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The impact of informational and relational continuity for people with palliative care needs: a mixed methods rapid review

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Abstract

Objective: To identify and synthesize existing literature exploring the impact of relational and informational continuity of care on preferred place of death, hospital admissions and satisfaction for palliative care patients in qualitative, quantitative and mixed methods literature.

Design: A mixed methods rapid review.

Methods: PUBMED, PsychINFO, CINAHL were searched from June 2008 to June 2018 in order to identify original peer reviewed, primary qualitative, quantitative or mixed methods research exploring the impact of continuity of care for people receiving palliative care. Synthesis methods as outlined by the Cochrane Qualitative and Implementation Methods Group were applied to qualitative studies while meta-analyses for quantitative data were planned.

Outcomes: The impact of interventions designed to promote continuity of care for people receiving palliative care on the following outcomes was explored: achieving preferred place of death, satisfaction with care and avoidable hospital admissions.

Results: 18 eligible papers were identified. (11 qualitative, 6 quantitative and 1 mixed methods papers) In all, 1,951 patients and 190 family caregivers were recruited across included studies. Meta-analyses were not possible due to heterogeneity in outcome measures and tools used. Two studies described positive impact on facilitating preferred place of death. Four described a reduction in avoidable hospital admissions. No negative impacts of interventions designed to promote continuity were reported. Patient

satisfaction was not assessed in quantitative studies. Participants described a significant impact on their experiences as a result of the lack of informational and relational continuity.

Conclusions: This rapid review highlights the impact that continuity of care can have on the experiences of patients receiving palliative care. The evidence for the impact of continuity on place of death and hospital admissions is limited. Methods for enhancing, and recording continuity should be considered in the design and development of future health care interventions to support people receiving palliative care.

Strengths and limitations of this study

- This is the first mixed methods rapid review to explore the impact of continuity of care for palliative care patients.
- The inclusion of both qualitative and quantitative data provides rich insights into the experiences of patients and families, although the views of health care providers were not included.
- Only studies written in English and published within the last 10 years were included, which may introduce a risk of bias.
- Half of included studies were conducted in the UK yet experiences associated with both good and poor continuity may transcend national borders.

Introduction

Continuity of care is an important aspect of health care, but is often lacking. Continuity of care can take a range of forms, from continuous relationships with clinicians (relational continuity) to coordinated, comprehensive information sharing (informational continuity) and shared management plans (management continuity) within a range of services or professionals^{1, 2}.

In a review of continuity across multidisciplinary contexts, Haggerty et al (2003) argue that continuity is experienced by patients as the *“perception that providers know what has happened before, that different providers agree on a management plan, and that a provider who knows them will care for them in the future”*.²

The generation of accumulated knowledge and trust between a health professional and patient achieved through relational continuity³ is valued by both patients⁴ and clinicians⁵. High levels of management and informational continuity contribute to effective and efficient care. On the other hand, the same long term relationships between health care providers and patients may also open the door to collusion⁶ or prevent patients benefitting from the opinions of a fresh pair of eyes⁷.

On balance, evidence suggests continuity is beneficial for a range of populations across a range of outcomes. Lower levels of continuity have been associated with higher emergency department utilization throughout the life span^{8, 9}. Continuity has also been associated with patient satisfaction¹⁰, fewer hospital

admissions ^{11, 12} and improved care for long term conditions such as diabetes ¹³. Compelling evidence for the promotion of relational continuity was provided in a recent systematic review which highlighted a relationship between increased continuity and lower mortality rates ¹⁴. In response, international policies and charters call for the promotion of continuity within health care services ¹⁵⁻¹⁷.

However, the challenges to ensuring continuity are many and multifaceted. Within health care services that face growing demands and reducing resources, promoting and achieving continuity of care can be difficult ¹⁸. The size of medical organisations is growing ¹⁹ and the number of physicians seeing patients on a part time basis is increasing ²⁰. The demands for rapid access to care are hard to balance with the demands for continuity.

Continuity may become increasingly important or valued in a person’s care as they age, develop co-morbid conditions or as their health deteriorates ^{1, 21}. It has been estimated that 69-82% of persons who die in high-income countries would benefit from palliative care ²², a figure which is likely to increase. As the population of many western countries continues to age, the need for greater continuity in services may become more pressing as the impact of the presence or absence of continuity may be more keenly felt towards the end of life.

The number of different professionals and services involved in community palliative care can make continuity of care challenging ²³, yet continuity was identified as one of the top 10 issues identified by the James Lind Alliance Palliative and end of life care Priority Setting Partnership ²⁴.

The literature exploring the impact of continuity in palliative care is relatively young, yet promising. Continuity has been reported to be independently associated with patient ratings of care during cancer treatment ²⁵, while greater involvement of primary care physicians at the end of life is associated with deaths outside of hospital, and receiving home care or hospice support ²⁶. A review of integrated palliative care models across Europe called for greater efforts to enhance continuity ²⁷.

In response, this rapid review aims to identify and synthesize the existing literature, exploring the impact of continuity of care (both relational and informational) on the experiences of palliative care patients and their families

Objectives

1. To identify, from the perspectives of people receiving palliative care and their families, friends or carers the potential impact of continuity (or lack of continuity) on their experiences of care.

2. To explore the impact of interventions designed to promote continuity for people receiving palliative care on achieving preferred place of death, reducing avoidable hospital admissions and satisfaction with care

Methods

The guidelines put forward by PaCERS²⁸ were used to shape this rapid review.

Inclusion criteria for studies

a) Types of participants

Interventions recruiting adults (aged over 18 years) receiving palliative care and/or their family, friends or carers. Participants at all stages of a terminal illness, including the dying phase were included, in line with previous systematic reviews in this area²⁹.

b) Types of studies & outcomes

Original peer reviewed studies published in English within the last 10 years (June 2008 – June 2018) presenting primary qualitative, quantitative or mixed methods interventions exploring the impact of continuity in palliative care were eligible for inclusion.

Specifically:

- Qualitative studies collecting information about the experience of continuity for palliative care patients or their families (including bereaved family members). Studies also including the views of health care providers were included if the voices of patients and carers could be separated.
- or
- Prospective interventions designed to promote continuity and explore the impact of this on reducing avoidable hospital admissions, enabling preference for place of death, or patient or carer satisfaction with care. The following methodologies were included randomized controlled trials, non-randomised controlled trials/quasi-experimental trials, and before-after studies.

Retrospective studies, grey literature, reviews, conference abstracts and qualitative studies exploring the perspectives of health care professionals were not eligible for inclusion.

Search method for identification of studies

Electronic searches

The following databases were searched for eligible articles; PUBMED, PsychINFO, CINAHL. Reference lists and forward searches of relevant publications were also screened.

Search terms

Based on previous reviews of the literature on palliative care and continuity^{23,30}, the free text and indexed terms listed in box 1 were used to identify relevant articles.

Box 1. PUBMED search strategy

Palliative care	((terminal* OR (advanced disease) OR palliativ* OR (palliative care) OR (palliative medicine) OR (end of life))
AND Continuity	((continuity) OR (partnership working) OR (collaborat*) OR (communication) OR (shared working) OR (joint working) OR (shared care) OR (extended team))
AND outcomes	((experience) OR (satisfaction) OR (place of death) OR (health care utilisation) OR (appointment*) OR (admission*) OR (hospital admission) OR (readmission) OR (emergency))

Data collection and analysis

Data screening

Studies were screened by one researcher (BH) and eligible studies were checked by a second (BN). Queries over the eligibility of studies were discussed with the research team (SB, BN and BH).

Data extraction

A unique form was developed to capture the following data from each eligible study. Figure 1 outlines the data that was extracted from each study.

INSERT FIGURE 1 HERE

Data analysis

Quality Assessment

To assess the methodological rigor of included studies, a tool developed by Hawker et al³¹ was used.

Quantitative data analysis

Due to the heterogeneity of outcomes, meta-analyses were not possible. A narrative summary of studies was provided.

Qualitative data analysis

Synthesis methods as outlined by the Cochrane Qualitative and Implementation Methods Group were applied and the review was reported according to ENTREQ guidelines (Enhancing transparency in reporting the synthesis of qualitative research)³². Qualitative synthesis involves reinterpretation by considering the findings of multiple studies within an analysis³³, using a three-step process: coding, developing descriptive themes and generating analytical themes³⁴. All data titled findings or results were entered into NVIVO for analysis, in line with previous reviews utilizing qualitative synthesis^{34, 35}.

Patient and public involvement

This review was motivated by the priorities identified in the James Lind Alliance Palliative and end of life care Priority Setting Partnership²⁴, which included the views of patients and the public. No further patient and public involvement was incorporated into this review.

Results

Figure 2 presents a flow diagram of the study selection process. The initial search yielded 339 citations and 18 articles met the inclusion criteria (11 qualitative, 6 quantitative and 1 mixed methods).

INSERT FIGURE 2 HERE

Study characteristics

Half of included studies were conducted in the UK (50%, n=9), 3 were conducted in the USA or Canada, 2 in Australia and 1 each in Iceland, the Netherlands, Sweden and Denmark. Tables 1 and 2 outlines the sample, methodology, components of intervention, types of continuity assessed, outcome measures included and whether the intervention was found to be effective.

Table 1. Summary of reviewed quantitative and mixed methods studies

Quantitative studies

Author	Country	Components of intervention	continuity *		N	Participants	Methodology	Outcomes relevant to review			Outcomes	Main findings	Intervention successful?
			R	I				S	P	H			
								o	d	a			
Mortel (2017)	Australia	Care coordinated by GP registrar who conducted an initial patient	x	x	191 (exp: n=99)	Adults ≥18 years with a terminal	A quasi-experimental design (no pre-	X		x	Hospital admissions per 100 patient-days proportion of	Controls were more likely to have ≥2 admissions than the intervention group (OR 2.67 (95%CI 1.39–5.11); P < 0.003) per	Yes although some significant differences

		assessment, and case conferenced with the medical and nursing teams and the family to develop the care plan. 3-month follow-up (for stable patients) or re-assessed and updated the plan if the patient deteriorated. This service was initially available during business hours, but was extended to after hours as funding became available				nal illnesses	test measures)				deaths at home	100 days. Controls were significantly less likely to die at home than intervention group (OR 0.41 (95%CI 0.20–0.86); P = 0.02)	between control and intervention participants
Inga dotti r (2010)	Iceland	Specialist nurse acts as a coordinator of interdisciplinary collaboration. Visits patients at home for initial assessment. Regular telephone contact. Nurse coordinates multidisciplinary response to acute exacerbations.	x	x	50	COPD patients	Interrupted time series study			x	BMI, capacity to use medications, length of hospitalisation, psychometrics (HRQL, HADS), smoking rate	Hospital admission rate and days spent in hospital because of COPD reduced by 79 and 78%, respectively. The number of days spent in the hospital because of other diseases was not significantly different in T1, T2 and T3	Yes
O'Connor (2016)	Australia	12-month evaluation of nurse practitioner role in palliative care. Aims of nurse practitioner were: To help patients achieve their preferred place of care. Enhance professional	x	x	683 Refereed to service	Palliative care patients	Mixed methods - Qualitative evaluation of nurse led practitioner role And note review (no pre-test data collected)		X	x	How quickly patient seen by NP after referral Decreased unplanned/preventable hospital admissions Place of death Qualitative feedback	Place of death 34 clients died in the evaluation period. Twenty died in their place of choice (59%). Hospital admissions 53 potential presentations to A&E had been averted, with only 9 presentations in the 12 month period,	Yes – fewer hospital admissions for those being cared for at home Outcome measures not clearly reported No comparator so hard to assess impact of intervention

		relationships between services											
		Facilitate timely discharges and admissions between services.											
Montero (2016)	USA	Health care professional education Call back from nurse and appointment with oncologist within 5 days (to discuss symptom management, education, medication review/compliance, and follow up appointment reminders) Mandatory early follow-up appointments with the patient's primary oncology care team help facilitate the transition from the hospital to the outpatient setting.		x	4,551 admissions during study period	Patients referred to palliative and general medical oncology services.	Interrupted time series design			x	readmission rates	During the 11-month post intervention period there was a significant reduction in unplanned 30-day readmissions risk. Unplanned readmission rates declined by 4.5% to 22.9% from baseline. Nurse call-backs improved a patient's capacity for self-care at home and compliance with medication.	Yes
Edwards (2014)	Canada	Generation of a seamless care report – shared with other professionals Rounds with palliative care physicians twice weekly Telephone consultations & point of contact for patients.	X	x	200 (100 in intervention)	Patients receiving chemotherapy	RCT			x	Self-reported health care service utilisation Number and type of drug related problems	Patients in intervention sought additional health care support (hospital admission, A&E) An average of 3.7 DRPs per patient in intervention arm	Not possible to tell from results – only gives % that accessed additional health support eg hospital admission no comparator
Morris (2016)	USA	(CARES): a collaborative consultative PC program Two PC physicians	X	x	170	Care home residents	Pilot intervention study No pretest data		X	x	Services provided Changes to care plans Hospitalization	Seven residents were hospitalized, despite orders for no hospitalization, 5 died in hospital. 96% (54 of 56) of LTC	Not clear No comparison group and preference for place of

		from EVMS under a medical director contract provided consultation A part-time facility-based chaplain provided spiritual & psychosocial support					collected			ns Place of death Hospice sage	residents died with hospice services. Two LTC residents declined hospice services and died in the hospital, which was consistent with their families expressed goals. Among the SNF residents, 36 (43%) of 82 have died: 9 transitioned to hospice services at home, an inpatient hospice unit, or LTC prior to death; 19 died under SNF care and were unable to access their hospice benefit; and 8 others died in the hospital	death not reported.
De graff (2016)	The Netherlands	The Hospice Assist at Home service consists of four components. (1) A GP requested home visit from the hospice nurse consultant (2) Multidisciplinary consultation, once a fortnight, led by a hospice GP and Supported by two HNC. (3) 24/7 hospice care telephone backup (4) one HCP selected by the patient, is responsible for coordination of care	X	x	130	Patients living at home, with a life expectancy of less than 1 year	A cross-sectional evaluation study (no baseline data collected)		x	Expressed end-of-life preferences and the congruence between preferred and actual place of death	If preferred place of death was known, 92/101 (91%) patients died in their preferred place of death.	yes

*Continuity
R = relational
I - Informational

+Outcomes
S – satisfaction with care
poD – place of death
Ha – reducing hospital admissions

Table 2. Summary of reviewed qualitative studies

Author	Country	n	Participants	Methodology	Main findings
Leydon (2013)	UK	32	Patients receiving palliative care	Longitudinal prospective qualitative study	Interpersonal or relationship continuity and management continuity are vital to the process of optimising the patient experience of out of hours palliative care

				using semi-structured interviews and telephone interviews over 6 months – qualitative descriptive approach to analysis	
Seamark (2014)	UK	54	Bereaved family members	Semi structured interviews, thematic analysis	Continuity of care that divided into personal, organisational, and informational continuity. Large numbers and changes in care staff diluted personal continuity and failure of the GPs to visit was viewed negatively. Family carers had low expectations of informational continuity, finding information often did not transfer between secondary and primary care and other care agencies. Organisational continuity when present provided comfort and reassurance, and a sense of control.
Payne (2017)	UK	patients (n = 34), carers (n = 13) and health professionals (n = 23)	Patients, carers and HCPs	Serial interviews with patients and family members (either together or apart) Focus groups with health care professionals (not included in analysis) Thematic analysis and cross case synthesis	While some care fell short of expectations, all patients reported high levels of satisfaction and valued continuity of care and efficient information sharing. All hospices supported and supplemented local providers, with three hospices also supplanting local provision by providing in-patient facilities.
Richards (2011)	UK	28	Patients with advanced cancer and caregivers	Interviews with patients and caregivers. Thematic analysis	Participants reported a lack of relational and informational continuity of care. Consulting with an unfamiliar clinician out-of-hours raised doubts in some participants' minds about the quality of care. While the themes suggest the delivery of out-of-hours care as a whole was not always perfect, around-the-clock access to professional sources of support and reassurance was highly valued. However, the transfer of information to out-of-hours providers remains a key challenge; participants did not understand why out-of-hours providers could not access more information on their medical histories given the level of computerisation within the National Health Service. The findings highlight the need to improve continuity between in-hours and out-of-hours services for patients with complex needs.
Klarare (2017)	Sweden	13	6 patients and 7 family members	Interviews Thematic analysis	Two themes were constructed through thematic analysis: (1) security and (2) continuity of care
Bailey (2016)	UK	109	39 patients (15 with COPD and 24 with lung cancer),	Semi structured interviews, after admission and following discharge Thematic analysis	Patients were satisfied with their 'emergency' care but not the care they received once their initial symptoms had been stabilised. The poorer quality care they experienced was characterised by a lack of attention to their fundamental needs, lack of involvement of the family, poor

			20 informal carers 50 healthcare professionals,		communication about care plans and a lack of continuity between primary and secondary care.
Mclaughlin (2010)	UK	26	Family caregivers of people with Parkinson disease	Semi structured interviews "a framework was used to guide analysis"	Lack of continuity between services mean that carers were unaware of support until they reached a crisis and described difficulty accessing information. Carers called for a more integration between primary, secondary and tertiary care. Patients sought advice from neurologists over GPs who were not seen as having high levels of knowledge about PD. Palliative care was not accessed by any patients.
Neergaard (2008)	Denmark	14	Bereaved caregivers (cancer patients)	Focus groups qualitative description approach	Relatives experience insufficient palliative care, mainly due to organizational and cultural problems among professionals. There is a lack of shared care Mixed experiences regarding relationships with GPs, some good, some bad. Lack of care coordinator identified as barrier to shared care and high quality care.
Browne (2014)	UK	115 patients (n = 30), carers (n = 30), professionals (n = 20), professionals (n = 65).	advanced HF patients (n = 30), carers (n = 20), and professionals (n = 65).	semi-structured interviews (patients and carers) and focus groups (HCPs) content analysis	four key problems: 1) Knowledge and understanding deficits; 2) Difficulties navigating and accessing health and social care support; 3) General challenges and barriers to optimal care; 4) Problems relating to emergency care. Fragmented care with lack of coordination and poor communication makes life difficult
Jack (2016)	UK	41 (16 patients and 25 family caregivers)	Eligible participants were in receipt of Hospice at Home service on at least three occasions and were deemed to have a life expectancy measured in weeks not days.	Interviews (individual or joint) Thematic analysis	Embracing Holism, by bringing Hospice care into the home and acting as a bridge from the Hospice, is clearly promoting patient choice in being able to be cared for and die in their own home. Hospice at home nurses helped patients to navigate services and different agencies Hospice at home helped avoid unwanted hospital admissions
Adam (2015)	UK	15	11 patients and 4 caregivers	Interviews Framework analysis	The importance of continuity of care and communication between all involved. The continuity of care from a single GP was important within the patient's registered practice. Continuity was not perceived to be as important in the OOH period when participants were happy to see any qualified practitioner. Prompt pain relief was their priority The importance of good communication between the OOH service, their registered practice, and in some cases palliative physicians and oncologists was emphasised. Those with palliative care summaries valued the informational continuity that they provided.

No studies were excluded following the quality assessment (Table 3).

Table 3. Quality assessment scores for included papers

Source Paper (n=12)	Title of paper	Abstract/Title	Intro / Aims	Method/ Data	Sampling	Data Analysis	Ethics / Bias	Results	Transferability	Implications	Quality score (out of 36)
Leydon (2013)	Discontinuity of care at end of life: a qualitative exploration of out of hours end of life care	4	4	4	4	4	3	4	4	3	34/36
Seamark (2014)	Dying at home: a qualitative study of family carers' views of support provided by GPs community staff	3 – method of data analysis absent from abstract	3	3	4	4	3	4	4	4	32/36
Payne (2017)	Enhancing integrated palliative care: what models are appropriate? A cross-case analysis	3	4	4	3 – no response rates reported	4	4	4	3	4	33/36
Richards (2011)	The experiences and needs of people seeking palliative health care out-of-hours: a qualitative study	4	4	3 – schedule not included	4	4	4	4	4	3- future research missing	34/36
Klarare (2017)	Experiences of security and continuity of care: Patients' and families' narratives about the work of specialized palliative home care teams	4	4	3	3	4	4	4	4	4	34/36
Bailey (2016)	Hospital care following emergency admission: a critical incident case study of the experiences of patients with advanced lung cancer and Chronic Obstructive Pulmonary Disease	4	4	4	4	4	4	4	3	4	35/36
McLaughlin (2010)	Living and coping with Parkinson's disease: Perceptions of informal carers	4	3	2	2	3	3	4	3	3 implications for practice	24/36

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										not outlined	
Neergaard (2008)	Palliative care for cancer patients in a primary health care setting: Bereaved relatives' experience, a qualitative group interview study	3	3 – brief literature review	4	4	4	2	4	3	4	31/36
Browne (2014)	Patient, Carer and Professional Perspectives on Barriers and Facilitators to Quality Care in Advanced Heart Failure	4	3	4	3	3	3	4	3	3 – no future research recommendations	30/36
Jack (2016)	Supporting older people with cancer and life-limiting conditions dying at home: a qualitative study of patient and family caregiver experiences of Hospice at Home care	4	4	3	3	4	4	4	3	4	29/36
Adam (2015)	Utilising out-of-hours primary care for assistance with cancer pain: a semi-structured interview study of patient and caregiver experiences	4	3	4	4	4	3	4	4	4	34/36
Mortel (2017)	Reducing avoidable admissions in rural community palliative care: a pilot study of care coordination by General Practice registrars.	4	4	4	3	4	4	4	3	3	33/36
Ingadotir (2010)	Partnership-based nursing practice for people with chronic obstructive pulmonary disease and their families: influences on health-related quality of life and hospital admission	4	4	4	3 – no power calculation data included	4	4	4	3	3	33/36
Montero (2016)	Reducing Unplanned Medical Oncology Readmissions by Improving	4	4	4	4 – all admitted patient	4	4	4	4	3 – relates to previous	35/36

	Outpatient Care Transitions: A Process Improvement Project at the Cleveland Clinic				ts were eligible					findings, no recommendations for research	
Edwards (2014)	Outcomes Assessment of a Pharmacist-Directed Seamless Care Program in an Ambulatory Oncology Clinic	3	4	4	3 – sample size justification and response rates not included.	3	4	4	4	3 – recommendations for future research missing	28/36
O'Connor (2016)	Establishing a nurse practitioner model to enhance continuity between palliative care settings.	4	4	2 – qualitative is anecdotal, quantitative methodology not very robust	3 – sample size justification and response rates not included.	2 – qualitative data analysis is lacking	3	2	3	3	26/36
De Graff (2016)	Hospice assist at home: does the integration of hospice care in primary healthcare support patients to die in their preferred location – A retrospective cross-sectional evaluation study	4	4	3	4	2	4	3	4	4	32/36
Morris (2017)	Caring About Residents' Experiences and Symptoms (CARES) Program: A Model of Palliative Care Consultation in the Nursing Home	4	4	3	2 – few details given of sample	3	1	2 – more information needed	3	3	25/36

Study methodology

The majority of eligible quantitative and mixed methods studies utilised quasi-experimental methodologies (86%, n= 6). One randomised controlled trial ³⁶ was included. Two interventional studies

included a control group^{36, 37}, 2 utilised an interrupted time series design^{38, 39} and 3 did not include a comparison group⁴⁰⁻⁴².

For qualitative studies, semi structured interviews with patients or their carers were the most common method of data collection⁴³⁻⁴⁹ (64% of qualitative studies, n=7), 3 studies undertook multiple interviews with participants⁵⁰⁻⁵², while 1 utilised focus groups⁵³. Qualitative data were analysed using thematic analysis^{44-46, 49, 51}, framework analysis^{47, 48}, a qualitative descriptive approach^{50, 53} or content analysis⁴³.

Participants

In all, 1,951 patients and 190 family caregivers were recruited across included studies. Most studies (n=10) recruited patients with a range of illnesses, identified as requiring palliative care, 3 studies recruited patients with cancer^{36, 45, 48} while 3 recruited patients with a different diagnosis (COPD³⁸, Parkinson's disease⁴⁷, advanced heart failure⁴³). Two studies recruited bereaved family members^{44, 53}.

Quantitative studies

Components of interventions

To examine which types of continuity were implemented within each intervention, we considered the elements within each intervention separately. Each intervention was complex and included multiple components. In total, the interventions included 12 different components, used in a variety of combinations (Table 4). All interventions included regular contact or follow up appointments with the same health care professional (relational continuity) and the majority included liaison between medical teams (informational continuity) (86%, n=6)

Table 4. Components of eligible interventions

	Type of continuity	De Graff (2016)	Edwards (2014)	Ingadottir (2010)	Montero (2016)	Morris (2016)	Mortel (2017)	O'Conner (2016)	Number of studies
Care coordinator identified	R&I	x		x			x	x	4
Sharing care plan with other professionals	R&I	x	x			x	x	x	5
Contact with same professionals out of hours	R&I						x		1
Initial patient assessment conducted by coordinator	R&I	x				x	x		3

Regular contact / follow up appointments with the same health care professional	R&I	x	x	x	x	x	x	x	7
Patient selects which professional acts as their coordinator	R	x							2
Regular telephone contact with coordinator/identified nurse	R		x	x	x			x	4
One point of contact identified for patients	R	x		x			x	x	4
Initial medication history interview and medical reconciliation conducted	I		x						2
Liaison between medical teams (MDTs, case conferences)	I	x	x	x		x	x	x	6
Education for health care professionals to promote buy in to intervention/ promote continuity	I	x			x	x			3
Creation of a (new) care plan / database/ report	I	x	x			x	x	x	5

R – relational continuity

I – informational continuity

MDTs – multidisciplinary team meetings

Impact of interventions upon identified outcomes

Due to the heterogeneous nature of studies it was not possible to conduct a meta-analysis. A narrative summary of the findings of interventional studies, with regards to preferred place of death, hospital admissions and satisfaction with care is provided.

Place of death

Over half of interventions identified explored impact on place of death (n=4, 57% interventional studies)^{37, 40-42}. Two interventions^{37, 42} reported a positive impact on facilitating preferred place of death while this was difficult to assess in 2 interventions due to a lack of comparator or limited information being reported. No studies described a negative impact, or a decrease in the number of deaths occurring in the preferred locations.

Preferred place of death was achieved for 91% of patients (92 of 101 participants for whom this was known) receiving care from the “Hospice Assist at Home” intervention⁴². Patients receiving care coordination from a GP registrar were more likely to die at home than control participants (OR 0.41 (95%CI 0.20–0.86); P = 0.02) in Mortel et al’s (2017) intervention.

O’Connor et al (2016) report that preferred place of death was achieved for 59% of participants that died during the study period (20/34 participants). In the absence of a control group, the authors compare this to figures from the wider Australian population which state that 14% of those that wish to die at home, do so. Morris et al (2017) did not report preference for place of death⁴¹.

Hospital admissions

Six studies explored the impact of intervention on hospital admission rates³⁶⁻⁴¹. The majority³⁷⁻⁴⁰ (n=4) described a reduction in avoidable hospital admissions for people enrolled in interventions. In two studies a lack of comparison information makes this difficult to assess, although no interventions describe increases in hospital admissions.

The four studies reporting a reduction in hospital admissions utilised the following types of intervention; care coordination by a GP registrar³⁷, a nurse practitioner⁴⁰, a specialist nurse³⁸ and an intervention to improve care transitions including post-surgical follow-up calls and mandatory early follow-up appointments with oncology teams³⁹. A number of limitations were observed including differences between the control and intervention groups at baseline³⁷, small sample sizes³⁸ and lack of pre-intervention data⁴⁰.

While Morris et al (2016) report that 90% (70 out of 78) of care home residents desiring a palliative course, enrolled in a model of palliative care consultation were never hospitalised, the lack of comparison data make conclusions difficult. Seven participants were hospitalised over the course of the intervention, despite orders for no hospitalisation, although this represents less than 10% of the sample.

Edwards et al (2014) relied on participant-reported healthcare utilisation to assess impact on hospital admissions. While participants were enrolled in a seamless care programme, other sources of medical care were still sought. Data from the control condition was not reported.

Patient satisfaction with care

No Interventional studies measured the impact of the intervention on patient or carer satisfaction with care.

Qualitative synthesis – patient experience of continuity

The impact of experiencing, or not experiencing continuity of care was explored via qualitative studies. The views of both patients and their informal carers are represented. Barriers to achieving continuity of care and continuity facilitators were identified. An overview of these barriers and facilitators are presented in table 5.

Table 5: *The barriers and facilitators to continuity in the provision of palliative care, and the impact of continuity on patient and carer experience.*

Barriers and facilitators of continuity	Impact on patient
Barriers to continuity • <i>Structure of systems</i> • Fragmented services • Multiple professionals involved • <i>Lack of information sharing</i> • Between primary and secondary services • limited access to medical records	Impact of poor continuity on patients and carers • <i>Impact on care</i> • Difficulties and delays in accessing support • Care plan is not clearly communicated to patients • <i>Impact on patient and carers</i> • Emotional impact • Additional burdens
Continuity facilitators • One point of contact - care coordinator • Multidisciplinary working	Benefits of continuity for patients and carers • Patient feels “known” • Patient is confident in care

Barriers to continuity

“We were never quite sure who was in charge of all this business, so who was in charge of it all?” – patient⁴⁴

The fragmented nature of services and the number of professionals involved made it difficult for some patients to navigate services^{44, 47, 50, 53}, decipher who was responsible for which aspects of their care^{43, 50} and ultimately access support. This appeared to be amplified outside normal working hours^{44, 47, 50}. In addition, a lack of information sharing, both between services, and between services and patients left families feeling frustrated and unsupported^{44, 45, 50}. Disbelief about the lack of access that professionals had to their medical records was expressed in several studies^{44, 45, 48, 50, 52, 53}.

Impact of low continuity on patients and families

A) Impact on care

(i) Difficulties and delays in accessing support

“You’re trying to navigate it and you’re dealing with so many agencies and you don’t know which way to go sometimes. They’re very good in that particular sphere in that they’ll try and help you as much as possible, but it’s so – I didn’t realize it was so complicated to die, I didn’t, honestly. I thought it’d be a fairly simple job, but it’s not, it’s not” (P2, 61- to 70-year-old male patient).⁴⁹

Participants described a significant impact on their experiences as a result of the lack of informational and relational continuity. Patients and carers described difficulty in navigating the numerous services and multiple people involved in their care^{44, 47, 50, 53}. Many described uncertainty about how^{43, 50} and when^{50 45} to access support. A lack of confidence in out of hour’s services was also described^{44, 47, 50}.

‘If anything goes wrong during the night, weekends, they were dreadful times because at weekends the NHS more or less closes down, and you can go and sit in A&E, somebody’ll come and see you after about half an hour and take some details, but then it’s about 4 hours wait then, and if you’re sat there in pain it’s a hell of a long time.’ – patient⁴⁴

As a result of such concerns and experiences, delays in seeking support out of hours were commonly described. Delays were connected to the lack of confidence in services (due to a lack of relational and informational continuity) as well as uncertainties around the legitimacy of their need^{45, 50} and concerns about putting additional strain on the health service, which they perceived as stretched^{45, 50}. Thus patients described waiting until they could speak to a professional who was familiar with them and their needs before seeking help. This resulted in many patients enduring unpleasant symptoms whilst they waited to contact their regular care providers, which was also disturbing for carers^{44, 45, 48, 50}.

“.... Um ... so, no, in the end I decided there wasn’t anybody, really, who could help me, (IV: Mmm), so I didn’t call anybody, I just sent my nurse a text and just hoped I’d survive the night. And I did [gentle laughter from P].” Patient⁵⁰

(ii) Care plan is poorly communicated

The lack of consistent communication, and difficulty in accessing support meant that often, it was hard for patients to build up a clear picture of their current status^{43, 52}. This ambiguity left patients feeling unsupported and unclear about what the future held for them.

"We're waiting to hear from them, the [regional hospital], they said a week or two ... it's actually three weeks [now] ... I know they say no news is probably good news, but waiting is the worst part. You just want to know how long you've got" Patient⁵²

The inability of all services to access a patient's medical records complicated care and was a source of much frustration and led to periods of unnecessary stress and discomfort. This again, was particularly pressing outside of normal working hours and necessitated much repetition of information and contributed to a reluctance to access out of hours support^{44, 45, 48, 50}

"Well by the time you phone one person and you try to explain to them that you've got a growth inside you and it's bothering you and you're in a lot of pain and stuff, then they have to go and get somebody else to phone you back and you have to wait a long time ... eventually they do phone you back ... and then you're in absolute agony on the phone." Patient⁴⁸

This was compounded by a lack of consistency in symptom management, with different professionals suggesting different approaches^{43, 47, 52}. This was sometimes described as a result of delayed or irregular medical reviews with specialists, or the lack of coordinated approach to care. This had a negative impact on both patients and carers^{51, 52}.

"They took a lot of tablets off me [in the hospital], and my doctor [GP] went mad, because they shouldn't have done ... I'm back on all my old medication now ... they shouldn't have changed it." Patient⁵²

In addition, in the absence of a coordinated approach meant that the care patients received was often not streamlined with repetition and multiple appointments within the same location, within the same week often taking place^{43, 46}.

" she says he is down at the same department three times in a week and he could be done in one day. Each of them that, the Sister, the Nurse and the anticoagulant clinic.

She says it's the same building and yet he has got to go three times daily, he's got to go three times a week, different days.' Carer⁴³

Further consequences of this lack of continuity were that some families described being unaware of sources of support (for example additional financial support or additional out of hours support), which could have been beneficial for them^{44, 47, 50}. Patients felt that some professionals presumed that someone else had already provided them with this information, A lack of continuity meant that gaps in information provision were sometimes left unfilled^{47, 50}.

"I was surprised in retrospect that I hadn't been told that [about Out-of-hours service]... perhaps they thought I knew... [Would have been less worried over the years if I'd known]" Patient⁵⁰

The lack of informational and relational consistency experienced by patients and families negatively impacted their experiences of care, with patients enduring periods of great discomfort in order to wait until they could seek help from a professional that was familiar with their needs, and with whom they felt confident and supported.

B) Impact on patient and carer experience

(i) Additional burdens

Taking on the role of coordinator

Due to a lack of informational continuity between services, patients and carers took on additional administrative burdens or duties to secure a coherent approach to care management^{44, 47, 51, 53}. Patients and carers described having to take on the role of "coordinator" as services did not seem to be effectively sharing information with each other. This was experienced as stressful and time consuming.

"It was up to me to contact her [the hospice nurse], and this is what people say, if you need any help ring, but it's an extra thing to do, to organise your own kind of help is an extra thing to do, and in the 24 hours you don't have much time or energy for extra things" Patient⁴⁴

Some carers described an "unspoken pressure" from health care professionals to become "semi-professionals"⁵³. This was also a role that many people did not want, patients were often too tired and carers preferred to concentrate on spending quality time with loved ones⁴⁵.

"I mean our own GP obviously knows Dad's case inside out, but there must be a way where the [out-of-hours] doctor can access at least a recapped version of what's wrong with him you would think he had to tap into his computer and access everything but, you know, he went solely on what I told him when we went in. So that to me was strange." Carer ⁴⁵

Feeling vulnerable or out of control

In addition to the more practical impacts of low continuity (both relational and informational) significant emotional impacts for patients and families were reported^{45, 50}. Many carers reported feeling vulnerable or out of control when they could not access advice or support from a professional who was familiar with their history and needs.

"And I remember thinking, I'm vulnerable, my wife is in pain and we want a service and, and I have to ring up this person – 'The doctor will contact you'! What, tonight? Tomorrow?" Carer ⁴⁵

For patients, a lack of relational continuity meant that they could feel alone and unsupported.

"All I wanted was a voice to recognize me, um, or, or a voice to recognize what I was doing and say, there, there, [name], that's OK, I'll speak to you tomorrow, I'm aware of what's wrong with you, um, and that's fine. And really, the only voice who could do that would be [name], my, my nurse, um ... but obviously she switches her phone off, I think she [finishes her shift] at 5 o'clock..." Patient ⁵⁰

Continuity facilitators

In response to the fragmented nature of systems, patients and carers agreed that it would be beneficial to have one point of contact for their queries and concerns^{44, 48, 51, 53}. Some participants suggested this role could be occupied by a GP^{48, 53}, while others felt that the qualifications of the individual were less important than their ability to be a consistent source of advice, signposting or support⁴⁹. Furthermore, to truly promote continuity the need for multidisciplinary teams was highlighted.

Benefits of continuity for patients and carers

a) Feeling known

One of the most positive aspects of continuity from the perspectives of participants was that of "feeling known", which was represented in a number of ways. "Feeling known" was related to recognition of who

the patient was as a person, being listened to and having the professional demonstrate their ability to use their knowledge of the individual to recognise and act upon their suffering in a person centered manner^{44, 46, 48-50}. Where this level of relational continuity was achieved, it was highly valued.

“Yes, there was a nurse, a man, who came last week and took some blood. And I think he has been here once or maybe twice before. So, he asks me, how is your eating? Because I’d had problems last autumn, I lost a lot of weight. . . . I think it is fantastic that he remembers. . . . They care about the little things, ask how I’ve been over the holidays, what I’ve done, and so on.” Patient ⁴⁶

Another aspect of “feeling known” that was appreciated by carers in particular was the ability to notice small but potentially significant changes in a patient that could only be achieved through consistent interactions^{44, 46, 49}. In addition, for patients being cared for at home, families felt more comfortable when they had developed a relationship with health care professionals.

“but it would be wonderful if one nurse could concentrate on a case because you would have that continuity and they would notice changes and things and it would help them and probably help the family in that it isn’t a different person every night and you’re having to explain where the coffee is and what to do, but I know it isn’t practical because they have to have time off. But if it were one person, or even two, because we did have several different nurses.” Carer ⁴⁴

b) Feeling confident in care

Continuity in all of its forms, bolstered a sense of confidence in both care providers and the care plans developed for them^{46, 49, 50, 53}. Patients described feeling confident that their team could support them.

“There’s nothing worse than feeling that you are on your own and there’s no support and like it’s the unknown. When you know that you can pick up the phone and at the other end are experienced professionals and they are like tuned in and that in a matter of minutes you can have assistance. That makes all the difference”. Patient ⁴⁵

The ability to contact a team that could respond quickly and appropriately was greatly appreciated by patients and carers and went some way to alleviating some of the anxiety associated with supporting a loved one with palliative care needs.

“ ... it happened in a few hours. He got a high temperature... but they came straight away and stood here with the doctor on the phone, and it felt like “Yes, they’ve got it covered.” That felt like WOW! ... They came for this and supported us, and that was great since ... It almost caused anxiety before [enrollment in SPHC] to have to call the healthcare center. ... No one [there] has the complete picture, and no one knows us. ... No continuity.” Carer ⁴⁶

Discussion

Summary of findings

This mixed methods rapid review explored the impact of continuity for patients receiving palliative care. The limited quantitative evidence reviewed indicated that improving continuity of care may be related to reduced hospital admissions and achieving preferred location of death, although this review does not provide conclusive evidence of this.

Poor continuity was described as related to delays and difficulties in accessing care and increasing the burdens experienced by patients and carers. Patients were often left feeling vulnerable or unsupported without a clear understanding of their care plan and how to access support. In contrast, when patients experienced good continuity of care they felt confident, known and supported by care providers.

Comparison to other literature and the wider context

Many of the facilitators for continuity for palliative patients identified in this review (having one point of contact, and strong multidisciplinary working and information sharing), and the perceived benefits of continuity (accumulated knowledge) were identified in a review of the impact of continuity for patients with a range of conditions ²¹. Waibel et al (2012) note that continuity could be enhanced when patients take an active approach to the management of their own care. In the current review, in palliative care, participants and carers experienced the need to adopt the role of coordinator as burdensome and unwelcome. This may reflect both similarities and differences in how to promote continuity for patients with different conditions and at different stages of illness.

The impact of poor informational continuity for palliative patients was highlighted in this review. Retrospective studies highlight potential strategies for promoting continuity for this group, including electronic information sharing. Electronic palliative care coordination systems (EPaCC systems) ⁵⁴ have been suggested as useful in promoting information continuity for palliative care patients, although further work is needed to develop and test such strategies.

This review also highlights the importance of relational continuity for palliative care patients. Informational continuity is clearly important, but in isolation may be insufficient to achieve optimal patient outcomes or experiences. The importance of “feeling known” by health care professionals was clear in this review, both for the emotional and physical wellbeing of patients (in terms of delaying access to out of hours services). These benefits have been described in previous research with in palliative populations⁵⁵.

Despite evidence of the beneficial impact of continuity of care on both patient outcomes and experiences, continuity is not “built in” to interventions in the same way as other aspects of health care delivery⁵⁶. The number of retrospective studies in this area suggests that continuity is currently considered more of an outcome than an integral part of the health care process. This needs to be addressed. While there are undoubtedly methodological challenges in exploring the impact of interventions designed to promote continuity, this is an area in which future research is needed.

Continuity of care is difficult to deliver but vitally important to patients. Relational continuity provides the context upon which to build individualised care plans for patients, that in turn, requires informational and managerial continuity between services to be effective.

Limitations

There are a number of limitations to this review that warrant consideration. This rapid review was completed within 12 weeks and only research published within the last 10 years was included, grey literature and the views of health care professionals were not included.

Half of included studies were conducted in the UK. We acknowledge that patient experiences are shaped by the health care services and structures of the country in which they are receiving care, however aspects of the experience of both good and poor continuity may transcend national borders.

Defining which interventions should be considered eligible for inclusion in this review was a challenge given the various definitions and approaches to continuity found in the literature. Consensus over whether an article was eligible for inclusion was assessed through consulting the full text articles, referring back to the definitions of continuity outlined in Haggerty et al’s review ² and discussion amongst the research team.

Implications for future research and practice

The development of future interventions to improve care for palliative patients should consider how strategies for promoting both information and relational continuity can be embedded within interventions, and subsequently health care, alongside robust methods to measure the extent and impact of continuity achieved.

Conclusions

The impact of poor continuity and the potential benefits of improved continuity highlighted in this review add additional evidence to the body of literature calling for increased efforts to promote both informational and relational continuity for palliative care patients. Methods for enhancing, and recording continuity should be considered in the design and development of future healthcare interventions, across the lifespan.

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Data sharing statement

No additional data is available for this review.

Competing interests

The authors declare that they have no competing interests

Authors' contributions

BH, BN and SB conceptualised the study. BH designed the search strategy. BH ran the search strategy. BH screened the articles, extracted data, analysed the results, and drafted the manuscript. BN reviewed eligible articles. All authors critically reviewed several drafts of the manuscript and approved the final draft.

Figure legend

Figure 1. Data extracted from identified studies

Figure 2. PRISMA Flow diagram outlining study identification, screening, eligibility and inclusion

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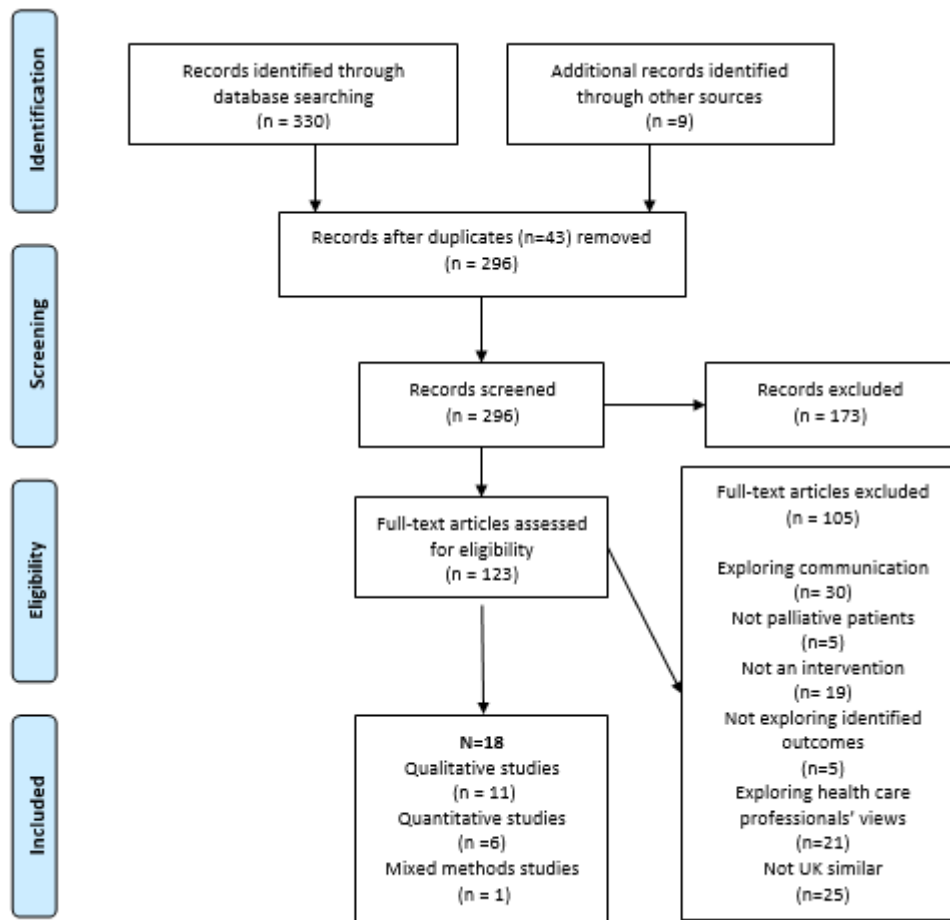
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Figure 1. Data extracted from eligible studies.

All studies	Intervention studies	Qualitative studies
- Participant type (patient, carer, both) - Diagnosis - Study design & methodology - Type of continuity explored (relational/informational) - Main findings	- Components of interventions - Impact of intervention on specified outcomes (patient/carers satisfaction with care, preferred place of death or reducing hospital admissions)	All text labeled as “results” or “findings” (both in the abstracts and texts of papers) were extracted.

Figure 2. PRISMA Flow diagram outlining study identification, screening, eligibility and inclusion.





PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	2
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	3
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	n/a
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	3,4
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	4
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	4
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	5
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	5
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	5
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	5
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	3
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I ²) for each meta-analysis.	5,6

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PRISMA 2009 Checklist

Page 1 of 2

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	12
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	n/a
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	6
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, follow-up period) and provide the citations.	7
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	12
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	n/a
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measure of consistency.	n/a qual synthesis page begins on page 18
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	12
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	n/a
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	24
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	25
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	26
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	26



PRISMA 2009 Checklist

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: the PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: www.prisma-statement.org.

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BMJ Open

The impact of informational and relational continuity for people with palliative care needs: a mixed methods rapid review

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Primary Subject Heading:	Palliative care
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Keywords:	PALLIATIVE CARE, continuity of patient care, systematic review, QUALITATIVE RESEARCH

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The impact of informational and relational continuity for people with palliative care needs: a mixed methods rapid review

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Key words: Palliative care, Continuity of Patient Care, Systematic review

Abstract

Objective: To identify and synthesize existing literature exploring the impact of relational and informational continuity of care on preferred place of death, hospital admissions and satisfaction for palliative care patients in qualitative, quantitative and mixed methods literature.

Design: A mixed methods rapid review.

Methods: PUBMED, PsychINFO, CINAHL were searched from June 2008 to June 2018 in order to identify original peer reviewed, primary qualitative, quantitative or mixed methods research exploring the impact of continuity of care for people receiving palliative care. Synthesis methods as outlined by the Cochrane Qualitative and Implementation Methods Group were applied to qualitative studies while meta-analyses for quantitative data were planned.

Outcomes: The impact of interventions designed to promote continuity of care for people receiving palliative care on the following outcomes was explored: achieving preferred place of death, satisfaction with care and avoidable hospital admissions.

Results: 18 eligible papers were identified. (11 qualitative, 6 quantitative and 1 mixed methods papers) In all, 1,951 patients and 190 family caregivers were recruited across included studies. Meta-analyses were not possible due to heterogeneity in outcome measures and tools used. Two studies described positive impact on facilitating preferred place of death. Four described a reduction in avoidable hospital admissions. No negative impacts of interventions designed to promote continuity were reported. Patient

satisfaction was not assessed in quantitative studies. Participants described a significant impact on their experiences as a result of the lack of informational and relational continuity.

Conclusions: This rapid review highlights the impact that continuity of care can have on the experiences of patients receiving palliative care. The evidence for the impact of continuity on place of death and hospital admissions is limited. Methods for enhancing, and recording continuity should be considered in the design and development of future health care interventions to support people receiving palliative care.

Strengths and limitations of this study

- This is the first mixed methods rapid review to explore the impact of continuity of care for palliative care patients.
- The inclusion of both qualitative and quantitative data provides rich insights into the experiences of patients and families, although the views of health care providers were not included.
- Only studies written in English and published within the last 10 years were included, which may introduce a risk of bias.
- Half of included studies were conducted in the UK yet experiences associated with both good and poor continuity may transcend national borders.

Introduction

Continuity of care is an important aspect of health care, but is often lacking. Continuity of care can take a range of forms, from continuous relationships with clinicians (relational continuity) to coordinated, comprehensive information sharing (informational continuity) and shared management plans (management continuity) within a range of services or professionals^{1, 2}.

In a review of continuity across multidisciplinary contexts, Haggerty et al (2003) argue that continuity is experienced by patients as the *“perception that providers know what has happened before, that different providers agree on a management plan, and that a provider who knows them will care for them in the future”*.²

The generation of accumulated knowledge and trust between a health professional and patient achieved through relational continuity³ is valued by both patients⁴ and clinicians⁵. High levels of management and informational continuity contribute to effective and efficient care. On the other hand, the same long term relationships between health care providers and patients may also open the door to collusion⁶ or prevent patients benefitting from the opinions of a fresh pair of eyes⁷.

On balance, evidence suggests continuity is beneficial for a range of populations across a range of outcomes. Lower levels of continuity have been associated with higher emergency department utilization throughout the life span^{8, 9}. Continuity has also been associated with patient satisfaction¹⁰, fewer hospital

admissions^{11, 12} and improved care for long term conditions such as diabetes¹³. Compelling evidence for the promotion of relational continuity was provided in a recent systematic review which highlighted a relationship between increased continuity and lower mortality rates¹⁴. In response, international policies and charters call for the promotion of continuity within health care services¹⁵⁻¹⁷.

However, the challenges to ensuring continuity are many and multifaceted. Within health care services that face growing demands and reducing resources, promoting and achieving continuity of care can be difficult¹⁸. The size of medical organisations is growing¹⁹ and the number of physicians seeing patients on a part time basis is increasing²⁰. The demands for rapid access to care are hard to balance with the demands for continuity.

Continuity may become increasingly important or valued in a person's care as they age, develop co-morbid conditions or as their health deteriorates^{1, 21}. It has been estimated that 69-82% of persons who die in high-income countries would benefit from palliative care²², a figure which is likely to increase. As the population of many western countries continues to age, the need for greater continuity in services may become more pressing as the impact of the presence or absence of continuity may be more keenly felt towards the end of life.

The number of different professionals and services involved in community palliative care can make continuity of care challenging²³, yet continuity was identified as one of the top 10 issues identified by the James Lind Alliance Palliative and end of life care Priority Setting Partnership²⁴.

The literature exploring the impact of continuity in palliative care is relatively young, yet promising. Continuity has been reported to be independently associated with patient ratings of care during cancer treatment²⁵, while greater involvement of primary care physicians at the end of life is associated with deaths outside of hospital, and receiving home care or hospice support²⁶. A review of integrated palliative care models across Europe called for greater efforts to enhance continuity²⁷.

In response, this rapid review aims to identify and synthesize the existing literature, exploring the impact of continuity of care (both relational and informational) on the experiences of palliative care patients and their families.

Objectives

1. To identify, from the perspectives of people receiving palliative care and their families, friends or carers the potential impact of continuity (or lack of continuity) on their experiences of care.

2. To explore the impact of interventions designed to promote continuity for people receiving palliative care on achieving preferred place of death, reducing avoidable hospital admissions and satisfaction with care

Methods

The guidelines put forward by PaCERS²⁸ were used to shape this rapid review.

Inclusion criteria for studies

a) Types of participants

Interventions recruiting adults (aged over 18 years) receiving palliative care and/or their family, friends or carers. Participants at all stages of a terminal illness, including the dying phase were included, in line with previous systematic reviews in this area²⁹.

b) Types of studies & outcomes

Original peer reviewed studies published in English within the last 10 years (June 2008 – June 2018) presenting primary qualitative, quantitative or mixed methods interventions exploring the impact of continuity in palliative care were eligible for inclusion.

Specifically:

- Qualitative studies collecting information about the experience of continuity for palliative care patients or their families (including bereaved family members). Studies also including the views of health care providers were included if the voices of patients and carers could be separated.
- or
- Prospective interventions designed to promote continuity and explore the impact of this on reducing avoidable hospital admissions, enabling preference for place of death, or patient or carer satisfaction with care. The following methodologies were included randomized controlled trials, non-randomised controlled trials/quasi-experimental trials, and before-after studies.

Retrospective studies, grey literature, reviews, conference abstracts and qualitative studies exploring the perspectives of health care professionals were not eligible.

Search method for identification of studies

Electronic searches

The following databases were searched; PUBMED, PsychINFO, CINAHL. Reference lists and forward searches of relevant publications were also screened.

Search terms

Based on previous reviews of the literature on palliative care and continuity^{23,30}, the free text and indexed terms listed in box 1 were used to identify relevant articles.

Box 1. PUBMED search strategy

Palliative care	((terminal* OR (advanced disease) OR palliativ* OR (palliative care) OR (palliative medicine) OR (end of life))
AND Continuity	((continuity) OR (partnership working) OR (collaborat*) OR (communication) OR (shared working) OR (joint working) OR (shared care) OR (extended team))
AND outcomes	((experience) OR (satisfaction) OR (place of death) OR (health care utilisation) OR (appointment*) OR (admission*) OR (hospital admission) OR (readmission) OR (emergency))

Data collection and analysis

Data screening

Studies were screened by one researcher (BH) and eligible studies were checked by a second (BN). Queries over the eligibility of studies were discussed with the research team (SB, BN and BH).

Data extraction

A unique form was developed to capture the following data from each eligible study. Figure 1 outlines the data that was extracted from each study.

INSERT FIGURE 1 HERE

Data analysis

Quality Assessment

To assess the methodological rigor of included studies, a tool developed by Hawker et al³¹ was used. The results are presented in Appendix 1.

Quantitative data analysis

Due to the heterogeneity of outcomes, meta-analyses were not possible. A narrative summary of studies was provided.

Qualitative data analysis

Synthesis methods as outlined by the Cochrane Qualitative and Implementation Methods Group were applied and the review was reported according to ENTREQ guidelines (Enhancing transparency in reporting the synthesis of qualitative research)³². Qualitative synthesis involves reinterpretation by considering the findings of multiple studies within an analysis³³, using a three-step process: coding, developing descriptive themes and generating analytical themes³⁴. All data titled findings or results were entered into NVIVO for analysis, in line with previous reviews utilizing qualitative synthesis^{34, 35}.

Patient and public involvement

This review was motivated by the priorities identified in the James Lind Alliance Palliative and end of life care Priority Setting Partnership²⁴, which included the views of patients and the public. No further patient and public involvement was incorporated into this review.

Results

Figure 2 presents a flow diagram of the study selection process. The initial search yielded 339 citations and 18 articles met the inclusion criteria (11 qualitative, 6 quantitative and 1 mixed methods).

INSERT FIGURE 2 HERE

Study characteristics

Half of included studies were conducted in the UK (50%, n=9), 3 were conducted in the USA or Canada, 2 in Australia and 1 each in Iceland, the Netherlands, Sweden and Denmark. Tables 1 and 2 outlines the sample, methodology, components of intervention, types of continuity assessed, outcome measures included and whether the intervention was found to be effective.

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Table 1. Summary of reviewed quantitative and mixed methods studies

Quantitative studies													
Author	Country	Components of intervention	continuity *		N	Participant s	Method	Outcomes relevant to review			Outcomes	Main findings	Intervention successful?
			R	I				S	Po d	Ha			
Mortel (2017)	Australia	Care coordinated by GP registrar who conducted an initial patient assessment, and case conferenced with the medical and nursing teams and the family to develop the care plan. 3-month follow-up (for stable patients) or re-assessed and updated the plan if the patient deteriorated. This service was initially available during business hours, but was extended to after hours as funding became available	x	x	191 (exp: n=99)	Adults ≥18 years with a terminal illness	A quasi-experimental design (no pre-test measures)		X	x	Hospital admissions per 100 patient-days proportion of deaths at home	Patients were more likely to be admitted to hospital than the intervention group (OR 2.67 1.39–5.11); P < 0.003) Patients were significantly less likely to die at home than the intervention group (OR 0.41 0.20–0.86); P = 0.02)	Yes although some significant differences between control and intervention participants
Ingadottir (2010)	Iceland	Specialist nurse acts as a coordinator of interdisciplinary collaboration. Visits patients at home for initial assessment Regular telephone contact Nurse coordinates multidisciplinary response to acute exacerbations.	x	x	50	COPD patients	Interrupted time series study			x	BMI, capacity to use medications, length of hospitalisation, psychometrics (HRQL, HADS), smoking rate	Hospital admission rate and days spent in hospital because of COPD reduced by 79 and 88%, respectively. The number of days spent in the hospital because of other diseases was not significantly different in T1, T2 and T3	Yes

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O'Conner (2016)	Australia	12-month evaluation of nurse practitioner role in palliative care. Aims of nurse practitioner were: To help patients achieved their preferred place of care. Enhance professional relationships between services Facilitate timely discharges and admissions between services.	x	x	683 Referred to service 105 records examined	Palliative care patients	Mixed methods - Qualitative evaluation of nurse led practitioner role And note review (no pre-test data collected)	X	x	How quickly patient seen by NP after referral Decreased unplanned/preventable hospital admissions Place of death Qualitative feedback	Place of death 42 patients died in the evaluation period. Twenty died at their place of choice 59% of hospital admissions had been averted, with 33% of presentations in the 12 month period,	Yes – fewer hospital admissions for those being cared for at home Outcome measures not clearly reported No comparator so hard to assess impact of intervention
Montero (2016)	USA	Health care professional education Call back from nurse and appointment with oncologist within 5 days (to discuss symptom management, education, medication review/compliance, and follow up appointment reminders) Mandatory early follow-up appointments with the patient's primary oncology care team help facilitate the transition from the hospital to the		x	4,551 admissions during study period	Patients referred to palliative and general medical oncology services.	Interrupted time series design		x	readmission rates	During the 11-month post intervention period there was a significant reduction in unplanned 30-day readmissions risk. Unplanned readmission rates declined by 4.5% to 22.9% from baseline. Nurse call-backs improved a patient's capacity for self-care at home and compliance with medication.	Yes

		outpatient setting.											
Edwards (2014)	Canada	Generation of a seamless care report – shared with other professionals Rounds with palliative care physicians twice weekly Telephone consultations & point of contact for patients.	X	x	200 (100 in intervention)	Patients receiving chemotherapy	RCT			x	Self-reported health care service utilisation Number and type of drug related problems	Patients in intervention sought additional health care support (hospital admission, A&E) On average of 3.7 DRPs per patient in intervention arm	Not possible to tell from results provided – only gives % that accessed additional health support eg hospital admission no comparator
Morris (2016)	USA	(CARES): a collaborative consultative PC program Two PC physicians from EVMS under a medical director contract provided consultation A part-time facility-based chaplain provided spiritual & psychosocial support	X	x	170	Care home residents	Pilot intervention study No pretest data collected		X	x	Services provided Changes to care plans Hospitalizations Place of death Hospice sage	Residents were decentralized, despite orders of hospitalization, 5 died in hospital. 54 of 56 of LTC residents died with hospice services. Two LTC residents declined hospice services and died in the hospital, which was consistent with their families expressed goals. Among the SNF residents, 36 of 82 have died: 9 transitioned to hospice services at home, an inpatient hospice unit, or LTC prior to death; 19 died under SNF care and were unable to access their hospice benefit; and 8 other died in the hospital	Not clear No comparison group and preference for place of death not reported.
De graff (2016)	The Netherlands	The Hospice Assist at Home service consists of four components. (1) A GP requested home visit from the hospice nurse consultant (2) Multidisciplinary consultation, once a fortnight, led by a	X	x	130	Patients living at home, with a life expectancy of less than 1 year	A cross-sectional evaluation study (no baseline data collected)			x	Expressed end-of-life preferences and the congruence between preferred and actual place of death	preferred place of death was known, 92/101 (91%) patients died in their preferred place of death.	yes

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+Outcomes
S – satisfaction with care
poD – place of death
Ha – reducing hospital admissions

Table 2. Summary of reviewed qualitative studies

Author	Country	n	Participants	Methodology	Main findings
Leydon (2013)	UK	32	Patients receiving palliative care	Longitudinal prospective qualitative study using semi-structured interviews and telephone interviews over 6 months – qualitative descriptive approach to analysis	Interpersonal or relationship continuity and management continuity are vital to the process of optimising the patient experience of out of hours palliative care
Seamark (2014)	UK	54	Bereaved family members	Semi structured interviews, thematic analysis	Continuity of care that divided personal, organisational, and informational continuity. Large numbers and changes in staff diluted personal continuity and failure of the GPs to visit was viewed negatively. Family carers had low expectations of informational continuity, finding information often did not transfer between secondary and primary care and other care agencies. Organisational continuity when present provided comfort and reassurance, and a sense of control.
Payne (2017)	UK	patients (n = 34), carers (n = 13) and health professional (n = 23)	Patients, carers and HCPs	Serial interviews with patients and family members (either together or apart) Focus groups with health care professionals (not included in analysis) Thematic analysis and cross case synthesis	While some care fell short of expectations, all patients reported high levels of satisfaction and valued continuity of care and efficient information sharing. All hospices supported and supplemented local providers, with three hospices also supplanting local provision by providing in-patient facilities.
Richards (2011)	UK	28	Patients with advanced cancer and caregivers	Interviews with patients and caregivers. Thematic analysis	Participants reported a lack of relational and informational continuity of care. Consulting with an unfamiliar clinician out-of-hours raised doubts in some participants' minds about the quality of care. While the themes suggest the delivery of out-of-hours care as a whole was not always perfect, around-the-clock access to professional sources of support and reassurance was highly valued. However, the transfer of information to out-of-hours providers remains a key challenge; participants did not understand why out-of-hours providers could not access more information on their medical histories given the level of computerisation within the National Health Service. The findings highlight the

					need to improve continuity between in-hours and out-of-hours services for patients with complex needs.
Klarare (2017)	Sweden	13	6 patients and 7 family members	Interviews Thematic analysis	Two themes were constructed through thematic analysis: (1) security and (2) continuity of care
Bailey (2016)	UK	109	39 patients (15 with COPD and 24 with lung cancer), 20 informal carers 50 healthcare professionals,	Semi structured interviews, after admission and following discharge Thematic analysis	Patients were satisfied with their 'emergency' care but not the care they received once their initial symptoms had been stabilised. The poorer quality care they experienced was characterised by a lack of attention to their fundamental needs, lack of involvement of the family or communication about care plans and a lack of continuity between primary and secondary care.
McLaughlin (2010)	UK	26	Family caregivers of people with Parkinson disease	Semi structured interviews "a framework was used to guide analysis"	Lack of continuity between services meant that carers were unaware of support until they reached a crisis and did not find difficulty accessing information. Carers called for a more integration between primary, secondary and tertiary care. Patients sought advice from neighbours over GPs who were not seen as having high levels of knowledge about palliative care. Palliative care was not accessed by any patients.
Neergaard (2008)	Denmark	14	Bereaved care givers (cancer patients)	Focus groups qualitative description approach	Relatives experience insufficient support in palliative care, mainly due to organizational and cultural problems among professionals. There is a lack of shared care. Mixed experiences regarding relationships with GPs, some good, some bad. Lack of care coordinator identified as barrier to shared care and high quality care.
Browne (2014)	UK	115 patients (n = 30), carers (n = 20), professionals (n = 65).	advanced HF patients (n = 30), carers (n = 20), and professionals (n = 65).	semi-structured interviews (patients and carers) and focus groups (HCPs) content analysis	four key problems: 1) Knowledge and understanding deficits; 2) Difficulties navigating and accessing health and social care support; 3) General challenges and barriers to optimal care; 4) Problems relating to emergency care. Fragmented care with lack of coordination and poor communication makes life difficult
Jack (2016)	UK	41 (16 patients and 25 family caregivers)	Eligible participants were in receipt of Hospice at Home service on at least three occasions and were deemed to have a life expectancy measured in weeks not days.	Interviews (individual or joint) Thematic analysis	Embracing Holism, by bringing Hospice care into the home and acting as a bridge from the Hospice, is clearly promoting patient choice in being able to be cared for and die in their own home. Hospice at home nurses help patients to navigate services and different agencies. Hospice at home helped avoid unwanted hospital admissions
Adam (2015)	UK	15	11 patients and 4 caregivers	Interviews Framework analysis	The importance of continuity of care and communication between all involved. The continuity of care from a single GP was important within the patient's registered practice. Continuity was not perceived to be as important in the OOH period when participants were happy to see any qualified practitioner. Prompt pain relief was their priority. The importance of good communication between the OOH service, their registered practice, and in some cases palliative physicians and oncologists was emphasised. Those with palliative care summaries valued the informational continuity that they provided.

Study methodology

The majority of eligible quantitative and mixed methods studies utilised quasi-experimental methodologies (86%, n= 6). One randomised controlled trial ³⁶ was included. Two interventional studies included a control group ^{36, 37}, 2 utilised an interrupted time series design ^{38, 39} and 3 did not include a comparison group ⁴⁰⁻⁴².

For qualitative studies, semi structured interviews with patients or their carers were the most common method of data collection ⁴³⁻⁴⁹ (64% of qualitative studies, n=7), 3 studies undertook multiple interviews with participants⁵⁰⁻⁵², while 1 utilised focus groups ⁵³. Qualitative data were analysed using thematic analysis^{44-46, 49, 51}, framework analysis ^{47, 48}, a qualitative descriptive approach ^{50, 53} or content analysis⁴³.

Participants

In all, 1,951 patients and 190 family caregivers were recruited across included studies. Most studies (n=10) recruited patients with a range of illnesses, identified as requiring palliative care, 3 studies recruited patients with cancer ^{36, 45, 48} while 3 recruited patients with a different diagnosis (COPD ³⁸, Parkinson's disease⁴⁷, advanced heart failure⁴³). Two studies recruited bereaved family members^{44, 53}.

Quantitative studies

Components of interventions

To examine which types of continuity were implemented within each intervention, we considered the elements within each intervention separately. Each intervention was complex and included multiple components. In total, the interventions included 12 different components, used in a variety of combinations (Table 3. All interventions included regular contact or follow up appointments with the same health care professional (relational continuity) and the majority included liaison between medical teams (informational continuity) (86%, n=6).

Table 3. Components of eligible interventions

	Type of continuity	De Graff (2016)	Edwards (2014)	Montero (2016)	Morris (2016)	Mortel (2017)	O'Conner (2016)	Number of studies
Care coordinator identified	R&I	x				x	x	4
Sharing care plan with other professionals	R&I	x	x		x	x	x	5
Contact with same professionals out of hours	R&I					x		1
Initial patient assessment conducted by coordinator	R&I	x			x	x		3
Regular contact / follow up appointments with the same health care professional	R&I	x	x	x	x	x	x	7
Patient selects which professional acts as their coordinator	R	x						2
Regular telephone contact with coordinator/identified nurse	R		x	x			x	4
One point of contact identified for patients	R	x				x	x	4
Initial medication history interview and medical reconciliation conducted	I		x					2
Liaison between medical teams (MDTs, case conferences)	I	x	x		x	x	x	6
Education for health care professionals to promote buy in to intervention/ promote continuity	I	x		x	x			3
Creation of a (new) care plan / database/ report	I	x	x		x	x	x	5

R – relational continuity

I – informational continuity

MDTs – multidisciplinary team meetings

Impact of interventions upon identified outcomes

Due to the heterogeneous nature of studies it was not possible to conduct a meta-analysis. A narrative summary of the findings of interventional studies, with regards to preferred place of death, hospital admissions and satisfaction with care is provided.

Place of death

Over half of interventions identified explored impact on place of death (n=4, 57% interventional studies)^{37, 40-42}. Two interventions^{37, 42} reported a positive impact on facilitating preferred place of death while this was difficult to assess in 2 interventions due to a lack of comparator or limited information being reported. No studies described a negative impact, or a decrease in the number of deaths occurring in the preferred locations.

Preferred place of death was achieved for 91% of patients (92 of 101 participants for whom this was known) receiving care from the “Hospice Assist at Home” intervention⁴². Patients receiving care coordination from a GP registrar were more likely to die at home than control participants (OR 0.41 (95%CI 0.20–0.86); P = 0.02) in Mortel et al’s (2017) intervention.

O’Connor et al (2016) report that preferred place of death was achieved for 59% of participants that died during the study period (20/34 participants). In the absence of a control group, the authors compare this to figures from the wider Australian population which state that 14% of those that wish to die at home, do so. Morris et al (2017) did not report preference for place of death⁴¹.

Hospital admissions

Six studies explored the impact of intervention on hospital admission rates³⁶⁻⁴¹. The majority³⁷⁻⁴⁰ (n=4) described a reduction in avoidable hospital admissions for people enrolled in interventions. In two studies a lack of comparison information makes this difficult to assess, although no interventions describe increases in hospital admissions.

The four studies reporting a reduction in hospital admissions utilised the following types of intervention; care coordination by a GP registrar³⁷, a nurse practitioner⁴⁰, a specialist nurse³⁸ and an intervention to improve care transitions including post-surgical follow-up calls and mandatory early follow-up appointments with oncology teams³⁹. A number of limitations were observed including differences between the control and intervention groups at baseline³⁷, small sample sizes³⁸ and lack of pre-intervention data⁴⁰.

While Morris et al (2016) report that 90% (70 out of 78) of care home residents desiring a palliative course, enrolled in a model of palliative care consultation were never hospitalised, the lack of comparison data make conclusions difficult. Seven participants were hospitalised over the course of the intervention, despite orders for no hospitalisation, although this represents less than 10% of the sample.

Edwards et al (2014) relied on participant-reported healthcare utilisation to assess impact on hospital admissions. While participants were enrolled in a seamless care programme, other sources of medical care were still sought. Data from the control condition was not reported.

Patient satisfaction with care

No Interventional studies measured the impact of the intervention on patient or carer satisfaction with care.

Qualitative synthesis – patient experience of continuity

The impact of experiencing, or not experiencing continuity of care was explored via qualitative studies. The views of both patients and their informal carers are represented. Barriers to achieving continuity of care and continuity facilitators were identified. An overview of these barriers and facilitators are presented in table 4.

Table 4: *The barriers and facilitators to continuity in the provision of palliative care, and the impact of continuity on patient and carer experience.*

Barriers and facilitators of continuity	Impact on patient
Barriers to continuity • <i>Structure of systems</i> • Fragmented services • Multiple professionals involved • <i>Lack of information sharing</i> • Between primary and secondary services • limited access to medical records	Impact of poor continuity on patients and carers • <i>Impact on care</i> • Difficulties and delays in accessing support • Care plan is not clearly communicated to patients • <i>Impact on patient and carers</i> • Emotional impact • Additional burdens
Continuity facilitators • One point of contact - care coordinator • Multidisciplinary working	Benefits of continuity for patients and carers • Patient feels “known” • Patient is confident in care

Barriers to continuity

“We were never quite sure who was in charge of all this business, so who was in charge of it all?” – patient ⁴⁴

The fragmented nature of services and the number of professionals involved made it difficult for some patients to navigate services^{44, 47, 50, 53}, decipher who was responsible for which aspects of their care^{43, 50} and ultimately access support. This appeared to be amplified outside normal working hours^{44, 47, 50}. In addition, a lack of information sharing, both between services, and between services and patients left families feeling frustrated and unsupported^{44, 45, 50}. Disbelief about the lack of access that professionals had to their medical records was expressed in several studies^{44, 45, 48, 50, 52, 53}.

Impact of low continuity on patients and families

A) Impact on care

(i) Difficulties and delays in accessing support

“You’re trying to navigate it and you’re dealing with so many agencies and you don’t know which way to go sometimes. They’re very good in that particular sphere in that they’ll try and help you as much as possible, but it’s so – I didn’t realize it was so complicated to die, I didn’t, honestly. I thought it’d be a fairly simple job, but it’s not, it’s not” (P2, 61- to 70-year-old male patient). ⁴⁹

Participants described a significant impact on their experiences as a result of the lack of informational and relational continuity. Patients and carers described difficulty in navigating the numerous services and multiple people involved in their care^{44, 47, 50, 53}. Many described uncertainty about how^{43, 50} and when^{50, 45} to access support. A lack of confidence in out of hour’s services was also described^{44, 47, 50}.

‘If anything goes wrong during the night, weekends, they were dreadful times because at weekends the NHS more or less closes down, and you can go and sit in A&E, somebody’ll come and see you after about half an hour and take some details, but then it’s about 4 hours wait then, and if you’re sat there in pain it’s a hell of a long time.’ – patient ⁴⁴

As a result of such concerns and experiences, delays in seeking support out of hours were commonly described. Delays were connected to the lack of confidence in services (due to a lack of relational and informational continuity) as well as uncertainties around the legitimacy of their need^{45, 50} and concerns

about putting additional strain on the health service, which they perceived as stretched^{45, 50}. Thus patients described waiting until they could speak to a professional who was familiar with them and their needs before seeking help. This resulted in many patients enduring unpleasant symptoms whilst they waited to contact their regular care providers, which was also disturbing for carers^{44, 45, 48, 50}.

".... Um ... so, no, in the end I decided there wasn't anybody, really, who could help me, (IV: Mmm), so I didn't call anybody, I just sent my nurse a text and just hoped I'd survive the night. And I did [gentle laughter from P]." Patient ⁵⁰

(ii) Care plan is poorly communicated

The lack of consistent communication, and difficulty in accessing support meant that often, it was hard for patients to build up a clear picture of their current status^{43, 52}. This ambiguity left patients feeling unsupported and unclear about what the future held for them.

"We're waiting to hear from them, the [regional hospital], they said a week or two ... it's actually three weeks [now] ... I know they say no news is probably good news, but waiting is the worst part. You just want to know how long you've got" Patient ⁵²

The inability of all services to access a patient's medical records complicated care and was a source of much frustration and led to periods of unnecessary stress and discomfort. This again, was particularly pressing outside of normal working hours and necessitated much repetition of information and contributed to a reluctance to access out of hours support^{44, 45, 48, 50}.

"Well by the time you phone one person and you try to explain to them that you've got a growth inside you and it's bothering you and you're in a lot of pain and stuff, then they have to go and get somebody else to phone you back and you have to wait a long time ... eventually they do phone you back ... and then you're in absolute agony on the phone." Patient ⁴⁸

This was compounded by a lack of consistency in symptom management, with different professionals suggesting different approaches^{43, 47, 52}. This was sometimes described as a result of delayed or irregular medical reviews with specialists, or the lack of coordinated approach to care. This had a negative impact on both patients and carers^{51, 52}.

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“They took a lot of tablets off me [in the hospital], and my doctor [GP] went mad, because they shouldn’t have done ... I’m back on all my old medication now ... they shouldn’t have changed it.” Patient ⁵²

In addition, in the absence of a coordinated approach meant that the care patients received was often not streamlined with repetition and multiple appointments within the same location, within the same week often taking place^{43, 46}.

“ she says he is down at the same department three times in a week and he could be done in one day. Each of them that, the Sister, the Nurse and the anticoagulant clinic. She says it’s the same building and yet he has got to go three times daily, he’s got to go three times a week, different days.’ Carer ⁴³

Further consequences of this lack of continuity were that some families described being unaware of sources of support (for example additional financial support or additional out of hours support), which could have been beneficial for them^{44, 47, 50}. Patients felt that some professionals presumed that someone else had already provided them with this information, A lack of continuity meant that gaps in information provision were sometimes left unfilled^{47, 50}.

“I was surprised in retrospect that I hadn’t been told that [about Out-of-hours service]... perhaps they thought I knew... [Would have been less worried over the years if I’d known]” Patient ⁵⁰

The lack of informational and relational consistency experienced by patients and families negatively impacted their experiences of care, with patients enduring periods of great discomfort in order to wait until they could seek help from a professional that was familiar with their needs, and with whom they felt confident and supported.

B) Impact on patient and carer experience

(i) Additional burdens

Taking on the role of coordinator

Due to a lack of informational continuity between services, patients and carers took on additional administrative burdens or duties to secure a coherent approach to care management^{44, 47, 51, 53}. Patients and carers described having to take on the role of “coordinator” as services did not seem to be effectively

sharing information with each other. This was experienced as stressful and time consuming.

"It was up to me to contact her [the hospice nurse], and this is what people say, if you need any help ring, but it's an extra thing to do, to organise your own kind of help is an extra thing to do, and in the 24 hours you don't have much time or energy for extra things" Patient ⁴⁴

Some carers described an "unspoken pressure" from health care professionals to become "semi-professionals"⁵³. This was also a role that many people did not want, patients were often too tired and carers preferred to concentrate on spending quality time with loved ones⁴⁵.

"I mean our own GP obviously knows Dad's case inside out, but there must be a way where the [out-of-hours] doctor can access at least a recapped version of what's wrong with him you would think he had to tap into his computer and access everything but, you know, he went solely on what I told him when we went in. So that to me was strange." Carer ⁴⁵

Feeling vulnerable or out of control

In addition to the more practical impacts of low continuity (both relational and informational) significant emotional impacts for patients and families were reported^{45, 50}. Many carers reported feeling vulnerable or out of control when they could not access advice or support from a professional who was familiar with their history and needs.

"And I remember thinking, I'm vulnerable, my wife is in pain and we want a service and, and I have to ring up this person – 'The doctor will contact you'! What, tonight? Tomorrow?" Carer ⁴⁵

For patients, a lack of relational continuity meant that they could feel alone and unsupported.

"All I wanted was a voice to recognize me, um, or, or a voice to recognize what I was doing and say, there, there, [name], that's OK, I'll speak to you tomorrow, I'm aware of what's wrong with you, um, and that's fine. And really, the only voice who could do that would be [name], my, my nurse, um ... but obviously she switches her phone off, I think she [finishes her shift] at 5 o'clock..." Patient ⁵⁰

Continuity facilitators

In response to the fragmented nature of systems, patients and carers agreed that it would be beneficial to have one point of contact for their queries and concerns^{44, 48, 51, 53}. Some participants suggested this role could be occupied by a GP^{48, 53}, while others felt that the qualifications of the individual were less important than their ability to be a consistent source of advice, signposting or support⁴⁹. Furthermore, to truly promote continuity the need for multidisciplinary teams was highlighted.

Benefits of continuity for patients and carers

a) Feeling known

One of the most positive aspects of continuity from the perspectives of participants was that of “feeling known”, which was represented in a number of ways. “Feeling known” was related to recognition of who the patient was as a person, being listened to and having the professional demonstrate their ability to use their knowledge of the individual to recognise and act upon their suffering in a person centered manner^{44, 46, 48-50}. Where this level of relational continuity was achieved, it was highly valued.

“Yes, there was a nurse, a man, who came last week and took some blood. And I think he has been here once or maybe twice before. So, he asks me, how is your eating? Because I’d had problems last autumn, I lost a lot of weight. ... I think it is fantastic that he remembers. ... They care about the little things, ask how I’ve been over the holidays, what I’ve done, and so on.” Patient ⁴⁶

Another aspect of “feeling known” that was appreciated by carers in particular was the ability to notice small but potentially significant changes in a patient that could only be achieved through consistent interactions^{44, 46, 49}. In addition, for patients being cared for at home, families felt more comfortable when they had developed a relationship with health care professionals.

“but it would be wonderful if one nurse could concentrate on a case because you would have that continuity and they would notice changes and things and it would help them and probably help the family in that it isn’t a different person every night and you’re having to explain where the coffee is and what to do, but I know it isn’t practical because they have to have time off. But if it were one person, or even two, because we did have several different nurses.” Carer ⁴⁴

b) Feeling confident in care

Continuity in all of its forms, bolstered a sense of confidence in both care providers and the care plans developed for them^{46, 49, 50, 53}. Patients described feeling confident that their team could support them.

“There’s nothing worse than feeling that you are on your own and there’s no support and like it’s the unknown. When you know that you can pick up the phone and at the other end are experienced professionals and they are like tuned in and that in a matter of minutes you can have assistance. That makes all the difference”. Patient⁴⁵

The ability to contact a team that could respond quickly and appropriately was greatly appreciated by patients and carers and went some way to alleviating some of the anxiety associated with supporting a loved one with palliative care needs.

“ ... it happened in a few hours. He got a high temperature... but they came straight away and stood here with the doctor on the phone, and it felt like “Yes, they’ve got it covered.” That felt like WOW! ... They came for this and supported us, and that was great since ... It almost caused anxiety before [enrollment in SPHC] to have to call the healthcare center. ... No one [there] has the complete picture, and no one knows us. ... No continuity.” Carer⁴⁶

Discussion

Summary of findings

This mixed methods rapid review explored the impact of continuity for patients receiving palliative care. The limited quantitative evidence reviewed indicated that improving continuity of care may be related to reduced hospital admissions and achieving preferred location of death, although this review does not provide conclusive evidence of this.

Poor continuity was described as related to delays and difficulties in accessing care and increasing the burdens experienced by patients and carers. Patients were often left feeling vulnerable or unsupported without a clear understanding of their care plan and how to access support. In contrast, when patients experienced good continuity of care they felt confident, known and supported by care providers.

Comparison to other literature and the wider context

Many of the facilitators for continuity for palliative patients identified in this review (having one point of contact, and strong multidisciplinary working and information sharing), and the perceived benefits of continuity (accumulated knowledge) were identified in a review of the impact of continuity for patients

with a range of conditions²¹. Waibel et al (2012) note that continuity could be enhanced when patients take an active approach to the management of their own care. In the current review, in palliative care, participants and carers experienced the need to adopt the role of coordinator as burdensome and unwelcome. This may reflect both similarities and differences in how to promote continuity for patients with different conditions and at different stages of illness.

The impact of poor informational continuity for palliative patients was highlighted in this review. Retrospective studies highlight potential strategies for promoting continuity for this group, including electronic information sharing. Electronic palliative care coordination systems (EPaCC systems)⁵⁴ have been suggested as useful in promoting information continuity for palliative care patients, although further work is needed to develop and test such strategies.

This review also highlights the importance of relational continuity for palliative care patients. Informational continuity is clearly important, but in isolation may be insufficient to achieve optimal patient outcomes or experiences. The importance of “feeling known” by health care professionals was clear in this review, both for the emotional and physical wellbeing of patients (in terms of delaying access to out of hours services). These benefits have been described in previous research within palliative populations⁵⁵.

Despite evidence of the beneficial impact of continuity of care on both patient outcomes and experiences, continuity is not “built in” to interventions in the same way as other aspects of health care delivery⁵⁶. The number of retrospective studies in this area suggests that continuity is currently considered more of an outcome than an integral part of the health care process. This needs to be addressed. While there are undoubtedly methodological challenges in exploring the impact of interventions designed to promote continuity, this is an area in which future research is needed. It was also interesting to note that no quantitative studies included measures of patient satisfaction with care. Given the themes identified in the qualitative data, highlighting the positive impact that continuity had on their experiences of care and support, this is perhaps something to be considered in future studies.

Continuity of care is difficult to deliver, and can be hard to measure, but is vitally important to patients. Relational continuity provides the context upon which to build individualised care plans for patients, that in turn, requires informational and managerial continuity between services to be effective. Improving continuity in palliative care may not remove every negative experience for palliative care patients and their families. However, the contrasts in reports of patients who had, and had not, perceived continuity

in their care in this review demonstrate the beneficial effects that continuity can have in terms of feeling safe, known and supported. While continuity may not be the panacea for all the challenges in providing high quality palliative care, we believe that good continuity, in a range of forms, can go a long way to improving a difficult time in a family or a person's life. We acknowledge that where continuity is more integrated into care, or where elements of interventions are not identified as continuity facilitators, they may not have been included in this review.

Limitations

There are a number of limitations to this review that warrant consideration. This rapid review was completed within 12 weeks and only research published within the last 10 years was included, grey literature and the views of health care professionals were not included.

Half of included studies were conducted in the UK. We acknowledge that patient experiences are shaped by the health care services and structures of the country in which they are receiving care, however aspects of the experience of both good and poor continuity may transcend national borders.

Defining which interventions should be considered eligible for inclusion in this review was a challenge given the various definitions and approaches to continuity found in the literature. Consensus over whether an article was eligible for inclusion was assessed through consulting the full text articles, referring back to the definitions of continuity outlined in Haggerty et al's review² and discussion amongst the research team.

Implications for future research and practice

The development of future interventions to improve care for palliative patients should consider how strategies for promoting both information and relational continuity can be embedded within interventions, and subsequently health care, alongside robust methods to measure the extent and impact of continuity achieved.

Conclusions

The impact of poor continuity and the potential benefits of improved continuity highlighted in this review add additional evidence to the body of literature calling for increased efforts to promote both informational and relational continuity for palliative care patients. Methods for enhancing, and recording

continuity should be considered in the design and development of future healthcare interventions, across the lifespan.

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Data sharing statement

No additional data is available for this review.

Competing interests

The authors declare that they have no competing interests

Authors' contributions

BH, BN and SB conceptualised the study. BH designed the search strategy. BH ran the search strategy. BH screened the articles, extracted data, analysed the results, and drafted the manuscript. BN reviewed eligible articles. BH, BN, SB and PS critically reviewed several drafts of the manuscript and approved the final draft.

Figure legend

Figure 1. Data extracted from identified studies

Figure 2. PRISMA Flow diagram outlining study identification, screening, eligibility and inclusion

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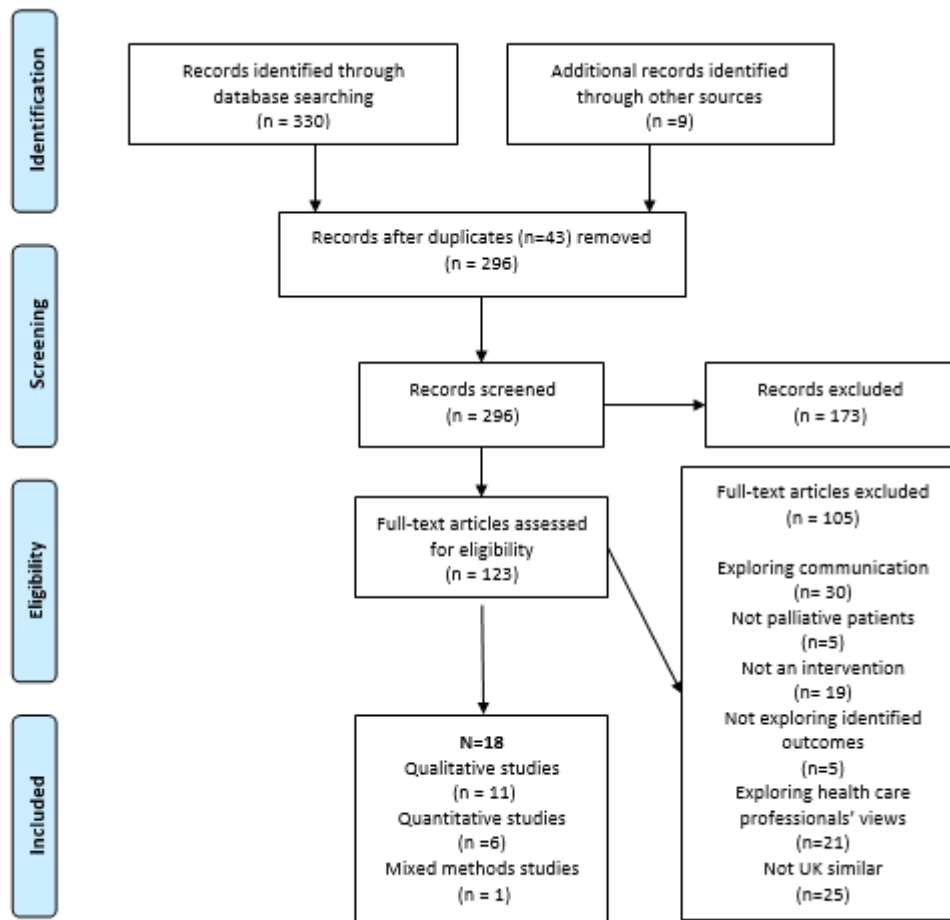
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Figure 1. Data extracted from eligible studies.

All studies	Intervention studies	Qualitative studies
- Participant type (patient, carer, both) - Diagnosis - Study design & methodology - Type of continuity explored (relational/informational) - Main findings	- Components of interventions - Impact of intervention on specified outcomes (patient/carers satisfaction with care, preferred place of death or reducing hospital admissions)	All text labeled as “results” or “findings” (both in the abstracts and texts of papers) were extracted.

Figure 2. PRISMA Flow diagram outlining study identification, screening, eligibility and inclusion.



Appendix 1

No studies were excluded following the quality assessment (Table 3).

Quality assessment scores for included papers

Source Paper (n=12)	Title of paper	Abstract/Title	Intro/Aims	Method/Data	Sampling	Data Analysis	Ethics/Bias	Transferability	Implications	Quality score (out of 36)
Leydon (2013)	Discontinuity of care at end of life: a qualitative exploration of out of hours end of life care	4	4	4	4	4	3	4	3	34/36
Seamark (2014)	Dying at home: a qualitative study of family carers' views of support provided by GPs community staff	3 – method of data analysis absent from abstract	3	3	4	4	3	4	4	32/36
Payne (2017)	Enhancing integrated palliative care: what models are appropriate? A cross-case analysis	3	4	4	3 – no response rates reported	4	4	3	4	33/36
Richards (2011)	The experiences and needs of people seeking palliative health care out-of-hours: a qualitative study	4	4	3 – schedule not included	4	4	4	4	3- future research missing	34/36
Klarare (2017)	Experiences of security and continuity of care:	4	4	3	3	4	4	4	4	34/36

	Patients' and families' narratives about the work of specialized palliative home care teams										
Bailey (2016)	Hospital care following emergency admission: a critical incident case study of the experiences of patients with advanced lung cancer and Chronic Obstructive Pulmonary Disease	4	4	4	4	4	4		3	4	35/36
McLaughlin (2010)	Living and coping with Parkinson's disease: Perceptions of informal carers	4	3	2	2	3	3		3	3 implications for practice not outlined	24/36
Neergaard (2008)	Palliative care for cancer patients in a primary health care setting: Bereaved relatives' experience, a qualitative group interview study	3	3 – brief literature review	4	4	4	2		3	4	31/36
Browne (2014)	Patient, Carer and Professional Perspectives on Barriers and Facilitators to Quality Care in Advanced Heart Failure	4	3	4	3	3	3		3	3 – no future research recommendations	30/36
Jack (2016)	Supporting older people with cancer and life-limiting conditions dying	4	4	3	3	4	4	4	3	4	29/36

	at home: a qualitative study of patient and family caregiver experiences of Hospice at Home care										
Adam (2015)	Utilising out-of-hours primary care for assistance with cancer pain: a semi-structured interview study of patient and caregiver experiences	4	3	4	4	4	3		4	4	34/36
Mortel (2017)	Reducing avoidable admissions in rural community palliative care: a pilot study of care coordination by General Practice registrars.	4	4	4	3	4	4		3	3	33/36
Ingadottir (2010)	Partnership-based nursing practice for people with chronic obstructive pulmonary disease and their families: influences on health-related quality of life and hospital admission	4	4	4	3 – no power calculation data included	4	4		3	3	33/36
Montero (2016)	Reducing Unplanned Medical Oncology Readmissions by Improving Outpatient Care Transitions: A Process Improvement Project at the Cleveland Clinic	4	4	4	4 – all admitted patients were eligible	4	4		4	3 – relates to previous findings, no recommendations for research	35/36
Edwards (2014)	Outcomes Assessment of a Pharmacist-Directed Seamless	3	4	4	3 – sample size justification and	3	4	4	4	3 – recommendations for future	28/36

	Care Program in an Ambulatory Oncology Clinic				response rates not included.					research missing	
O'connor (2016)	Establishing a nurse practitioner model to enhance continuity between palliative care settings.	4	4	2 – qualitative is anecdotal, quant methodology not very robust	3 – sample size justification and response rates not included.	2 – qual data analysis lacking Quant data analysis not robust	3		3	3	26/36
De graff (2016)	Hospice assist at home: does the integration of hospice care in primary healthcare support patients to die in their preferred location – A retrospective cross-sectional evaluation study	4	4	3	4	2	4		4	4	32/36
Morris (2017)	Caring About Residents' Experiences and Symptoms (CARES) Program: A Model of Palliative Care Consultation in the Nursing Home	4	4	3	2 – few details given of sample	3	1	2 – more information needed	3	3	25/36



PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	2
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	3
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	n/a
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	3,4
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	4
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	4
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	5
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	5
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	5
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	5
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	3
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I ²) for each meta-analysis.	5,6

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PRISMA 2009 Checklist

Page 1 of 2

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	12
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	n/a
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	6
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, follow-up period) and provide the citations.	7
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	12
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	n/a
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measure of consistency.	n/a qual synthesis page begins on page 18
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	12
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	n/a
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	24
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	25
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	26
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	26



PRISMA 2009 Checklist

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: the PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

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BMJ Open

The impact of informational and relational continuity for people with palliative care needs: a mixed methods rapid review

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Secondary Subject Heading:	Health services research, Patient-centred medicine
Keywords:	PALLIATIVE CARE, continuity of patient care, systematic review, QUALITATIVE RESEARCH

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The impact of informational and relational continuity for people with palliative care needs: a mixed methods rapid review

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Key words: Palliative care, Continuity of Patient Care, Systematic review

Abstract

Objective: To identify and synthesize existing literature exploring the impact of relational and informational continuity of care on preferred place of death, hospital admissions and satisfaction for palliative care patients in qualitative, quantitative and mixed methods literature.

Design: A mixed methods rapid review.

Methods: PUBMED, PsychINFO, CINAHL were searched from June 2008 to June 2018 in order to identify original peer reviewed, primary qualitative, quantitative or mixed methods research exploring the impact of continuity of care for people receiving palliative care. Synthesis methods as outlined by the Cochrane Qualitative and Implementation Methods Group were applied to qualitative studies while meta-analyses for quantitative data were planned.

Outcomes: The impact of interventions designed to promote continuity of care for people receiving palliative care on the following outcomes was explored: achieving preferred place of death, satisfaction with care and avoidable hospital admissions.

Results: 18 eligible papers were identified. (11 qualitative, 6 quantitative and 1 mixed methods papers) In all, 1,951 patients and 190 family caregivers were recruited across included studies. Meta-analyses were not possible due to heterogeneity in outcome measures and tools used. Two studies described positive impact on facilitating preferred place of death. Four described a reduction in avoidable hospital admissions. No negative impacts of interventions designed to promote continuity were reported. Patient

satisfaction was not assessed in quantitative studies. Participants described a significant impact on their experiences as a result of the lack of informational and relational continuity.

Conclusions: This rapid review highlights the impact that continuity of care can have on the experiences of patients receiving palliative care. The evidence for the impact of continuity on place of death and hospital admissions is limited. Methods for enhancing, and recording continuity should be considered in the design and development of future health care interventions to support people receiving palliative care.

Strengths and limitations of this study

- This is the first mixed methods rapid review to explore the impact of continuity of care for palliative care patients.
- The inclusion of both qualitative and quantitative data provides rich insights into the experiences of patients and families, although the views of health care providers were not included.
- Only studies written in English and published within the last 10 years were included, which may introduce a risk of bias.
- Half of included studies were conducted in the UK yet experiences associated with both good and poor continuity may transcend national borders.

Introduction

Continuity of care is an important aspect of health care, but is often lacking. Continuity of care can take a range of forms, from continuous relationships with clinicians (relational continuity) to coordinated, comprehensive information sharing (informational continuity) and shared management plans (management continuity) within a range of services or professionals^{1, 2}.

In a review of continuity across multidisciplinary contexts, Haggerty et al (2003) argue that continuity is experienced by patients as the *“perception that providers know what has happened before, that different providers agree on a management plan, and that a provider who knows them will care for them in the future”*.²

The generation of accumulated knowledge and trust between a health professional and patient achieved through relational continuity³ is valued by both patients⁴ and clinicians⁵. High levels of management and informational continuity contribute to effective and efficient care. On the other hand, the same long term relationships between health care providers and patients may also open the door to collusion⁶ or prevent patients benefitting from the opinions of a fresh pair of eyes⁷.

On balance, evidence suggests continuity is beneficial for a range of populations across a range of outcomes. Lower levels of continuity have been associated with higher emergency department utilization throughout the life span^{8, 9}. Continuity has also been associated with patient satisfaction¹⁰, fewer hospital

admissions^{11, 12} and improved care for long term conditions such as diabetes¹³. Compelling evidence for the promotion of relational continuity was provided in a recent systematic review which highlighted a relationship between increased continuity and lower mortality rates¹⁴. In response, international policies and charters call for the promotion of continuity within health care services¹⁵⁻¹⁷.

However, the challenges to ensuring continuity are many and multifaceted. Within health care services that face growing demands and reducing resources, promoting and achieving continuity of care can be difficult¹⁸. The size of medical organisations is growing¹⁹ and the number of physicians seeing patients on a part time basis is increasing²⁰. The demands for rapid access to care are hard to balance with the demands for continuity.

Continuity may become increasingly important or valued in a person’s care as they age, develop co-morbid conditions or as their health deteriorates^{1, 21}. It has been estimated that 69-82% of persons who die in high-income countries would benefit from palliative care²², a figure which is likely to increase. As the population of many western countries continues to age, the need for greater continuity in services may become more pressing as the impact of the presence or absence of continuity may be more keenly felt towards the end of life.

The number of different professionals and services involved in community palliative care can make continuity of care challenging²³, yet continuity was identified as one of the top 10 issues identified by the James Lind Alliance Palliative and end of life care Priority Setting Partnership²⁴.

The literature exploring the impact of continuity in palliative care is relatively young, yet promising. Continuity has been reported to be independently associated with patient ratings of care during cancer treatment²⁵, while greater involvement of primary care physicians at the end of life is associated with deaths outside of hospital, and receiving home care or hospice support²⁶. A review of integrated palliative care models across Europe called for greater efforts to enhance continuity²⁷.

In response, this rapid review aims to identify and synthesize the existing literature, exploring the impact of continuity of care (both relational and informational) on the experiences of palliative care patients and their families.

Objectives

1. To identify, from the perspectives of people receiving palliative care and their families, friends or carers the potential impact of continuity (or lack of continuity) on their experiences of care.

2. To explore the impact of interventions designed to promote continuity for people receiving palliative care on achieving preferred place of death, reducing avoidable hospital admissions and satisfaction with care

Methods

The guidelines put forward by PaCERS²⁸ were used to shape this rapid review.

Inclusion criteria for studies

a) Types of participants

Interventions recruiting adults (aged over 18 years) receiving palliative care and/or their family, friends or carers. Participants at all stages of a terminal illness, including the dying phase were included, in line with previous systematic reviews in this area²⁹.

b) Types of studies & outcomes

Original peer reviewed studies published in English within the last 10 years (June 2008 – June 2018) presenting primary qualitative, quantitative or mixed methods interventions exploring the impact of continuity in palliative care were eligible for inclusion.

Specifically:

- Qualitative studies collecting information about the experience of continuity for palliative care patients or their families (including bereaved family members). Studies also including the views of health care providers were included if the voices of patients and carers could be separated.
- or
- Prospective interventions designed to promote continuity and explore the impact of this on reducing avoidable hospital admissions, enabling preference for place of death, or patient or carer satisfaction with care. The following methodologies were included randomized controlled trials, non-randomised controlled trials/quasi-experimental trials, and before-after studies.

Retrospective studies, grey literature, reviews, conference abstracts and qualitative studies exploring the perspectives of health care professionals were not eligible.

Search method for identification of studies

Electronic searches

The following databases were searched; PUBMED, PsychINFO, CINAHL. Reference lists and forward searches of relevant publications were also screened.

Search terms

Based on previous reviews of the literature on palliative care and continuity^{23,30}, the free text and indexed terms listed in box 1 were used to identify relevant articles.

Box 1. PUBMED search strategy

Palliative care	((terminal* OR (advanced disease) OR palliativ* OR (palliative care) OR (palliative medicine) OR (end of life))
AND Continuity	((continuity) OR (partnership working) OR (collaborat*) OR (communication) OR (shared working) OR (joint working) OR (shared care) OR (extended team))
AND outcomes	((experience) OR (satisfaction) OR (place of death) OR (health care utilisation) OR (appointment*) OR (admission*) OR (hospital admission) OR (readmission) OR (emergency))

Data collection and analysis

Data screening

Studies were screened by one researcher (BH) and eligible studies were checked by a second (BN). Queries over the eligibility of studies were discussed with the research team (SB, BN and BH).

Data extraction

A unique form was developed to capture the following data from each eligible study. Figure 1 outlines the data that was extracted from each study.

INSERT FIGURE 1 HERE

Data analysis

Quality Assessment

To assess the methodological rigor of included studies, a tool developed by Hawker et al³¹ was used. The results are presented in Appendix 1.

Quantitative data analysis

Due to the heterogeneity of outcomes, meta-analyses were not possible. A narrative summary of studies was provided.

Qualitative data analysis

Synthesis methods as outlined by the Cochrane Qualitative and Implementation Methods Group were applied and the review was reported according to ENTREQ guidelines (Enhancing transparency in reporting the synthesis of qualitative research)³². Qualitative synthesis involves reinterpretation by considering the findings of multiple studies within an analysis³³, using a three-step process: coding, developing descriptive themes and generating analytical themes³⁴. All data titled findings or results were entered into NVIVO for analysis, in line with previous reviews utilizing qualitative synthesis^{34, 35}.

Patient and public involvement

This review was motivated by the priorities identified in the James Lind Alliance Palliative and end of life care Priority Setting Partnership²⁴, which included the views of patients and the public. No further patient and public involvement was incorporated into this review.

Results

Figure 2 presents a flow diagram of the study selection process. The initial search yielded 339 citations and 18 articles met the inclusion criteria (11 qualitative, 6 quantitative and 1 mixed methods).

INSERT FIGURE 2 HERE

Study characteristics

Half of included studies were conducted in the UK (50%, n=9), 3 were conducted in the USA or Canada, 2 in Australia and 1 each in Iceland, the Netherlands, Sweden and Denmark. Tables 1 and 2 outlines the sample, methodology, components of intervention, types of continuity assessed, outcome measures included and whether the intervention was found to be effective.

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Table 1. Summary of reviewed quantitative and mixed methods studies

Quantitative studies													
Author	Country	Components of intervention	continuity *		N	Participant s	Method	Outcomes relevant to review			Outcomes	Main findings	Intervention successful?
			R	I				S	Po d	Ha			
Mortel (2017)	Australia	Care coordinated by GP registrar who conducted an initial patient assessment, and case conferenced with the medical and nursing teams and the family to develop the care plan. 3-month follow-up (for stable patients) or re-assessed and updated the plan if the patient deteriorated. This service was initially available during business hours, but was extended to after hours as funding became available	x	x	191 (exp: n=99)	Adults ≥18 years with a terminal illness	A quasi-experimental design (no pre-test measures)		X	x	Hospital admissions per 100 patient-days proportion of deaths at home	Patients were more likely to be admitted to hospital than the intervention group (OR 2.67 1.39–5.11); P < 0.003) Patients were significantly less likely to die at home than the intervention group (OR 0.41 0.20–0.86); P = 0.02)	Yes although some significant differences between control and intervention participants
Ingadottir (2010)	Iceland	Specialist nurse acts as a coordinator of interdisciplinary collaboration. Visits patients at home for initial assessment Regular telephone contact Nurse coordinates multidisciplinary response to acute exacerbations.	x	x	50	COPD patients	Interrupted time series study			x	BMI, capacity to use medications, length of hospitalisation, psychometrics (HRQL, HADS), smoking rate	Hospital admission rate and days spent in hospital because of COPD reduced by 79 and 8%, respectively. The number of days spent in the hospital because of other diseases was not significantly different in T1, T2 and T3	Yes

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O'Conner (2016)	Australia	12-month evaluation of nurse practitioner role in palliative care. Aims of nurse practitioner were: To help patients achieved their preferred place of care. Enhance professional relationships between services Facilitate timely discharges and admissions between services.	x	x	683 Referred to service 105 records examined	Palliative care patients	Mixed methods - Qualitative evaluation of nurse led practitioner role And note review (no pre-test data collected)	X	x	How quickly patient seen by NP after referral Decreased unplanned/preventable hospital admissions Place of death Qualitative feedback	Place of death 42 patients died in the evaluation period. Twenty died at their place of choice 59% of hospital admissions had been averted, with 33% of presentations in the 12 month period,	Yes – fewer hospital admissions for those being cared for at home Outcome measures not clearly reported No comparator so hard to assess impact of intervention
Montero (2016)	USA	Health care professional education Call back from nurse and appointment with oncologist within 5 days (to discuss symptom management, education, medication review/compliance, and follow up appointment reminders) Mandatory early follow-up appointments with the patient's primary oncology care team help facilitate the transition from the hospital to the		x	4,551 admissions during study period	Patients referred to palliative and general medical oncology services.	Interrupted time series design		x	readmission rates	During the 11-month post intervention period there was a significant reduction in unplanned 30-day readmissions risk. Unplanned readmission rates declined by 4.5% to 22.9% from baseline. Nurse call-backs improved a patient's capacity for self-care at home and compliance with medication.	Yes

		outpatient setting.											
Edwards (2014)	Canada	Generation of a seamless care report – shared with other professionals Rounds with palliative care physicians twice weekly Telephone consultations & point of contact for patients.	X	x	200 (100 in intervention)	Patients receiving chemotherapy	RCT			x	Self-reported health care service utilisation Number and type of drug related problems	Patients in intervention sought additional health care support (hospital admission, A&E) On average of 3.7 DRPs per patient in intervention arm	Not possible to tell from results provided – only gives % that accessed additional health support eg hospital admission no comparator
Morris (2016)	USA	(CARES): a collaborative consultative PC program Two PC physicians from EVMS under a medical director contract provided consultation A part-time facility-based chaplain provided spiritual & psychosocial support	X	x	170	Care home residents	Pilot intervention study No pretest data collected		X	x	Services provided Changes to care plans Hospitalizations Place of death Hospice sage	Residents were decentralized, despite orders of hospitalization, 5 died in hospital. 54 of 56 of LTC residents died with hospice services. Two LTC residents declined hospice services and died in the hospital, which was consistent with their families expressed goals. Among the SNF residents, 36 of 82 have died: 9 transitioned to hospice services at home, an inpatient hospice unit, or LTC prior to death; 19 died under SNF care and were unable to access their hospice benefit; and 8 other died in the hospital	Not clear No comparison group and preference for place of death not reported.
De graff (2016)	The Netherlands	The Hospice Assist at Home service consists of four components. (1) A GP requested home visit from the hospice nurse consultant (2) Multidisciplinary consultation, once a fortnight, led by a	X	x	130	Patients living at home, with a life expectancy of less than 1 year	A cross-sectional evaluation study (no baseline data collected)			x	Expressed end-of-life preferences and the congruence between preferred and actual place of death	preferred place of death was known, 92/101 (91%) patients died in their preferred place of death.	yes

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Intervention	Comparison	Outcomes	Quality of Evidence	Notes
Intervention	Comparison	+Outcomes <i>S – satisfaction with care</i> <i>poD – place of death</i> <i>Ha – reducing hospital admissions</i>		

+Outcomes
S – satisfaction with care
poD – place of death
Ha – reducing hospital admissions

Table 2. Summary of reviewed qualitative studies

Author	Country	n	Participants	Methodology	Main findings
Leydon (2013)	UK	32	Patients receiving palliative care	Longitudinal prospective qualitative study using semi-structured interviews and telephone interviews over 6 months – qualitative descriptive approach to analysis	Interpersonal or relationship continuity and management continuity are vital to the process of optimising the patient experience of out of hours palliative care
Seamark (2014)	UK	54	Bereaved family members	Semi structured interviews, thematic analysis	Continuity of care that divided personal, organisational, and informational continuity. Large numbers and changes in staff diluted personal continuity and failure of the GPs to visit was viewed negatively. Family carers had low expectations of informational continuity, finding information often did not transfer between secondary and primary care and other care agencies. Organisational continuity when present provided comfort and reassurance, and a sense of control.
Payne (2017)	UK	patients (n = 34), carers (n = 13) and health professional (n = 23)	Patients, carers and HCPs	Serial interviews with patients and family members (either together or apart) Focus groups with health care professionals (not included in analysis) Thematic analysis and cross case synthesis	While some care fell short of expectations, all patients reported high levels of satisfaction and valued continuity of care and efficient information sharing. All hospices supported and supplemented local providers, with three hospices also supplanting local provision by providing in-patient facilities.
Richards (2011)	UK	28	Patients with advanced cancer and caregivers	Interviews with patients and caregivers. Thematic analysis	Participants reported a lack of relational and informational continuity of care. Consulting with an unfamiliar clinician out-of-hours raised doubts in some participants' minds about the quality of care. While the themes suggest the delivery of out-of-hours care as a whole was not always perfect, around-the-clock access to professional sources of support and reassurance was highly valued. However, the transfer of information to out-of-hours providers remains a key challenge; participants did not understand why out-of-hours providers could not access more information on their medical histories given the level of computerisation within the National Health Service. The findings highlight the

					need to improve continuity between in-hours and out-of-hours services for patients with complex needs.
Klarare (2017)	Sweden	13	6 patients and 7 family members	Interviews Thematic analysis	Two themes were constructed through thematic analysis: (1) security and (2) continuity of care
Bailey (2016)	UK	109	39 patients (15 with COPD and 24 with lung cancer), 20 informal carers 50 healthcare professionals,	Semi structured interviews, after admission and following discharge Thematic analysis	Patients were satisfied with their 'emergency' care but not the care they received once their initial symptoms had been stabilised. The poorer quality care they experienced was characterised by a lack of attention to their fundamental needs, lack of involvement of the family or communication about care plans and a lack of continuity between primary and secondary care.
McLaughlin (2010)	UK	26	Family caregivers of people with Parkinson disease	Semi structured interviews "a framework was used to guide analysis"	Lack of continuity between services meant that carers were unaware of support until they reached a crisis and did not find difficulty accessing information. Carers called for a more integration between primary, secondary and tertiary care. Patients sought advice from neighbours over GPs who were not seen as having high levels of knowledge about palliative care. Palliative care was not accessed by any patients.
Neergaard (2008)	Denmark	14	Bereaved care givers (cancer patients)	Focus groups qualitative description approach	Relatives experience insufficient support in palliative care, mainly due to organizational and cultural problems among professionals. There is a lack of shared care. Mixed experiences regarding relationships with GPs, some good, some bad. Lack of care coordinator identified as barrier to shared care and high quality care.
Browne (2014)	UK	115 patients (n = 30), carers (n = 20), professionals (n = 65).	advanced HF patients (n = 30), carers (n = 20), and professionals (n = 65).	semi-structured interviews (patients and carers) and focus groups (HCPs) content analysis	four key problems: 1) Knowledge and understanding deficits; 2) Difficulties navigating and accessing health and social care support; 3) General challenges and barriers to optimal care; 4) Problems relating to emergency care. Fragmented care with lack of coordination and poor communication makes life difficult
Jack (2016)	UK	41 (16 patients and 25 family caregivers)	Eligible participants were in receipt of Hospice at Home service on at least three occasions and were deemed to have a life expectancy measured in weeks not days.	Interviews (individual or joint) Thematic analysis	Embracing Holism, by bringing Hospice care into the home and acting as a bridge from the Hospice, is clearly promoting patient choice in being able to be cared for and die in their own home. Hospice at home nurses help patients to navigate services and different agencies Hospice at home helped avoid unwanted hospital admissions
Adam (2015)	UK	15	11 patients and 4 caregivers	Interviews Framework analysis	The importance of continuity of care and communication between all involved. The continuity of care from a single GP was important within the patient's registered practice. Continuity was not perceived to be as important in the OOH period when participants were happy to see any qualified practitioner. Prompt pain relief was their priority. The importance of good communication between the OOH service, their registered practice, and in some cases palliative physicians and oncologists was emphasised. Those with palliative care summaries valued the informational continuity that they provided.

Study methodology

The majority of eligible quantitative and mixed methods studies utilised quasi-experimental methodologies (86%, n= 6). One randomised controlled trial ³⁶ was included. Two interventional studies included a control group ^{36, 37}, 2 utilised an interrupted time series design ^{38, 39} and 3 did not include a comparison group ⁴⁰⁻⁴².

For qualitative studies, semi structured interviews with patients or their carers were the most common method of data collection ⁴³⁻⁴⁹ (64% of qualitative studies, n=7), 3 studies undertook multiple interviews with participants⁵⁰⁻⁵², while 1 utilised focus groups ⁵³. Qualitative data were analysed using thematic analysis^{44-46, 49, 51}, framework analysis ^{47, 48}, a qualitative descriptive approach ^{50, 53} or content analysis⁴³.

Participants

In all, 1,951 patients and 190 family caregivers were recruited across included studies. Most studies (n=10) recruited patients with a range of illnesses, identified as requiring palliative care, 3 studies recruited patients with cancer ^{36, 45, 48} while 3 recruited patients with a different diagnosis (COPD ³⁸, Parkinson's disease⁴⁷, advanced heart failure⁴³). Two studies recruited bereaved family members^{44, 53}.

Quantitative studies

Components of interventions

To examine which types of continuity were implemented within each intervention, we considered the elements within each intervention separately. Each intervention was complex and included multiple components. In total, the interventions included 12 different components, used in a variety of combinations (Table 3. All interventions included regular contact or follow up appointments with the same health care professional (relational continuity) and the majority included liaison between medical teams (informational continuity) (86%, n=6).

Table 3. Components of eligible interventions

	Type of continuity	De Graff (2016)	Edwards (2014)	Montero (2016)	Morris (2016)	Mortel (2017)	O'Conner (2016)	Number of studies
Care coordinator identified	R&I	x				x	x	4
Sharing care plan with other professionals	R&I	x	x		x	x	x	5
Contact with same professionals out of hours	R&I					x		1
Initial patient assessment conducted by coordinator	R&I	x			x	x		3
Regular contact / follow up appointments with the same health care professional	R&I	x	x	x	x	x	x	7
Patient selects which professional acts as their coordinator	R	x						2
Regular telephone contact with coordinator/identified nurse	R		x	x			x	4
One point of contact identified for patients	R	x				x	x	4
Initial medication history interview and medical reconciliation conducted	I		x					2
Liaison between medical teams (MDTs, case conferences)	I	x	x		x	x	x	6
Education for health care professionals to promote buy in to intervention/ promote continuity	I	x		x	x			3
Creation of a (new) care plan / database/ report	I	x	x		x	x	x	5

R – relational continuity

I – informational continuity

MDTs – multidisciplinary team meetings

Impact of interventions upon identified outcomes

Due to the heterogeneous nature of studies it was not possible to conduct a meta-analysis. A narrative summary of the findings of interventional studies, with regards to preferred place of death, hospital admissions and satisfaction with care is provided.

Place of death

Over half of interventions identified explored impact on place of death (n=4, 57% interventional studies)^{37, 40-42}. Two interventions^{37, 42} reported a positive impact on facilitating preferred place of death while this was difficult to assess in 2 interventions due to a lack of comparator or limited information being reported. No studies described a negative impact, or a decrease in the number of deaths occurring in the preferred locations.

Preferred place of death was achieved for 91% of patients (92 of 101 participants for whom this was known) receiving care from the "Hospice Assist at Home" intervention⁴². Patients receiving care coordination from a GP registrar were more likely to die at home than control participants (OR 0.41 (95%CI 0.20–0.86); P = 0.02) in Mortel et al's (2017) intervention.

O'Connor et al (2016) report that preferred place of death was achieved for 59% of participants that died during the study period (20/34 participants). In the absence of a control group, the authors compare this to figures from the wider Australian population which state that 14% of those that wish to die at home, do so. Morris et al (2017) did not report preference for place of death⁴¹.

Hospital admissions

Six studies explored the impact of intervention on hospital admission rates³⁶⁻⁴¹. The majority³⁷⁻⁴⁰ (n=4) described a reduction in avoidable hospital admissions for people enrolled in interventions. In two studies a lack of comparison information makes this difficult to assess, although no interventions describe increases in hospital admissions.

The four studies reporting a reduction in hospital admissions utilised the following types of intervention; care coordination by a GP registrar³⁷, a nurse practitioner⁴⁰, a specialist nurse³⁸ and an intervention to improve care transitions including post-surgical follow-up calls and mandatory early follow-up appointments with oncology teams³⁹. A number of limitations were observed including differences between the control and intervention groups at baseline³⁷, small sample sizes³⁸ and lack of pre-intervention data⁴⁰.

While Morris et al (2016) report that 90% (70 out of 78) of care home residents desiring a palliative course, enrolled in a model of palliative care consultation were never hospitalised, the lack of comparison data make conclusions difficult. Seven participants were hospitalised over the course of the intervention, despite orders for no hospitalisation, although this represents less than 10% of the sample.

Edwards et al (2014) relied on participant-reported healthcare utilisation to assess impact on hospital admissions. While participants were enrolled in a seamless care programme, other sources of medical care were still sought. Data from the control condition was not reported.

Patient satisfaction with care

No Interventional studies measured the impact of the intervention on patient or carer satisfaction with care.

Qualitative synthesis – patient experience of continuity

The impact of experiencing, or not experiencing continuity of care was explored via qualitative studies. The views of both patients and their informal carers are represented. Barriers to achieving continuity of care and continuity facilitators were identified. An overview of these barriers and facilitators are presented in table 4.

Table 4: *The barriers and facilitators to continuity in the provision of palliative care, and the impact of continuity on patient and carer experience.*

Barriers and facilitators of continuity	Impact on patient
Barriers to continuity • <i>Structure of systems</i> • Fragmented services • Multiple professionals involved • <i>Lack of information sharing</i> • Between primary and secondary services • limited access to medical records	Impact of poor continuity on patients and carers • <i>Impact on care</i> • Difficulties and delays in accessing support • Care plan is not clearly communicated to patients • <i>Impact on patient and carers</i> • Emotional impact • Additional burdens
Continuity facilitators • One point of contact - care coordinator • Multidisciplinary working	Benefits of continuity for patients and carers • Patient feels “known” • Patient is confident in care

Barriers to continuity

“We were never quite sure who was in charge of all this business, so who was in charge of it all?” – patient ⁴⁴

The fragmented nature of services and the number of professionals involved made it difficult for some patients to navigate services^{44, 47, 50, 53}, decipher who was responsible for which aspects of their care^{43, 50} and ultimately access support. This appeared to be amplified outside normal working hours^{44, 47, 50}. In addition, a lack of information sharing, both between services, and between services and patients left families feeling frustrated and unsupported^{44, 45, 50}. Disbelief about the lack of access that professionals had to their medical records was expressed in several studies^{44, 45, 48, 50, 52, 53}.

Impact of low continuity on patients and families

A) Impact on care

(i) Difficulties and delays in accessing support

“You’re trying to navigate it and you’re dealing with so many agencies and you don’t know which way to go sometimes. They’re very good in that particular sphere in that they’ll try and help you as much as possible, but it’s so – I didn’t realize it was so complicated to die, I didn’t, honestly. I thought it’d be a fairly simple job, but it’s not, it’s not” (P2, 61- to 70-year-old male patient). ⁴⁹

Participants described a significant impact on their experiences as a result of the lack of informational and relational continuity. Patients and carers described difficulty in navigating the numerous services and multiple people involved in their care^{44, 47, 50, 53}. Many described uncertainty about how^{43, 50} and when^{50, 45} to access support. A lack of confidence in out of hour’s services was also described^{44, 47, 50}.

‘If anything goes wrong during the night, weekends, they were dreadful times because at weekends the NHS more or less closes down, and you can go and sit in A&E, somebody’ll come and see you after about half an hour and take some details, but then it’s about 4 hours wait then, and if you’re sat there in pain it’s a hell of a long time.’ – patient ⁴⁴

As a result of such concerns and experiences, delays in seeking support out of hours were commonly described. Delays were connected to the lack of confidence in services (due to a lack of relational and informational continuity) as well as uncertainties around the legitimacy of their need^{45, 50} and concerns

about putting additional strain on the health service, which they perceived as stretched^{45, 50}. Thus patients described waiting until they could speak to a professional who was familiar with them and their needs before seeking help. This resulted in many patients enduring unpleasant symptoms whilst they waited to contact their regular care providers, which was also disturbing for carers^{44, 45, 48, 50}.

".... Um ... so, no, in the end I decided there wasn't anybody, really, who could help me, (IV: Mmm), so I didn't call anybody, I just sent my nurse a text and just hoped I'd survive the night. And I did [gentle laughter from P]." Patient ⁵⁰

(ii) Care plan is poorly communicated

The lack of consistent communication, and difficulty in accessing support meant that often, it was hard for patients to build up a clear picture of their current status^{43, 52}. This ambiguity left patients feeling unsupported and unclear about what the future held for them.

"We're waiting to hear from them, the [regional hospital], they said a week or two ... it's actually three weeks [now] ... I know they say no news is probably good news, but waiting is the worst part. You just want to know how long you've got" Patient ⁵²

The inability of all services to access a patient's medical records complicated care and was a source of much frustration and led to periods of unnecessary stress and discomfort. This again, was particularly pressing outside of normal working hours and necessitated much repetition of information and contributed to a reluctance to access out of hours support ^{44, 45, 48, 50}

"Well by the time you phone one person and you try to explain to them that you've got a growth inside you and it's bothering you and you're in a lot of pain and stuff, then they have to go and get somebody else to phone you back and you have to wait a long time ... eventually they do phone you back ... and then you're in absolute agony on the phone." Patient ⁴⁸

This was compounded by a lack of consistency in symptom management, with different professionals suggesting different approaches^{43, 47, 52}. This was sometimes described as a result of delayed or irregular medical reviews with specialists, or the lack of coordinated approach to care. This had a negative impact on both patients and carers^{51, 52}.

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“They took a lot of tablets off me [in the hospital], and my doctor [GP] went mad, because they shouldn’t have done ... I’m back on all my old medication now ... they shouldn’t have changed it.” Patient ⁵²

In addition, in the absence of a coordinated approach meant that the care patients received was often not streamlined with repetition and multiple appointments within the same location, within the same week often taking place^{43, 46}.

“ she says he is down at the same department three times in a week and he could be done in one day. Each of them that, the Sister, the Nurse and the anticoagulant clinic. She says it’s the same building and yet he has got to go three times daily, he’s got to go three times a week, different days.’ Carer ⁴³

Further consequences of this lack of continuity were that some families described being unaware of sources of support (for example additional financial support or additional out of hours support), which could have been beneficial for them^{44, 47, 50}. Patients felt that some professionals presumed that someone else had already provided them with this information, A lack of continuity meant that gaps in information provision were sometimes left unfilled^{47, 50}.

“I was surprised in retrospect that I hadn’t been told that [about Out-of-hours service]... perhaps they thought I knew... [Would have been less worried over the years if I’d known]” Patient ⁵⁰

The lack of informational and relational consistency experienced by patients and families negatively impacted their experiences of care, with patients enduring periods of great discomfort in order to wait until they could seek help from a professional that was familiar with their needs, and with whom they felt confident and supported.

B) Impact on patient and carer experience

(i) Additional burdens

Taking on the role of coordinator

Due to a lack of informational continuity between services, patients and carers took on additional administrative burdens or duties to secure a coherent approach to care management^{44, 47, 51, 53}. Patients and carers described having to take on the role of “coordinator” as services did not seem to be effectively

sharing information with each other. This was experienced as stressful and time consuming.

"It was up to me to contact her [the hospice nurse], and this is what people say, if you need any help ring, but it's an extra thing to do, to organise your own kind of help is an extra thing to do, and in the 24 hours you don't have much time or energy for extra things" Patient ⁴⁴

Some carers described an "unspoken pressure" from health care professionals to become "semi-professionals"⁵³. This was also a role that many people did not want, patients were often too tired and carers preferred to concentrate on spending quality time with loved ones⁴⁵.

"I mean our own GP obviously knows Dad's case inside out, but there must be a way where the [out-of-hours] doctor can access at least a recapped version of what's wrong with him you would think he had to tap into his computer and access everything but, you know, he went solely on what I told him when we went in. So that to me was strange." Carer ⁴⁵

Feeling vulnerable or out of control

In addition to the more practical impacts of low continuity (both relational and informational) significant emotional impacts for patients and families were reported^{45, 50}. Many carers reported feeling vulnerable or out of control when they could not access advice or support from a professional who was familiar with their history and needs.

"And I remember thinking, I'm vulnerable, my wife is in pain and we want a service and, and I have to ring up this person – 'The doctor will contact you'! What, tonight? Tomorrow?" Carer ⁴⁵

For patients, a lack of relational continuity meant that they could feel alone and unsupported.

"All I wanted was a voice to recognize me, um, or, or a voice to recognize what I was doing and say, there, there, [name], that's OK, I'll speak to you tomorrow, I'm aware of what's wrong with you, um, and that's fine. And really, the only voice who could do that would be [name], my, my nurse, um ... but obviously she switches her phone off, I think she [finishes her shift] at 5 o'clock..." Patient ⁵⁰

Continuity facilitators

In response to the fragmented nature of systems, patients and carers agreed that it would be beneficial to have one point of contact for their queries and concerns^{44, 48, 51, 53}. Some participants suggested this role could be occupied by a GP^{48, 53}, while others felt that the qualifications of the individual were less important than their ability to be a consistent source of advice, signposting or support⁴⁹. Furthermore, to truly promote continuity the need for multidisciplinary teams was highlighted.

Benefits of continuity for patients and carers

a) Feeling known

One of the most positive aspects of continuity from the perspectives of participants was that of “feeling known”, which was represented in a number of ways. “Feeling known” was related to recognition of who the patient was as a person, being listened to and having the professional demonstrate their ability to use their knowledge of the individual to recognise and act upon their suffering in a person centered manner^{44, 46, 48-50}. Where this level of relational continuity was achieved, it was highly valued.

“Yes, there was a nurse, a man, who came last week and took some blood. And I think he has been here once or maybe twice before. So, he asks me, how is your eating? Because I’d had problems last autumn, I lost a lot of weight. ... I think it is fantastic that he remembers. ... They care about the little things, ask how I’ve been over the holidays, what I’ve done, and so on.” Patient ⁴⁶

Another aspect of “feeling known” that was appreciated by carers in particular was the ability to notice small but potentially significant changes in a patient that could only be achieved through consistent interactions^{44, 46, 49}. In addition, for patients being cared for at home, families felt more comfortable when they had developed a relationship with health care professionals.

“but it would be wonderful if one nurse could concentrate on a case because you would have that continuity and they would notice changes and things and it would help them and probably help the family in that it isn’t a different person every night and you’re having to explain where the coffee is and what to do, but I know it isn’t practical because they have to have time off. But if it were one person, or even two, because we did have several different nurses.” Carer ⁴⁴

b) Feeling confident in care

Continuity in all of its forms, bolstered a sense of confidence in both care providers and the care plans developed for them^{46, 49, 50, 53}. Patients described feeling confident that their team could support them.

“There’s nothing worse than feeling that you are on your own and there’s no support and like it’s the unknown. When you know that you can pick up the phone and at the other end are experienced professionals and they are like tuned in and that in a matter of minutes you can have assistance. That makes all the difference”. Patient⁴⁵

The ability to contact a team that could respond quickly and appropriately was greatly appreciated by patients and carers and went some way to alleviating some of the anxiety associated with supporting a loved one with palliative care needs.

“ ... it happened in a few hours. He got a high temperature... but they came straight away and stood here with the doctor on the phone, and it felt like “Yes, they’ve got it covered.” That felt like WOW! ... They came for this and supported us, and that was great since ... It almost caused anxiety before [enrollment in SPHC] to have to call the healthcare center. ... No one [there] has the complete picture, and no one knows us. ... No continuity.” Carer⁴⁶

Discussion

Summary of findings

This mixed methods rapid review explored the impact of continuity for patients receiving palliative care. The limited quantitative evidence reviewed indicated that improving continuity of care may be related to reduced hospital admissions and achieving preferred location of death, although this review does not provide conclusive evidence of this.

Poor continuity was described as related to delays and difficulties in accessing care and increasing the burdens experienced by patients and carers. Patients were often left feeling vulnerable or unsupported without a clear understanding of their care plan and how to access support. In contrast, when patients experienced good continuity of care they felt confident, known and supported by care providers.

Comparison to other literature and the wider context

Many of the facilitators for continuity for palliative patients identified in this review (having one point of contact, and strong multidisciplinary working and information sharing), and the perceived benefits of continuity (accumulated knowledge) were identified in a review of the impact of continuity for patients

with a range of conditions²¹. Waibel et al (2012) note that continuity could be enhanced when patients take an active approach to the management of their own care. In the current review, in palliative care, participants and carers experienced the need to adopt the role of coordinator as burdensome and unwelcome. This may reflect both similarities and differences in how to promote continuity for patients with different conditions and at different stages of illness.

The impact of poor informational continuity for palliative patients was highlighted in this review. Retrospective studies highlight potential strategies for promoting continuity for this group, including electronic information sharing. Electronic palliative care coordination systems (EPaCC systems)⁵⁴ have been suggested as useful in promoting information continuity for palliative care patients, although further work is needed to develop and test such strategies.

This review also highlights the importance of relational continuity for palliative care patients. Informational continuity is clearly important, but in isolation may be insufficient to achieve optimal patient outcomes or experiences. The importance of “feeling known” by health care professionals was clear in this review, both for the emotional and physical wellbeing of patients (in terms of delaying access to out of hours services). These benefits have been described in previous research within palliative populations⁵⁵.

Despite evidence of the beneficial impact of continuity of care on both patient outcomes and experiences, continuity is not “built in” to interventions in the same way as other aspects of health care delivery⁵⁶. The number of retrospective studies in this area suggests that continuity is currently considered more of an outcome than an integral part of the health care process. This needs to be addressed. While there are undoubtedly methodological challenges in exploring the impact of interventions designed to promote continuity, this is an area in which future research is needed. It was also interesting to note that no quantitative studies included measures of patient satisfaction with care. Given the themes identified in the qualitative data, highlighting the positive impact that continuity had on their experiences of care and support, this is perhaps something to be considered in future studies.

Continuity of care is difficult to deliver, and can be hard to measure, but is vitally important to patients. Relational continuity provides the context upon which to build individualised care plans for patients, that in turn, requires informational and managerial continuity between services to be effective. Improving continuity in palliative care may not remove every negative experience for palliative care patients and their families. However, the contrasts in reports of patients who had, and had not, perceived continuity

in their care in this review demonstrate the beneficial effects that continuity can have in terms of feeling safe, known and supported. While continuity may not be the panacea for all the challenges in providing high quality palliative care, we believe that good continuity, in a range of forms, can go a long way to improving a difficult time in a family or a person's life. We acknowledge that where continuity is more integrated into care, or where elements of interventions are not identified as continuity facilitators, they may not have been included in this review.

Limitations

There are a number of limitations to this review that warrant consideration. This rapid review was completed within 12 weeks and only research published within the last 10 years was included, grey literature and the views of health care professionals were not included.

Half of included studies were conducted in the UK. We acknowledge that patient experiences are shaped by the health care services and structures of the country in which they are receiving care, however aspects of the experience of both good and poor continuity may transcend national borders.

Defining which interventions should be considered eligible for inclusion in this review was a challenge given the various definitions and approaches to continuity found in the literature. Consensus over whether an article was eligible for inclusion was assessed through consulting the full text articles, referring back to the definitions of continuity outlined in Haggerty et al's review² and discussion amongst the research team.

Implications for future research and practice

The development of future interventions to improve care for palliative patients should consider how strategies for promoting both information and relational continuity can be embedded within interventions, and subsequently health care, alongside robust methods to measure the extent and impact of continuity achieved.

Conclusions

The impact of poor continuity and the potential benefits of improved continuity highlighted in this review add additional evidence to the body of literature calling for increased efforts to promote both informational and relational continuity for palliative care patients. Methods for enhancing, and recording

continuity should be considered in the design and development of future healthcare interventions, across the lifespan.

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Data sharing statement

No additional data is available for this review.

Competing interests

The authors declare that they have no competing interests

Authors' contributions

BH, BN and SB conceptualised the study. BH designed the search strategy. BH ran the search strategy. BH screened the articles, extracted data, analysed the results, and drafted the manuscript. BN reviewed eligible articles. BH, BN, SB and PS critically reviewed several drafts of the manuscript and approved the final draft.

Figure legend

Figure 1. Data extracted from identified studies

Figure 2. PRISMA Flow diagram outlining study identification, screening, eligibility and inclusion

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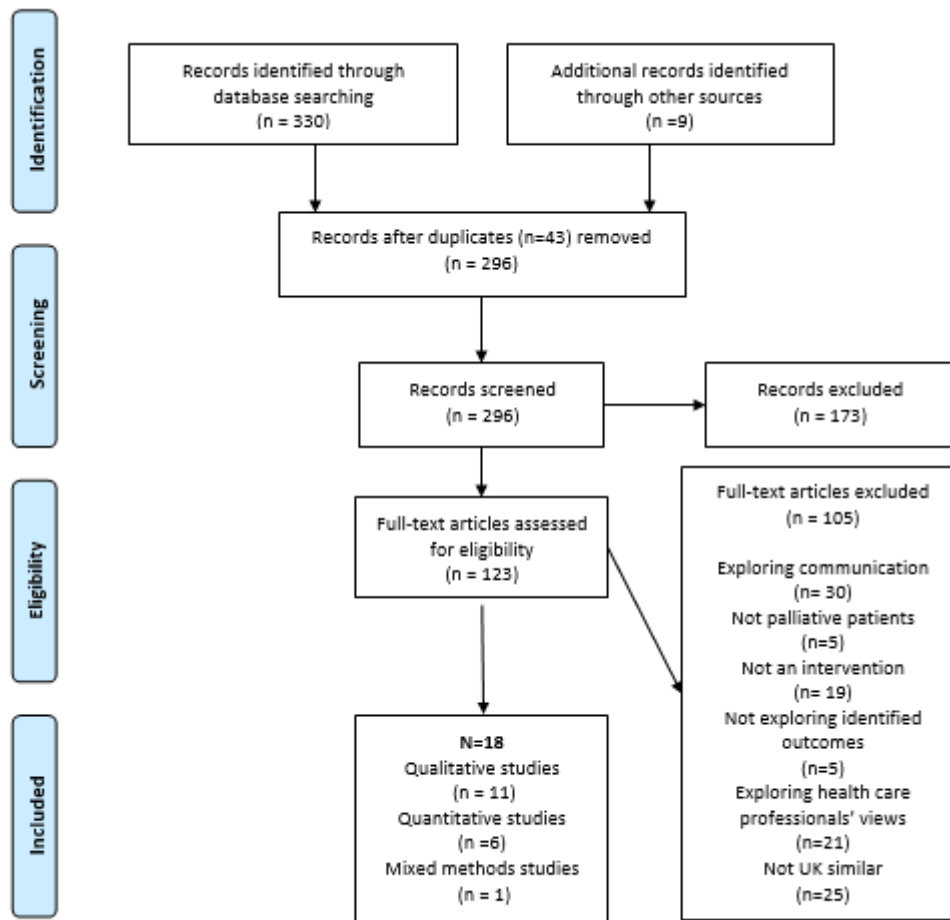
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Figure 1. Data extracted from eligible studies.

All studies	Intervention studies	Qualitative studies
- Participant type (patient, carer, both) - Diagnosis - Study design & methodology - Type of continuity explored (relational/informational) - Main findings	- Components of interventions - Impact of intervention on specified outcomes (patient/carers satisfaction with care, preferred place of death or reducing hospital admissions)	All text labeled as “results” or “findings” (both in the abstracts and texts of papers) were extracted.

Figure 2. PRISMA Flow diagram outlining study identification, screening, eligibility and inclusion.



Appendix 1

No studies were excluded following the quality assessment (Table 3).

Quality assessment scores for included papers

Source Paper (n=12)	Title of paper	Abstract/Title	Intro/Aims	Method/Data	Sampling	Data Analysis	Ethics/Bias	Transferability	Implications	Quality score (out of 36)
Leydon (2013)	Discontinuity of care at end of life: a qualitative exploration of out of hours end of life care	4	4	4	4	4	3	4	3	34/36
Seamark (2014)	Dying at home: a qualitative study of family carers' views of support provided by GPs community staff	3 – method of data analysis absent from abstract	3	3	4	4	3	4	4	32/36
Payne (2017)	Enhancing integrated palliative care: what models are appropriate? A cross-case analysis	3	4	4	3 – no response rates reported	4	4	3	4	33/36
Richards (2011)	The experiences and needs of people seeking palliative health care out-of-hours: a qualitative study	4	4	3 – schedule not included	4	4	4	4	3- future research missing	34/36
Klarare (2017)	Experiences of security and continuity of care:	4	4	3	3	4	4	4	4	34/36

	Patients' and families' narratives about the work of specialized palliative home care teams										
Bailey (2016)	Hospital care following emergency admission: a critical incident case study of the experiences of patients with advanced lung cancer and Chronic Obstructive Pulmonary Disease	4	4	4	4	4	4		3	4	35/36
McLaughlin (2010)	Living and coping with Parkinson's disease: Perceptions of informal carers	4	3	2	2	3	3		3	3 implications for practice not outlined	24/36
Neergaard (2008)	Palliative care for cancer patients in a primary health care setting: Bereaved relatives' experience, a qualitative group interview study	3	3 – brief literature review	4	4	4	2		3	4	31/36
Browne (2014)	Patient, Carer and Professional Perspectives on Barriers and Facilitators to Quality Care in Advanced Heart Failure	4	3	4	3	3	3		3	3 – no future research recommendations	30/36
Jack (2016)	Supporting older people with cancer and life-limiting conditions dying	4	4	3	3	4	4	4	3	4	29/36

	at home: a qualitative study of patient and family caregiver experiences of Hospice at Home care										
Adam (2015)	Utilising out-of-hours primary care for assistance with cancer pain: a semi-structured interview study of patient and caregiver experiences	4	3	4	4	4	3		4	4	34/36
Mortel (2017)	Reducing avoidable admissions in rural community palliative care: a pilot study of care coordination by General Practice registrars.	4	4	4	3	4	4		3	3	33/36
Ingadottir (2010)	Partnership-based nursing practice for people with chronic obstructive pulmonary disease and their families: influences on health-related quality of life and hospital admission	4	4	4	3 – no power calculation data included	4	4		3	3	33/36
Montero (2016)	Reducing Unplanned Medical Oncology Readmissions by Improving Outpatient Care Transitions: A Process Improvement Project at the Cleveland Clinic	4	4	4	4 – all admitted patients were eligible	4	4		4	3 – relates to previous findings, no recommendations for research	35/36
Edwards (2014)	Outcomes Assessment of a Pharmacist-Directed Seamless	3	4	4	3 – sample size justification and	3	4	4	4	3 – recommendations for future	28/36

	Care Program in an Ambulatory Oncology Clinic				response rates not included.				research missing	
O'connor (2016)	Establishing a nurse practitioner model to enhance continuity between palliative care settings.	4	4	2 – qualitative is anecdotal, quant methodology not very robust	3 – sample size justification and response rates not included.	2 – qual data analysis lacking Quant data analysis not robust	3		3	26/36
De graff (2016)	Hospice assist at home: does the integration of hospice care in primary healthcare support patients to die in their preferred location – A retrospective cross-sectional evaluation study	4	4	3	4	2	4	4	4	32/36
Morris (2017)	Caring About Residents' Experiences and Symptoms (CARES) Program: A Model of Palliative Care Consultation in the Nursing Home	4	4	3	2 – few details given of sample	3	1	2 – more information needed	3	25/36



PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	2
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	3
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	n/a
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	3,4
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	4
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	4
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	5
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	5
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	5
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	5
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	3
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I ²) for each meta-analysis.	5,6

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PRISMA 2009 Checklist

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Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	12
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	n/a
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	6
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, follow-up period) and provide the citations.	7
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	12
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	n/a
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measure of consistency.	n/a qual synthesis page begins on page 18
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	12
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	n/a
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	24
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	25
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	26
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	26



PRISMA 2009 Checklist

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