little is known about the extent to which patients and families have been engaged as co-designers in out-of-hours palliative care services or research about these services. Co-design, in this context, refers to patients and families working in partnership with staff to improve out-of-hours palliative care services.<sup>16,20</sup> The principles of co-design include equal partnership, openness, respect, empathy, and design together.<sup>16</sup> To date, there have been very few studies that have reported end-users directing their palliative care needs and priorities as a part of service planning.<sup>14,21-26</sup>

## Aim

This paper therefore aims to systematically search and review the research literature that reports on how out-of-hours palliative care services are provided in the community and to identify the extent to which the principles of co-design were identified and used to inform the planning and design of these services.

## Methods

A systematic literature search and review was undertaken to address the research aim. This methodology combines the strengths of a critical review with a comprehensive and exhaustive search process. It involves a synthesis and analysis of knowledge about a topic.<sup>27,28</sup> Rather than focusing on a preferred type of study design, studies included demonstrate a wide range of study designs incorporating quantitative, qualitative, multiple and mixed method approaches. This type of review provides greater flexibility on the types of studies included<sup>29</sup> and broadens the scope of the search to include, for example, service evaluations and outcomes based research studies on out-of-hours palliative care services.

**Table 1.** Eligibility criteria.

Category	Inclusion criteria
Phenomena of interest	Studies about the design, planning or evaluation of out-of-hours palliative care services.
Types of study	International research published in a refereed journal. Study type: primary studies, qualitative, quantitative, mixed method studies, descriptive, correlational, cross sectional, cohort, longitudinal, case-control, retrospective, prospective, observational, randomised-controlled trials.
Settings	Home or community settings.
Types of participants	End-users (patient, family, carer, community, healthcare professionals, & stakeholder) receiving and/or providing out-of-hours palliative care services. Adult: 18 years old and above.
Intervention	Clinical or non-clinical palliative care services delivered out-of-hours that support patient's and family's physical, psychosocial or spiritual comfort and wellbeing. Service development and quality improvement initiatives to provide out-of-hours palliative care. Generalist or specialist services providing care to palliative patients. Services is described as any service that can contribute to improved health or the diagnosis, treatment, and rehabilitation of sick people; it is not necessarily limited to medical or health-care services. <sup>31</sup>
Context/Impact or focus	Service models and frameworks, types and outcome of service provided, quality of life (QOL). Use of co-design principles in service planning or evaluation. Patient, family, caregiver and healthcare provider perceptions and experiences of care.
Exclusion criteria	Palliative care services provided within usual working hours (Monday to Friday, 9 am–5 pm). Non-palliative services. In-patient settings such as hospitals and units such as ICU, CCU, HDU, emergency department, rehabilitation. Institutional settings with an in-house palliative care service/bed. Primary Care services that do not specifically identify palliative care or end-of-life care as part of the service. Out-of-hours paediatric palliative care services.

### Eligibility criteria

A set of eligibility criteria was initially determined by the authors then refined through an iterative process as articles were screened and questions were raised, discussed and resolved about the inclusion and exclusion criteria. The process of constructing the inclusion criteria was adapted from that described by Merner et al.<sup>30</sup> This approach uses seven eligibility categories: phenomena of interest, types of study, settings, participants, intervention, context and exclusion criteria (Table 1).

### Search strategy

A search strategy was developed by the team in consultation with a health specialist librarian. A list of main concepts and keywords and their synonyms was compiled from journal articles about the topic, thesauri and a search of electronic database-controlled vocabulary indexes. Keywords and the application of Boolean operators, proximity operators, truncation and phrase searching was developed and their application to the search process reviewed and validated by the specialist librarian (Supplemental Appendix 1). The search was undertaken by two authors (CL and TB) through electronic databases:

MEDLINE, PsycINFO, Embase, Emcare, PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Web of Science. Reference lists of all included studies were hand searched to identify additional, potentially relevant articles. The search was limited to papers written in the English language. To secure a large and robust sample, international research articles published in refereed journals over a period of 12 years, from January 2010 to December 2021, were selected. Articles located were exported to EndNote (Version 9) and duplicates removed.

### Screening and study selection

At the first level of screening, titles and abstracts were independently reviewed by two authors (CL and PN). Articles excluded were all those that were clearly not related to out-of-hours palliative care services. Full-texts of the remaining articles were obtained and assessed against study eligibility criteria by two authors (CL and PN). A third reviewer, TB, was consulted in the event of disagreements as well as for any citation that required further discussion and refinement of the eligibility criteria. Reference list searches of included papers were undertaken to source additional relevant literature. The

study selection process and reasons for exclusion of publications are presented using the updated Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram<sup>32</sup> (Figure 1).

To explore the extent to which the principles of co-design had been used in planning and developing out-of-hours palliative care services, the team drew upon the five core principles or values of co-design proposed by the NSW Agency for Clinical Innovation (ACI)<sup>16</sup>: equal partnership, openness, respect, empathy, and design together. Face validity of these five principles was confirmed by cross-reference to those principles and elements described in other key policy documents including the Social Care Institute for Excellence (SCIE),<sup>33</sup> National Standards for Public Involvement (NIHR),<sup>34</sup> INVOLVE,<sup>35</sup> Canadian Institutes of Health Research,<sup>36</sup> co-design resources produced by the Australia Healthcare and Hospital Association (AHHA)<sup>37</sup> as well as the Australian Government Department of Health (DOH)<sup>38</sup> (Table 2).

### *Data extraction and analysis*

Retrieved studies were screened to identify if they reported on the engagement of patients, families and/or carers together with researcher, healthcare providers and/or other stakeholders. This subset was further reviewed to ascertain if one or more co-design principles was described or referred to in the report. To do this, text was examined by applying manifest content analysis.<sup>39–41</sup> In this method, textual elements, such as words and phrases, are identified that could reflect the principles of co-design. These elements are then grouped based on similar denotations as evidence of one or more of the five co-design principles.<sup>39,42</sup>

Data were extracted from the selected studies using a customised spreadsheet within Microsoft Excel tailored to address the research question. The characteristic domains included publication year, author, country of origin, setting, method & study design, participant, aim/s, intervention, outcome measured, results and recommendations. Data extraction was undertaken by CL and reviewed by TB and PN. This approach was initially trialled using five articles and minor modifications made to data categorisation through team discussion. Extracted data was subject to descriptive analysis.

### *Critical appraisal of individual sources of evidence*

As the purpose of this review was to address broad questions about out-of-hours palliative care services, retrieved articles did not undergo quality assessment. However, the authors selected and included peer reviewed research papers based on the inclusion and exclusion criteria established for the review. Studies included in the review were

selected based on their relevance to the research question rather than their research design.

## **Results**

### *Search outcome*

Seventy-seven articles were included. The initial search retrieved 787 articles across all databases. Removal of duplicates resulted in 384 articles selected. After title and abstract screening, 283 were excluded, resulting in 103 articles which were subject to full text screening. Twenty-five articles were located through reference lists of selected articles. Fifty-three articles were excluded because they did not meet the inclusion criteria (Figure 1).

### *Study characteristics*

*Study location.* Of the 77 research papers included in this study, 30 (39%) studies were conducted in the United Kingdom, nine (11.7%) from the Netherlands, eight (10.4%) from Scotland, five (6.5%) each from the United States of America, Australia, and Canada, four (5.2%) from Denmark, two (2.6%) from India and Taiwan and one (1.3%) each from France, Germany, Norway, Sweden, Switzerland, Ireland and Japan (Table 3).

*Study period.* The numbers of studies published each year from 2010 to 2021 tended to decline though on average, there were seven papers published per year (Figure 2). The largest number of publications was recorded in 2015 and 2020 ( $n = 10$ ) and the lowest was recorded in 2021 ( $n = 1$ ).

*Study design.* A diverse range of research methods were used. Thirty-eight (49.4%) studies used quantitative methods, 25 (32.5%) used qualitative methods and the remainder, (18.2%) used mixed-methods. Of the quantitative studies, a majority used a retrospective design to identify populations with palliative care needs who had received out-of-hours services. Qualitative research approaches were used to identify and explore end-users as well as healthcare professionals' experiences, perceptions, and opinions regarding out-of-hours services (Table 3).

*Study participants and sample sizes.* Across all studies, the largest grouping of participants was patients or their medical records ( $n = 28$ ). Sample sizes ranged from 1 to 56,407 participants. The second largest participant group was general practitioners ( $n = 24$ ), samples ranged from 1 to 5333 ( $n = 24$ ). This was followed by family and/or caregivers ( $n = 21$ ), ranged within 1–24 participants. Other groups of participants that have been reported on were nurses ( $n = 16$ ), palliative care specialists ( $n = 9$ ), and paramedics, emergency medical team and rapid response team ( $n = 10$ ).

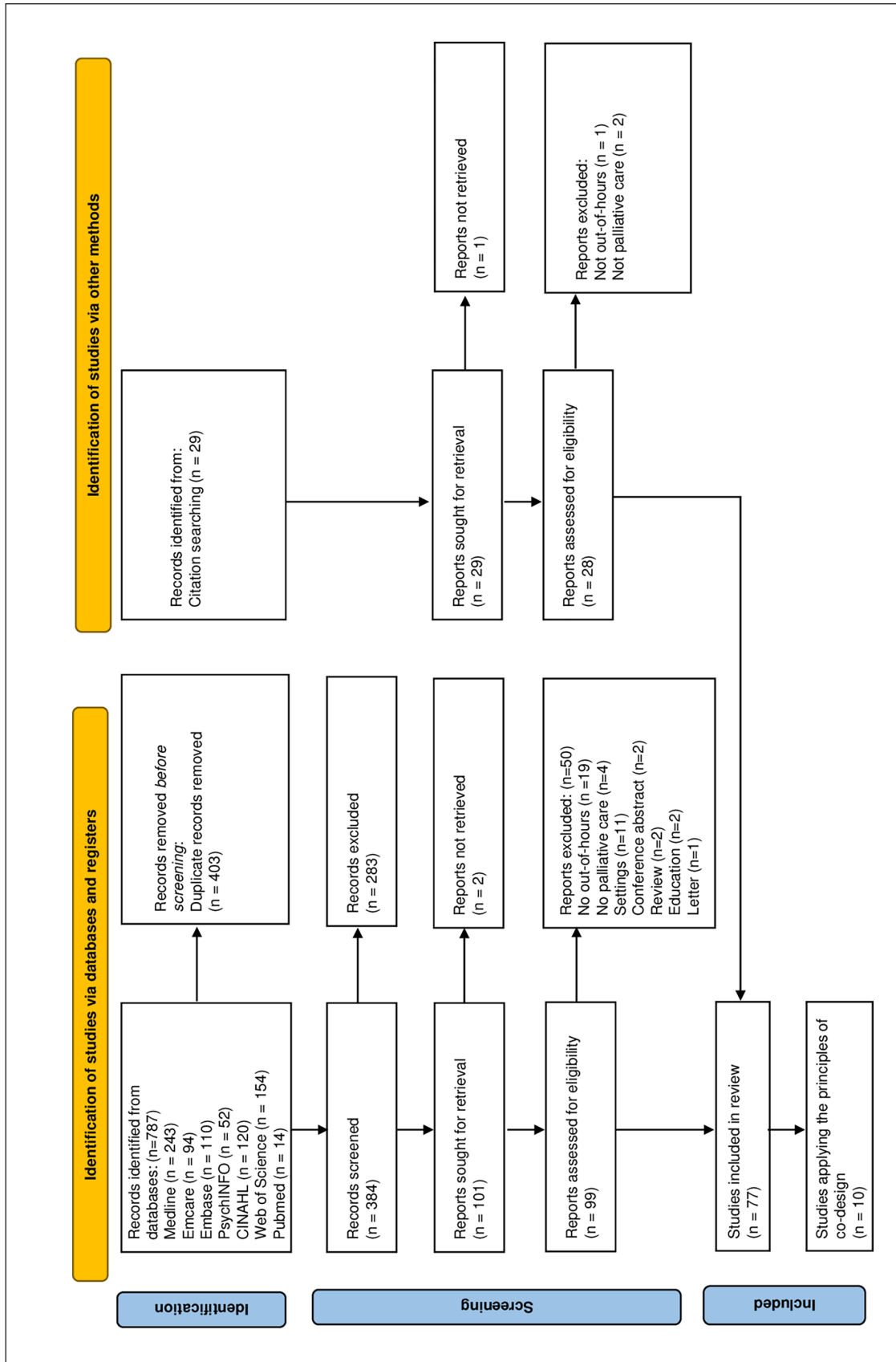
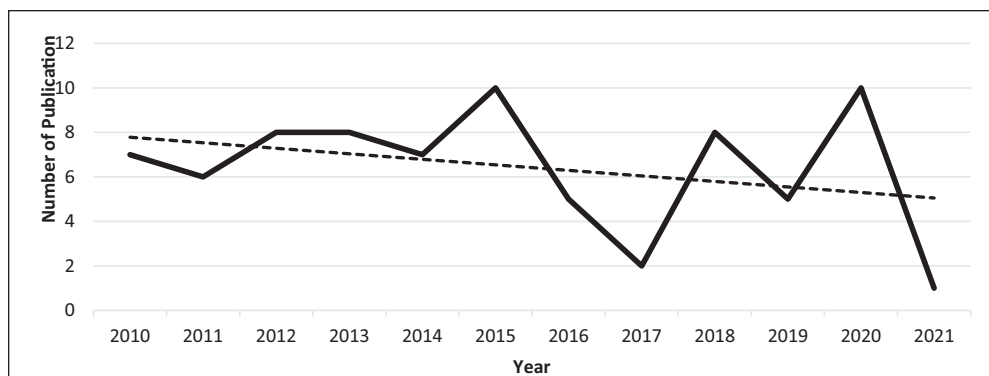


Figure 1. PRISMA 2020 flow diagram.

**Table 2.** Co-design principles.

Principle	Cross-references
<p><b>Equal partnership:</b> Consumers, families and staff work together from the beginning with an equal voice and shared ownership and control).</p>	<p>Inclusiveness: Patient engagement in research integrates a diversity of patient perspectives and research is reflective of their contribution.<sup>36</sup>                      Inclusive opportunities: Offer public involvement opportunities that are accessible and that reach people and groups according to research needs.<sup>34</sup>                      Equality: everyone has something to give and nobody is more important than anyone else.<sup>33</sup>                      Equity: Co-design is collaborative promoting an equitable partnership between stakeholders.<sup>37</sup>                      Openness and willingness for providers to proactively suggest new and innovative ideas.<sup>38</sup>                      Working together: Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.<sup>34</sup>                      Governance: Involve the public in research management, regulation, leadership and decision making.<sup>34</sup>                      Mutual Respect: Researchers, practitioners and patients acknowledge and value each other's expertise and experiential knowledge.<sup>36</sup>                      Respectful: All participants are seen as experts and their input is valued and has equal standing. Strategies are used to remove potential or perceived inequality. Partners manage their own and others' feelings in the interest of the process. Co-design requires everyone to negotiate personal and practical understandings at the expense of differences.<sup>35</sup>                      Impact: Seek improvement by identifying and sharing the difference that public involvement makes to research.<sup>34</sup>                      Respect for the confidential nature and commercial value of the intellectual property that potential providers might share.<sup>38</sup></p>
<p><b>Openness:</b> Consumers, families and staff work together on a shared goal, trust the process and learn together.</p>	<p>Support: Adequate support and flexibility are provided to patient participants to ensure that they can contribute fully to discussions and decisions. This implies creating safe environments that promote honest interactions, cultural competence, training, and education. Support also implies financial compensation for their involvement.<sup>36</sup>                      Participative: The process itself is open, empathetic and responsive. Co-design uses a series of conversations and activities where dialogue and engagement generate new, shared meanings based on expert knowledge and lived experience. Major themes can be extracted and used as the basis for co-designed solutions. All participants are responsible for the effectiveness of the process.<sup>35</sup>                      Support and learning: Offer and promote support and learning opportunities that build confidence and skills for public involvement in research.<sup>34</sup></p>
<p><b>Empathy:</b> Practice empathy and maintain an environment which feels safe and brings confidence to everyone. Participants commit to learning from each other towards meaningful outcome.</p>	<p>Co-Build: Patients, researchers and practitioners work together from the beginning to identify problems and gaps, set priorities for research and work together to produce and implement solutions.<sup>36</sup>                      Iterative: Ideas and solutions are continually tested and evaluated with the participants. Changes and adaptations are a natural part of the process, trialling possibilities and insights as they emerge, taking risks and allowing for failure. This process is also used to fine-tune potential outcomes or solutions as it reaches fruition and can later be used to evaluate its effectiveness.<sup>35</sup>                      Co-created: Participants commit to learning from each other Purposeful. Co-design works towards real outcomes that are meaningful to all participants.<sup>37</sup></p>
<p><b>Respect:</b> Acknowledge and value the views, experiences and diversity of consumers, families and staff.</p>	<p><b>Design together:</b> Consumers, families, and staff work together to design, implement, and evaluate improvements, activities, products and services.</p>



**Figure 2.** Publication distribution by year ( $n = 77$ ).

Additional groups of service management teams ( $n = 7$ ), pharmacists ( $n = 4$ ), allied healthcare ( $n = 2$ ) and community and/or public participants ( $n = 2$ ) were also identified in some studies (Table 3).

**Service provider.** The studies included a range of service providers. Most studies reported on services delivered by primary care providers ( $n = 31$ ) such as general (GP) medical practices, out-of-hours GP co-operatives, national service provider, primary care trust, clinics and hospitals. Twenty studies examined out-of-hours services delivered by hospice and/or palliative care specialists either independently or as an integrated service. There were 12 studies that included services provided by the emergency department. The pre-hospital emergency team, emergency medical team, paramedic, rapid-response team and ambulance team were also responsible for delivering out-of-hours services in the community. Across all of these studies, emergency departments worked in collaboration with the palliative care or hospice and/or palliative care unit or primary care service providers. Five studies reported the community home care as the main setting to access palliative care service during out-of-hours. Four services were provided from the hospital and two services were provided by the community pharmacy (Table 3).

**Type of service delivered.** There was a range of services delivered, with many providers delivering more than one 'type' of service to patients out-of-hours. Telehealth consultation (including telephone helplines/advice line services) was the most common type of service reported followed by Specialist Palliative Care services and various types of home visit services. The least reported services that have been the subject of research were services about out-of-hours clinical pharmacist and medication delivery as well as dedicated out-of-hours palliative care services that specifically for community based care (Table 4).

**Recommendations for further research.** The majority of the studies include recommendations for further research to be conducted into out-of-hours palliative care services and pointed to the need to prioritise end-user preferences within different service contexts. This includes investigation on end-users perspectives, preferences and partnership models to optimise the delivery of personalised out-of-hours services. Future work could also involve out-of-hours interventions on service outcomes by different healthcare providers. Other recommendations included the out-of-hours planning on care coordination and application of telehealth. Additional studies on cost benefit of services provided to different types of patients and care for wider range of terminal conditions were also proposed.

**Use of a co-design approach.** From the 77 reviewed studies, none clearly identified or described the application of a co-design principle. However, there were 10 studies that reported the involvement of patients, families and/or carers in addressing out-of-hours service issues. There was evidence that these studies had, to some degree, embedded at least one of the five principles of co-design (Table 2) at some stage of the research process. Only two studies reflected all five principles. 'Design Together' appeared to be the principle most applied by the studies identified. Other co-design principles to feature more commonly were 'Respect', 'Openness' followed by 'Equal Partnership' and 'Empathy' (Supplemental Appendix 2).

## Discussion

This review aims to systematically search and review the research literature that reports on how out-of-hours palliative care services are provided in the community and to identify the extent to which the principles of co-design have been used to inform the planning and design of these services.

**Table 3.** The characteristics and findings of included articles (n=77).

Author Year	Country	Service provider & Setting	Method/ Design	Aims	Sample	Relevant Findings
Adam et al (2014) (86)	Scotland	Grampian Medical Emergency Department Primary Care OOH Service	Retrospective study	Explore the reasons for contact & the range & prevalence of presenting symptoms in patients who presented to a primary care OOH department.	950 Case records of cancer patients who contacted OOH for general service.	OOH primary medical care was contacted for poor pain control.
Adam et al (2015) (87)	Scotland	Grampian Medical Emergency Department Primary Care OOH Service	Qualitative	Explore patients & their caregiver's experiences with OOH primary care on cancer pain management.	11 Cancer Patients & their 4 caregivers.	Effective daytime & anticipatory care can positively influence OOH care.
Akram, et al (2017)(43)	Scotland	The Isle of Skye Primary-community pharmacies	Qualitative	Describe the experiences of developing & delivering palliative care pharmacies service in a remote & rural area.	Stakeholders consist of 1 patient, 1 carer, & 8 healthcare professionals.	24/7 palliative care pharmacist & medication access in rural area is crucial.
Ali, et al (2013)(85)	Scotland	Grampian Medical Emergency Department Primary care OOH Service	Retrospective study	Hospice at home service on people dying in their preferred place, & carer quality of life, compared to usual care.	401 Cancer patients.	Structured palliative care plan can aid decision making in an OOH period & prevent unplanned hospital admission.
Asprey, et al (2013)(7)	United Kingdom	Primary care organisations NHS Devon & NHS Plymouth.	Qualitative	Design & implementation of handover forms to support information transfer between daytime & OOH primary care services.	8 palliative care patients with carers & 30 healthcare professionals.	Modification on OOH primary care handover forms to support palliative care patient.
Baird-Bower, et al (2016)(93)	Australia	Statewide Tasmania Hospice@ Home	Retrospective study	Evaluate the use of a state-wide OOH palliative care support telephone service.	146 Patients who engaged with OOH service.	24-hour palliative care telephone support is a valuable tool for providers to support end-of-life patients.
Brettel, et al (2018)(44)	United Kingdom	Oxfordshire Out-of-hours primary care services	Retrospective cohort study	Establish the proportion of patients who were seen by the OOH service within the last 30 days of life.	102,877 OOH primary care service contacts made by 67, 943 palliative patients & patients dying within 30 days over a year.	Most patients at the end-of-life are not documented as palliative by OOH services & are less likely to receive ongoing care at home.
Brettel, et al (2019)(45)	United Kingdom	Oxfordshire Out-of-hours primary care services	Retrospective cohort study	Examine the volume & type of prescriptions issued by OOH services at the end of life.	102,876 OOH primary care service contacts made 67942 palliative & non-palliative patients.	Prescribing rates are low in the 30 days prior to death.
Burnod, et al (2012) (110)	France	Hospital Emergency Department, North Paris	Retrospective study	Evaluate if patient's wishes were respected by prehospital emergency medical teams after implementing collaboration & a standardized process between a community-based palliative network & the Emergency Medical Service (EMS) system.	40 palliative care patients.	Collaboration between prehospital emergency medical teams & community-based palliative care networks seem to enable a better respect of the care plan in the event of emergency affecting patient in palliative.
Carlebach & Shucksmith (2010)(46)	United Kingdom	Primary Care Trust in the Northeast of England.	Qualitative	Evaluation of an out-of-hours service on the use of a telephone support service, backed up domiciliary visits by specialist palliative care nurses.	27 participants: 6 palliative care patients, 8 Carers, 13 healthcare professionals & 1 service users.	Staff, patients & carers appreciative, felt supported & confident to contact 24-telephone service.
Carron, et al (2014) (114)	Switzerland	Prehospital Emergency services, Lausanne in the State of Vaud	Retrospective study	To understand & evaluate cases of palliative care situations that were managed by prehospital emergency physicians (EPs).	1586 cases of palliative care situations that were managed by prehospital emergency physician in last 8 months.	EPs commonly encountered patients & families who faced sudden worsening of condition, exacerbated by lack of resources & care distress.
Carter, et al (2019)(98)	Canada	Nova Scotia & Prince Edward Island	Prospective, cross-sectional & Qualitative	Determine the impact of Emergency Medical Service program.	255 Palliative care patient/family survey & 1,255 Paramedics	Patients & families are satisfied with the service. Paramedics strongly agreed that palliative care should be integrated into their practice.
De bock, et al (2011) (79)	Netherlands	Groningen Primary care	Retrospective & Qualitative	1) Investigate frequency of information transferred to patients receiving palliative care, 2) Explore the perceptions of GP's on this information transfer & study the relation between information transfer & the used GP information systems.	9 GPs	There were only few palliative patients who contacted OOH services, have their transfer information available. Large variation in the opinions of GPs on how to manage continuity of care.

(Continued)



Table 3. (Continued)

Author Year	Country	Service provider & Setting	Method/ Design	Aims	Sample	Relevant Findings
De Korte-Verhoef, et al (2012)(78)	Netherlands	Primary care, Amsterdam	Retrospective study	To explore hospital referrals of palliative care patients for whom an out-of-hours GP was called.	529 records of palliative care patients call record from OOH GP co-operatives.	Palliative patients who received professional nursing care & had documents transferred to OOH GP cooperative have lower changes of being referred to the hospital.
Dent, et al (2020)(47)	United Kingdom	Hospice & Ambulance service Northwest London	Retrospective study	Evaluate outcomes of ambulance call to 24-hour hospice nursing telephone advice service.	Data records of 44 patients who were attended by the ambulance service clinicians.	Telephone advice service to support ambulance clinicians attending palliative care needs was feasible & acceptable.
Dhilliwal & Muckaden (2015)(406)	India	Specialist Palliative homecare Mumbai Tata Memorial Hospital	Prospective non-randomised observational study	Assess the impact of specialist home-based palliative care services.	690 registered palliative care patients.	Specialist home-based palliative care improved symptoms control, health related communication & psychosocial support.
Dhilliwal & Salins (2015) (107)	India	Specialist Palliative homecare Mumbai Tata Memorial Hospital	Case studies	Describe Smartphone Applications in Palliative Homecare.	Patients & their families in palliative care.	Smartphones applications through video consultation, phone call & sending text messages provide cost effective approach, timely & continued palliative care input.
Dore & Willis (2018)(48)	United Kingdom	Shropshire Doctors Co-operative in Shropshire, Telford, Wrekin, & Pows	Cross-sectional study	Defining general practitioners' OOH workload & patients' demographics, symptomology, & interventions.	Attending OOH GPs attending 161 palliative patients in 1 year.	OOH GPs deal with a wide variety of scenarios in heterogeneous populations.
Fauli, et al (2013)(49)	United Kingdom	Primary care & Community Health Leicestershire, Leicester & Rutland	Qualitative	Explored the challenges encountered by practitioners in management of anticipatory medication for terminally ill patients who wish to die at home.	54 Healthcare professionals providing care for people who wished to die at home.	Service providers found that working across different services during "usual" hours & OOH can be unstable.
Fergus, et al (2010)(80)	Scotland	Levenmouth Primary care & Specialist Palliative care.	Mixed-methods	Identify key challenges & improvements to out-of-hours palliative care in a mixed urban & rural deprived area.	7 Palliative care patients with carers. 27 Health professionals.	The access to OOH services were perceived or presented with actual difficulties by palliative care patients with complex needs.
Finucane, et al (2020) (81)	Scotland	Primary care GP practice	Retrospective & Qualitative	Estimate the proportion of people with an advanced progressive illness with a Key Information Summary (KIS) by the time of death, to examine when planning information is documented, & suggest improvements for electronic care coordination systems.	17 GPs & 2 Nurses from 18 general practices.	Most people with advanced progressive illness had a KIS & KIS are being commenced earlier. Up-to-date free-text information, informal carer information, regular updating, & a focus on generating a KIS for people with organ failure is require.
Firth, et al (2019)(50)	United Kingdom	Specialist Palliative Care unit	Qualitative	Identify the core components that characterise & differentiate existing models of specialist palliative care in the United Kingdom.	Specialist palliative care stakeholders.	OOH care is one of the criteria in the models of specialist palliative care.
Fisher, et al (2016)(51)	United Kingdom	Oxfordshire Out-of-hours primary care services	Descriptive study	Describe patterns of usage of patients presenting to an OOH service & coded as 'palliative'.	495 931 contacts to OOH primary care services.	OOH service is used predominantly during weekend daytime periods & over a third had more than one contact.
Flarup, et al (2014)(103)	Denmark	Primary care Central Denmark region	Cohort Study	Analyse the 30-day prognosis after OOH contact for patients with one of five selected chronic diseases.	11897 adult's data from OOH contacts survey	Increased demands for OOH service for patients with chronic disease & with short-term prognosis.
Flarup, et al (2014) (105)	Denmark	Primary care Central Denmark region	Cohort Study	Analyse association between OOH contacts due to chronic disease exacerbation & recent use of daytime GP.	Data of 21457 randomly sampled patients who contacted OOH services	Patients with severe chronic illness tend to use GP services more.
Flarup, et al (2014)(102)	Denmark	Primary care, Central Denmark Region	Cross-sectional study	Described contacts to OOH services from chronic patients in terms of reason for encounter, OOH diagnosis, assessed severity of symptoms & GP action.	Data of 15229 contacts to the OOH services	Patients with chronic disease were often managed by OOH GPs whereas other patients were not.

(Continued)

**Table 3. (Continued)**

Author Year	Country	Service provider & Setting	Method/ Design	Aims	Sample	Relevant Findings
Gage, et al (2015)(52)	United Kingdom	Hospice Rapid Response Southeast England	Randomised stepped wedge design	1. Compare the characteristics of users of the rapid response service (RRS) with those of people that did not use it.2. Explore differences between users & non-users in the proportions of patients dying in the place of their choice. 3. Monitor the overall service utilisation of users & nonusers & compare costs.	1704 newly referred patients during 18 months of study period.	Use of rapid response service was associated with increased likelihood of dying in the preferred place. Chances of dying in the preferred place were enhanced 2.1 times by being a RRS user, compared to a non-user. The RRS is cost neutral.
Gagnon, et al (2019)(101)	Canada	Family health clinics in Ontario & the Eastern regions of Quebec	Cross-sectional survey	Explore the extent to which family health clinics in Ontario & the eastern regions of the province of Quebec provide palliative care.	Family health clinics with patient enrolment model.	Family health clinics provided OOH palliative care support which include telephone call&home visits.
Grindrod & Rumbold (2018)(95)	Australia	Community located in the Dandenong Ranges of Victoria	Multiple methods	Outlines a comprehensive community development project that identifies local end of life needs & meets them through the efficient use of community resources.	8 local leaders, 6 community development workers & 6 carers, 16 attending community meetings.	Individual skills, community capacity & network are resources to assist patient & family in times of illness, dying, death & bereavement.
Hall, et al (2012)(82)	Scotland	Grampian Primary care	Qualitative	1. Identify key issues related to the introduction of Electronic Palliative Care Summary (ePCS) from primary care & OOH staff.2. Identify facilitators & barriers to their use.3. Explore the experiences of patients & carers & to make recommendations for improvements.	2 palliative patients, 4 carers & 16 primary care & OOH healthcare professionals.	ePCS allows staff to make better informed in decision making, in carrying out home visits & structuring advance care planning. Implementation issues & technical problems are ePCS barriers.
Hoexum, et al (2012) (71)	Netherlands	Primary care	Cross-sectional study	Determine to which level GPs are available OOH for their own terminally ill patients & to elicit what factors are relevant to this availability.	327 GPs	GPs OOH care availability for terminally ill patients correlates most strongly with the GPs' perception of duties of care.
Holdsworth, et al (2015) (53)	United Kingdom	Hospice Rapid Response Southeast England	Quasi-experimental multi-centred controlled evaluation	Assess the impact of a rapid response hospice at home service on people dying in their preferred place & carer quality of life, compared to usual care.	64 Family carers.	Rapid response hospice service did not have a significant impact on helping patients to die where they wanted in an area already well served by community palliative care. Improved mental health component for carer receiving the service.
Jiang, et al (2012)(92)	United States of America	Western Pennsylvania local hospice & palliative care organization	Retrospective study	Examines the timing of out-of-hours telephone triage services, the reasons & nursing interventions offered.	4434 out-of-hours triage calls records from approximately 3500 patients.	Highest calls on the weekends with symptoms management issue. Nursing OOH interventions assist continuation of care.
Johnston, et al (2011) (54)	United Kingdom	Palliative care	Qualitative	Evaluate current use of Telehealth applications within palliative care & future applications	8 Stakeholder 22 Palliative care patients & carers.	Telehealth technology appears usable & acceptable by patients, families & healthcare professionals in palliative care setting.
Kaasalainen, et al (2014)(100)	Canada	Rural Ontario community care	Exploratory descriptive	Explore nurses' experiences of providing palliative care in rural communities, with a particular focus on the impact of the physical residential setting.	24 rural nurses	Unique experiences of nurses providing OOH palliative care to patient & carers in rural communities.
Kao, et al (2018)(108)	Taiwan	Emergency Department Southern Taiwan	Case-control	Investigate the factors for emergency department use during out-of-hours periods.	468 medical records of advanced cancer patients.	Patients with distressing conditions were significantly more likely to use emergency services during OOH.
Keall & Lovell (2020) (96)	Australia	Community palliative care	Retrospective	Evaluate the efficacy of a pilot extended hours palliative care service (EHPCS).	992 calls record in 6-month period by 747 callers.	EHPCS can positively impact on reducing avoidable hospitalisations & facilitate palliative care patients to be in their preferred place of care.

(Continued)

Table 3. (Continued)

Author Year	Country	Service provider & Setting	Method/ Design	Aims	Sample	Relevant Findings
Kiely, et al (2013)(115)	Ireland	Primary care Southwest of Ireland	Cross-sectional	Assess views of GPs on the importance of developing a formalised method of information transfer to the OOH GP co-operative regarding palliative care patients.	414 GPs	Structured format for information transfer is deemed important by GPs when working OOH.
Kjellstadli, et al (2020) (112)	Norway	Primary care	Retrospective cohort	Investigate patients' contacts with GPs, GPs interdisciplinary collaboration, OOH services & hospitalizations.	80813 deceased people records within 2012-2013.	GP home visits & interdisciplinary collaboration increased likelihood for people to die at home.
Kuruville, et al (2018)(8)	Australia	Regional Australian Palliative care service	Qualitative	Identify perceived gaps & challenges to medication management within community palliative care (CPC) & assess stakeholder opinion.	12 Healthcare professionals 8 Consumer Groups.	Identified gaps & limitations in community-based palliative care. An appropriately qualified & skilled pharmacist within the palliative care team may help to address some of the gaps.
Lamba, et al (2013)(88)	United States of America	Emergency Department	Case studies	1. review four case scenarios that relate to palliative care.2. provide a road map to start an EMS.	Emergency Medical Service providers.	Identified 4 elements of practice to initiate start an EMS-palliative care & the domains related to palliative care in the out-of-hospital settings.
Lancaster, et al (2018) (55)	United Kingdom	Specialist Palliative care London	Quantitative	Assess commissioning of palliative & end-of-life care services by Clinical Commissioning Groups.	209 Clinical Commissioning Groups Services.	There is variation in service provision in out-of-hours support by the specialist palliative care team.
Latter, et al (2020) (69)	United Kingdom	Nationwide Primary care, Specialist palliative care & Community Care	Quantitative	Evaluate community-based health professionals' medicine access, practice, perceived effectiveness & influencing factors.	307 Healthcare professionals.	All healthcare professionals are engaged in supporting access to prescriptions using different methods.
Latham & Nyatanga (2018)(56)	United Kingdom	West Midlands 13 hospices	Interpretive phenomenology	Explore the lived experiences of clinical nurse specialists as independent prescribers with palliative care patients in the community.	10 Clinical nurse specialists.	Independent prescribing by community nurse specialists improved access of medication during OOH.
Leydon, et al (2013)(57)	United Kingdom	General Practices and 3 Hospices in Southern England	Longitudinal prospective	Understand the experiences of palliative care patients when accessing or making decisions about OOH services.	20 Patients with carers/families.	Interpersonal relationship & management continuity are important to optimise patient experience in OOH.
Lin, et al (2020) (109)	Taiwan	Taipei Veteran General Hospital, Palliative Care unit	Quantitative Retrospective	Evaluate the implementation of personalized discharged end-of-life care plan.	Not described	There were decreased number of calls from patients who were discharged.
Mason, et al (2015)(84)	Scotland	Nationwide Primary Care	Mixed-methods	Understand the impact of Palliative Care Directed Enhanced Service (DES).	Completed data form by practice manager & GP from 512 practices.	DES helped more patients with long-term conditions to receive generalist palliative care.
Mason, et al (2020) (70)	United Kingdom	Nationwide Primary Care	Retrospective	Analyse patterns of use & costs of unscheduled National Health Service (NHS) services for people in the last year of life.	56 407 people who died in Scotland in 2016 aged 18 or older.	Over 90% of people used NHS unscheduled care in their last year of life. The cost of providing services in the community was estimated at 3.9% of total unscheduled care costs.
Mayahara & Fogg (2020)(91)	United States of America	Hospice Midwest	Descriptive retrospective	1. Identify factors that contribute to potentially avoidable OOH calls.2. Examine the differences between patient care teams in utilizing OOH calls.	1596 OOH calls from 339 patients/ daily census.	OOH calls may be avoidable if issues can be appropriately addressed during regular daytime hours. There were significant differences between the numbers of calls received by patient care teams.
Milton, Grady & Cook (2012)(83)	Scotland	Prince & Princess of Wales Hospice	Mixed-methods	Examine the need for a 7-day community clinical nurse specialist (CNS) service.	3 Patients & 14 families & 6 CNS team.	There is a need for 7-day/week service which benefited patients, families & valued by professional team.

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**Table 3. (Continued)**

Author Year	Country	Service provider & Setting	Method/ Design	Aims	Sample	Relevant Findings
Norøxe, et al (2017) (104)	Denmark	Nationwide Primary care	Cross sectional study	1. Assess frequency & the characteristics of "medically inappropriate" OOH-palliative care calls performed by adult patients, 2. Identify factors associated with contacts assessed by GPs as medically inappropriate, 3. Examine the patient assessed problem severity & the fulfilment of expectations in relation to the GP-assessed medical inappropriateness of the contact.	1733 Patients & 5333 GPs.	Potential of optimising OOH-palliative care utilisation as one in four calls was considered medically inappropriate which related to unfulfilled patient expectations. Factors associated with younger age, longer symptom duration, exacerbation of chronic condition & length of contact during office hours.
O'Brien & Jack (2010) (58)	United Kingdom	Community care & Specialist Palliative Care Northwest of England	Qualitative	Explore the views of community nurses regarding end-of-life care & the place of death for patients with cancer.	19 district nurses & specialist palliative care nurses.	Inadequate OOH medical provision was a factor contributing to hospital admissions for terminally ill patients.
Plat, et al (2018)(77)	Netherlands	Netherlands GP Primary care	Cross-sectional observational study	Examine the availability, perceived problems & attitude of GPs providing palliative care for their own patients in OOH.	1722 GPs with an own daytime general practice.	GPs are personally available for telephone consultation and/or willing to provide palliative care during OOH.
Plummer & Allan (2011)(67)	United Kingdom	Mount Vernon Hospital	Mixed-methods	Evaluation of 24-hour telephone advice line.	456 calls with 196 callers.	Advice line is providing a highly valued service, with calls being managed by experienced nurses.
Purdy, et al (2015)(59)	United Kingdom	Emergency Department North Somerset & Somerset	Retrospective Cohort	Investigate the impact of Delivering Choice Programme on place of death & hospital usage.	3594 palliative patients who died over 6-month period.	Recipients of the programme were less likely to die in or use hospital services.
Richards, et al (2011)(9)	United Kingdom	Primary Care Trusts Plymouth & South Hams & West Devon	Qualitative	Explore the experiences & decision-making of advanced cancer patients & their caregivers when accessing primary OOH care.	28 advanced cancer patients and/or their caregivers.	Advanced cancer patients & their families require support & assurance when assessing OOH service.
Savage, et al (2013)(60)	United Kingdom	3 Primary Care Trust	Qualitative	Explore & describe community pharmacists' current & potential place in the cancer pain pathway.	25 Pharmacists	There is significant scope for improving access to & interaction with community pharmacists by people with cancer pain & their families.
Schweitzer, et al (2011) (76)	Netherlands	Primary care in rural & urban areas	Qualitative	Investigate the experiences of GPs on the quality of OOH palliative care provided by GP co-operatives & elements of care that might need to be improved.	20 GPs	There are concerns about the quality of palliative care as provided by the GP co-operatives.
Schweitzer, et al (2016) (75)	Netherlands	Amsterdam GP cooperatives	Controlled trial	Evaluate the effect of the implementation of an information handover form.	426 GPs	Introduction of a handover form resulted in a moderate increase of information transfers to the GP co-operative.
Seow, et al (2020)(97)	Canada	Community Palliative care in Ontario	Qualitative	Explore similarities in care practices among effective & diverse specialist teams to inform the development of other community-based teams.	78 Specialist palliative care teams.	Despite wide variation in models of care among community-based specialist palliative care teams, this large qualitative study identified several common themes in care practices that can guide the development of other teams.
Smits, et al (2015)(74)	Netherlands	GP Clinics	Cross sectional observational study	Examine which aspects of the organisation of daytime primary care are related to the use of OOH GP cooperatives.	100 GPs who were connected to 5 OOH GPs cooperatives.	Accessibility & availability for palliative care patients in daily practice were associated with the use of OOH care.
Stern, et al (2012)(99)	Canada	Hospital community based palliative care service	Randomised Controlled Trial & Qualitative	Explore family caregivers & palliative patients' patterns of use, perceptions of, & experiences with home telehealth.	11 Palliative oncology patients 12 caregivers, Multidisciplinary healthcare professionals.	Importance of timely & accessible care for a group of clinically vulnerable, dying cancer patients & their family.

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Table 3. (Continued)

Author Year	Country	Service provider & Setting	Method/ Design	Aims	Sample	Relevant Findings
Swetenham, et al (2014)(94)	Australia	Emergency Department & Specialist Palliative care Metropolitan area of Adelaide	Mixed Method	To examine the effectiveness of the partnership model to meet the expectations of the patients & the carers & the expectations of the clinicians.	26 Patients with Caregivers 26 Extended care paramedics	Partnership model has enabled out-of-hours service to be provided between specialist palliative care & ambulance service.
Taubert & Nelson (2010) (61)	United Kingdom	Cardiff OOH Service	Qualitative	Explore OOH GPs on how they feel about palliative care situations & what affects their confidence.	9 GPs worked in the OOH setting for at least 1 year, seen palliative care patient.	GPs felt sense of isolation when working during OOH & less inclined to contact specialist palliative care.
Taubert & Nelson (2010)(62)	United Kingdom	Primary care Cardiff	Qualitative	Explore factors that GPs identified as detrimental or beneficial for good communication in palliative care.	9 GPs	OOH services need to be mindful of the needs of the GPs they employ, relating to the palliative care they provide in this setting.
Taubert, Robert & Nelson (2011)(63)	United Kingdom	Cardiff OOH service	Qualitative	Determine aspects of care provision that augmented or challenged palliative care delivery from the perspective of GPs providing OOH care.	9 GPs	OOH GPs identified several areas perceived as burdensome in the provision of palliative care.
van Gorp, et al (2013) (72)	Netherlands	Hospital - based Expertise Center for Palliative Care	Qualitative	Describing elements of both physical workplace & the cultural-social context of the palliative care practice, which are imperative to implementing a teleconsultation technology.	8 Staff/ palliative care professionals.	Professionals assume teleconsultation co-defines a new patient-professional relationship by extending hospital-based caregivers' perceptions of as well as attention for their patients.
van Gorp, et al (2016) (73)	Netherlands	Home based Palliative care	Qualitative	To describe: 1. Whether & how teleconsultation supports the integration of primary care, specialist palliative care & patient perspectives & services. 2. How patients & informal caregivers experience collaboration in a teleconsultation approach.	18 home-based palliative care patients 17 primary care physicians, 12 specialist palliative care clinicians.	Teleconsultation has the potential to facilitate interdisciplinary care-stimulated the integration of primary care & specialist palliative care.
Waldrop, et al (2015) (89)	United States of America	Emergency Department New York	Cross-sectional survey.	Explore frequencies of different types of end-of life calls, signs & symptoms of dying in prehospital care, & Medical Orders for Life Sustaining Treatment.	76 Emergency medical Technicians basic 102 Emergency medical Technician Paramedics.	Synergy exists between the fields of prehospital, hospice, & palliative medicine which offers potential for improvement education & care.
Walker & McPherson (2010)(90)	United States of America	Maryland Hospices	Comparison study	Compare perceptions of hospice managers & clinicians regarding the value of emergency medical kit (EMK) & to assess outcomes.	21 hospice manager & clinicians.	EMK is perceived to be valuable in areas of quality, cost & service satisfaction.
Ward, et al (2021) (68)	United Kingdom	Hospice in the South England	Qualitative	To establish how a nurse lead night service supported patients & family carers to remain at home & avoid hospital admissions.	38 family carers 9 hospice-at-home staff	Family carers felt supported by specialist hospice staff.
Weinman, et al (2020) (113)	Sweden	Community home care Gothenburg	Exploratory- Interview	Explore the experiences of receiving advanced home care among patients affected by life-threatening illness & their close relatives.	19 Patients & their families.	Patients & families perceived that advanced home care was a safe & secure form of caring during advanced & end-of-life care.

(Continued)

**Table 3. (Continued)**

Author Year	Country	Service provider & Setting	Method/ Design	Aims	Sample	Relevant Findings
Wiese Christoph, et al (2010)(411)	Germany	Emergency Medical Care services	Retrospective investigation & Prospective study	Investigation on the strategic & therapeutic approach by Emergency Medical Teams for palliative care patients in cardiac arrest.	88 palliative care patients in cardiac arrest records.	Strategic & therapeutic approaches in outpatient palliative care patients with cardiac arrest differ depending on medical qualification.
Williams, et al (2019) (64)	United Kingdom	National Primary care	Cross-sectional analysis	Explore the nature & causes of unsafe care delivered to patients receiving palliative care from primary-care services outside normal working hours.	1072 patient safety incident reports.	There are actual & potential harms occurring to patients requiring palliative care in OOH setting.
Wilson, et al (2015)(65)	United Kingdom	Community home care & Specialist Palliative Care Lancaster & South Cumbria & Midlands	Ethnographic study	Examine nurses' decisions, aims & concerns when using anticipatory medications.	61 registered nurses who is providing end-of-life care at the study site.	Nurses take a leading role in the administration of anticipatory medications but some experience emotional burden.
Wye, et al (2016)(66)	United Kingdom	Community home care Somerset & North Somerset	Mixed-method	Explore the relationship between EPaCCS. (Electronic palliative care coordinating systems) & home deaths.	101 professionals who used EPaCCS.	EPaCCS was predominantly used by community staff who care for patients at home.
Yamagishi, et al (2012) (116)	Japan	Primary care Hamamatsu, Kashiwa, Tsuruoka & Nagasaki	Cross-Sectional	To clarify: 1. Clinical exposure of GPs & District Nurses to cancer patients dying at home, 2. Availability of symptom control procedures, 3. Willingness to participate in out-of-hours cooperation & palliative care consultation services, 4. Reasons for admission of terminally ill cancer patients.	1106 of General practitioners & 70 District nurses.	Compared to GPs, district nurses had more experience caring for cancer patients dying at home. Oral opioids, subcutaneous opioids, & haloperidol were unavailable in most GP clinics, whereas majority of the district nursing services had access to them. GPs & DNs were willing to use community palliative care consultation services if available. Common reasons for admission to hospital were the family burden of caregiving & uncontrolled symptoms.

Abbreviations: \*OOH=out-of-hours, \*GPs=General Practitioners

**Table 4.** Types of service delivered.

Types of service	n (%)
Telehealth including telephone consultation <sup>8,43,47,48,60,69,70,74,86,90,102–107,109</sup>	17 (22.1)
Specialist Palliative Care Service <sup>47,48,68,69,74,80,86,94,102–107,109,110</sup>	16 (20.8)
Home visit <sup>44,48,74,77,83,91,92,99,100,102–106,112</sup>	15 (19.5)
Triage Service (deliver via telephone or face-to-face) <sup>47,71,74,86,91–93,102–105</sup>	11 (14.3)
Domiciliary Service <sup>46,47,68,71,74,86,91–93,104</sup>	10 (13.0)
Electronics information sharing systems <sup>47,66,69,81,84,85,92,104,115</sup>	9 (11.7)
Clinical consultation <sup>69,74,89,92,102–105</sup>	9 (11.7)
Dedicated out-of-hours emergency service <sup>52,88,89,94,98,110,111,114</sup>	8 (10.4)
Clinical Pharmacist & Medication Service <sup>8,43,48,60,69,90</sup>	6 (7.8)
Dedicated Out-of-hours Palliative Care Community Service <sup>59,83,113</sup>	3 (3.9)

### *Out-of-hours palliative care services in the community*

The research was predominately retrospective and cross-sectional, drawing on data collected by the services themselves. A majority of the reported studies originated from the United Kingdom and western European countries.

Over the study period, there was a decline of research outputs that focussed on out-of-hours care. Given that out-of-hours service is a component a 24/7 model of care, research effort may have been directed to improving the planning and management of service links with in-patient care and coordination of shared services in the community.<sup>70,117,118</sup>

In general, primary care services (primarily those provided by General Practitioners) was observed to be the predominant mechanism to access out-of-hours palliative care services. Nurses, palliative care specialists, pharmacists and increasingly, the emergency care team and other allied healthcare workers also actively contribute, though some groups appear to be reported less frequently in the research literature. Increased consumer demand and, a broader acceptance of a palliative approach to the care indicates that out-of-hours care is provided by a broader team of health care professionals and other care providers.<sup>119,120</sup> This suggests that more research into multidisciplinary care, including that delivered in collaboration with families and caregivers with may be warranted.

The relative proportion of out-of-hours palliative care research conducted into primary care, specialist palliative care and Emergency Department services point to the research interest and importance of each area to out-of-hours service provision. Whilst some specialist services have been designed to address specific needs of out-of-hours care,<sup>52,59,83,113</sup> primary care services clearly play a major and critical role in coordinating with secondary and tertiary care agencies to ensure continuity of care.

There was range of services provided during out-of-hours. This included home visits, outpatient face-to-face

consultation and telephone and/or telehealth consultation. This suggests that interprofessional collaboration and coordination is an important component of effective out-of-hours care in the community.<sup>80,97,121</sup> According to the WHO,<sup>122</sup> in order for services to deliver the highest quality of care across health system, a workforce drawn from different professions that can work together with patients, carers and communities is required. In taking this approach, out-of-hours service providers have the potential to expand the availability of palliative care services, prevent service duplication and reduce the burden on carers during out-of-hours.

In many reports, whilst there was an implicit recognition of the importance of incorporating end-user's priorities and preferences, only a few studies demonstrated collaboration with patients, their families, and carers.

### *Co-design principles*

For this review, we drew upon the co-design principles established by the ACI.<sup>16</sup> These included: equal partnership, openness, mutual respect, empathy, and the concept of design together, where in this context, patients and families work in partnership with providers to improve out-of-hours palliative care services. Whilst not an exhaustive list, these principles were quite broad and had much in common with those used internationally.

For most studies, the involvement of patients and families in out-of-hours palliative care service planning is low and was difficult to assess. If it did occur, such engagement was not often made explicit. There were only a few studies that reported how service planners had positioned themselves to engage with patients and families to inform and improve out-of-hours services using a co-design process. This was, perhaps, not surprising, given the time-limited nature of the services provided to a palliative patient. Patients who have limited life expectancy may only be able to provide input to service planning at a single point of time rather than making an ongoing contribution.

Furthermore, it can be more challenging to engage patients who are receiving care if they are geographically dispersed and if these services are not well integrated.<sup>123</sup> Service planners may also be concerned about patients' and families' knowledge of services and may feel they have sufficient information about a patient's needs through regular contact with care providers<sup>124,125</sup> and may also source data collected through other mechanisms such as advance care plans and directives. Studies have also found that there is a lack of resources available to service providers to facilitate co-design activity.<sup>126</sup> Some may hold a negative attitude towards engaging end-users in service planning and design<sup>24,26</sup> and may also exert a gatekeeper effect believing that such engagement causes unnecessary stress to the patient.<sup>124,126</sup>

How palliative care patients and other end-users can be engaged, as partners, in service design process presents a significant challenge and has not been well described in the research literature. Co-design may not be widely reported by the sector because it is resource intensive (and would negatively impact on service delivery), a relatively low priority for those investigating out-of-hours care or, has been embedded in such ways that it has proved difficult to articulate in research reports. As a consequence, there was limited advice on how to apply the principles of co-design to enhance patients and families involvement and measure the outcome of their involvement in research.<sup>127,128</sup>

It should also be recognised that many organisations obtain feedback about the services they provide through mechanisms such as case audits and carer satisfaction surveys administered sometime after a patient has died. Also, palliative care workers are sensitive to their patients' needs and can be protective. Not wishing to burden them or impose an additional stress, they may feel confident in their ability to relate their experiences and authentically convey the wishes of their patients throughout the out-of-hours palliative care planning process.

### *Recommendations for future research*

Co-design and the principles of co-design has been successfully applied across many areas of health care. Since patient, family and other stakeholder hold unique and valuable experiences, future research that explores their experiences may enrich and add value to out-of-hours palliative care services planning. Reporting how and in what capacity end-users are engaged in service planning and design process could be an additional quality indicator for palliative care research in this area.

Further research about the principles of co-design and application of the co-design process in the planning and development of out-of-hours palliative care services in the community is warranted. This would include investigating ways to successfully engage and collaborate with diverse range of key stakeholders, strategies to address

key challenges and barriers to participation and evaluating the impact of end-user involvement on the quality of care and patient outcomes.

### *Strengths and limitations*

Drawing on the research literature, this study outlined how out-of-hours palliative care services are provided across a number of countries, provided a summary of where this research was conducted, when published and the methodologies used. To ensure rigour, the review used established guidelines and adhered to a careful process of review throughout the selection and screening of articles. To our knowledge, this is the first review to identify the extent to which co-design principles have been reported about out-of-hours palliative care services in the research literature.

Study limitations relate to the search strategy and the selection and application of key search terms. Our approach may have excluded studies with components of out-of-hours palliative care services that were not identified. Similarly, in the initial screening of title and abstract of studies found, we may have excluded study that did not focus on out-of-hours services but may have link to services provided during out-of-hours in the community. The search was also limited to research studies in the English language published from January 2010 to December 2021. The grey literature was not searched. Policy documents, government reports, service provider accreditation reports and evaluations were not included though these could prove fertile ground for further investigation of the topic. Additionally, most of the studies reviewed in this study were related to cancer patients. A review targeted to chronic conditions and frailty may uncover additional novel findings.

### **Conclusion**

The review found that out-of-hours palliative care service research does not report a high level of end-user engagement. Whilst challenging, incorporating end-users' priorities and preferences through the application of co-design principles in the planning and designing of out-of-hours palliative care service can help align care to the needs and values prioritised by patients and their families. Service transformation can be augmented through the co-design process by placing end-users' needs and values at centre stage in a respectful and authentic way. Timely engagement of patients and their significant others may contribute to good quality out-of-hours palliative care service design.

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### Ethics approval

Ethics committee approval was not required for this systematic search and review because the study does not involve human subjects.

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### Supplemental material

Supplemental material for this article is available online.

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