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Facilitators of and barriers to continuity with GPs in primary palliative cancer care: A mixed-methods systematic review

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Background: General practitioners (GPs) have a key role in palliative care provision for patients with advanced cancer. Continuity is valued by patients with such needs but is limited within current primary care systems. Exploration of the facilitators of and barriers to continuity in this complex context is required.
Aim: To identify facilitators of and barriers to continuity with GPs in primary palliative care among people with advanced cancer and/or their close persons.
Design: Mixed-methods systematic review with content and thematic analyses.
Data sources: Keyword searches were carried out in five databases (Ovid MEDLINE(R), Ovid EMBASE(R), CINAHL, Web of Science, and Cochrane), policy documents and grey literature search engines in December 2020. Evidence was reviewed using relevant quality appraisal tools; data were extracted and tabulated. Findings were reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement, and the review was prospectively registered on PROSPERO.
Results: Seventeen studies were included. Six studies originated from the UK; six from Europe; three from Canada; and two from Australia. Two studies were mixed-methods, four presented quantitative data, and 11 papers reported on qualitative studies. Four themes were developed: (1) the role of GPs in facilitating continuity; (2) the role of patients and/or close persons in facilitating continuity; (3) changing needs throughout the disease trajectory; and (4) the organisational context in primary care.
Conclusions: Facilitators of and barriers to continuity in primary palliative care are outlined. Further research is required to explore how patients and/or their close persons experience continuity in primary palliative care. Specifically, the work required of them to achieve their desired level of continuity, and their capacity for action in this context, needs further attention.

Keywords: Palliative supportive care, Palliative care medicine, Neoplasms, Continuity of patient care, Primary care

Key messages

What was already known?

- Continuity of care reduces mortality and hospital use, improves clinical outcomes and medication compliance, increases patient and clinician satisfaction, and is cost-effective.
- Patients with palliative care need value primary care continuity, which can be limited by organisational constraints.

What are the new findings?

- Barriers to and facilitators of continuity in primary palliative care for people with advanced cancer are identified.
- The role of patients and their close persons in facilitating continuity is noted to be underexplored.

What is their significance?

- Further research is needed to understand the role, responsibility and capacity among service users in facilitating continuity in primary palliative care.
- Supporting patients and their close persons to facilitate continuity in this context may improve their experience and health-related outcomes.

Introduction

Continuity of care is defined as: 'the extent to which a person experiences an ongoing relationship with a clinician and the coordinated clinical care that progresses smoothly as the patient moves between different parts of the health service'.[1] This complex concept can be considered in terms of relational continuity

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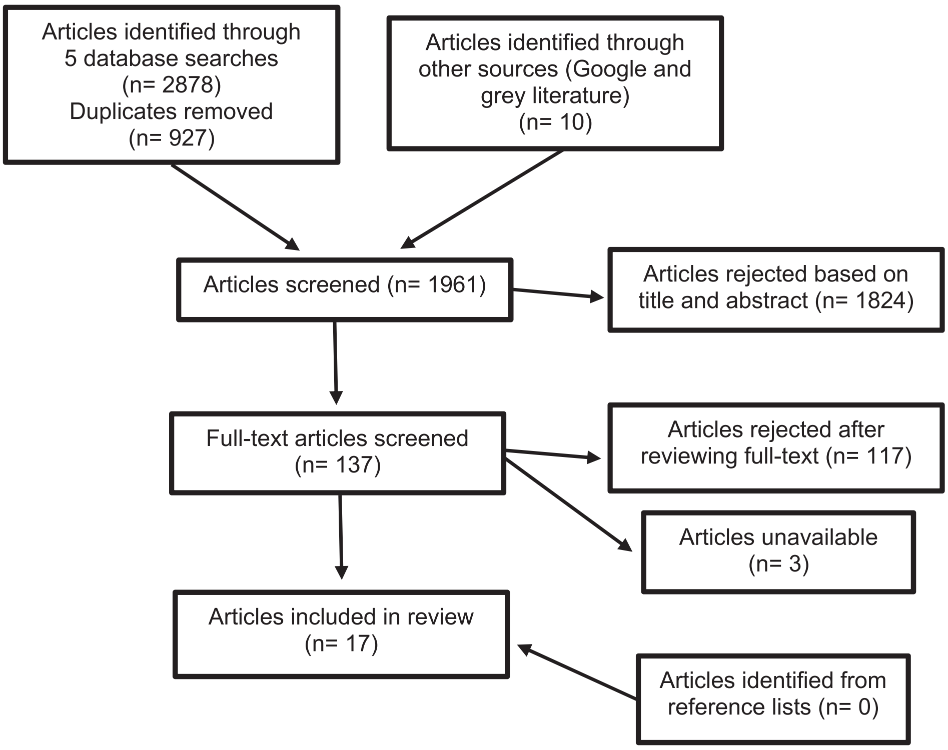
(the same professional seeing the same patient over a period of time); informational continuity (professionals having access to accurate, up-to-date patient records); and managerial continuity (timely and efficient handovers of care between clinicians, teams, and organisations). Continuity of care reduces mortality and hospital use, improves clinical outcomes and medication compliance, increases patient and clinician satisfaction, and is cost-effective.[1]

Primary palliative care provision is a progressively important issue, given the ageing population with increasingly complex health and social care needs.[2] Continuity is especially valued by patients with palliative care needs.[3–6] Broad definitions of palliative care, as treatment and support to improve the quality of life of people with any life-threatening condition,[7] echo descriptions of primary care, which 'provides holistic, person-centred, continuing, comprehensive and coordinated care to patients and their families in their communities'.[8,9] GPs have a key role in providing palliative care, which is often delivered in primary care without being labelled as such.[10] The term 'primary palliative care' is used throughout this review to describe the delivery of palliative care in primary care. Primary care faces additional pressure given the current COVID-19 pandemic, for example the number of deaths in private homes and care homes has dramatically increased.[11]

Internationally, primary care structures are changing, which may complicate (and compromise) the ability to provide relational, managerial and informational continuity of care.[2] For example, in both the Canadian and UK primary care contexts, the GP assumes the 'gatekeeper' role. Both settings have a reducing overall number of GPs, who are increasingly working part-time, relocating frequently, and withdrawing from hospital work.[12,13] However, the perception of the GP's role in continuity may vary internationally[14,15]. For example, in both Germany and Belgium, patients can freely consult with specialist healthcare professionals, so the GP is not the 'gatekeeper' to secondary care services.

This review examined the facilitators of and barriers to continuity from the perspectives of patients with advanced cancer and their close persons.[14,16]



Reasons for rejection

Economic analysis only; Secondary care/hospital setting only; Specialist palliative services only; Nursing only, no mention of GP; Diagnostic or survivorship stage only; Patients not palliative or with advanced cancer; Paediatric participants; Focus on euthanasia/assisted dying; Comparing malignant vs non-malignant care; Medical education/training only; Review articles; Poster abstracts; Non-malignant conditions only (or if cancer patient data not able to be separated); Healthcare professional perspectives only (or if patient data not able to be separated)

Figure 1 PRISMA flow diagram

There is a significant gap in our understanding of the delivery of continuity in primary palliative care, despite evidence that such patients value and derive significant benefit from this type of care.[1,2,4] These individuals often have complex health and social care needs requiring the involvement of multiple healthcare professionals in a range of settings, and a consistent rapport with their GP could provide a much-needed anchor and a comforting relationship within which to discuss fears at a distressing time of life.[6] Though the review focussed primarily on the GP's role in continuity, the increasingly multidisciplinary primary healthcare context for patients with advanced cancer is recognised.

Aim

This mixed-methods review aimed to explore facilitators of and barriers to continuity with GPs in primary palliative care for people with advanced cancer and/or their close persons.

Review question

- What are the facilitators of and barriers to continuity with GPs in primary palliative care for people with advanced cancer and/or their close persons?

The review adhered to a combination of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 statement,[17] and the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) framework.[18] It was registered prospectively on PROSPERO (ID: CRD42020223117).[19]

Method

Sampling and search strategy

A comprehensive search strategy was developed, in conjunction with a Health Sciences librarian, to capture quantitative, qualitative and mixed-methods papers relating to continuity of care in primary palliative care for patients with advanced cancer and/or their close persons. An iterative approach, rather than the standardised use of a formal search filter tool, was decided upon to ensure all relevant studies were captured. The Medical Subject Headings and keywords used were appropriately modified for each bibliographic database searched (Tables 1 and 2).

Searches were carried out in five databases (Ovid MEDLINE(R), Ovid EMBASE(R), CINAHL, Web of Science, and Cochrane), relevant policy and voluntary sector websites and grey literature search engines (MedNar, OpenDOAR, Royal College of General Practitioners; Nuffield Trust; King's Fund) in December 2020. The reference and citation lists of included studies were reviewed. A Google search was undertaken using an advanced search string based on Boolean logic, and the first 10 pages of results were assessed. Input from the review team was sought to ensure relevant publications, guidelines or policies were identified (Fig. 1).

Table 1 Search terms

	MeSH	Free Text
Cancer	Neoplasms Oncology Nursing Medical Oncology Carcinoma	Cancer Onco*
Palliative care	Palliative Care Terminal Care Palliative Medicine	Palliati* End of life End stage Dying
Primary care	Primary Health Care Family Practice Physicians, Family General Practice General Practitioners Community Health Services Home Care Services After-Hours Care	Primary care General practi* Community care
Continuity	Continuity of Patient Care	Continuity

Table 2 Sample search strategy (Medline via OVID)

Database: Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily <1946 to November 25, 2020>
Search Strategy:
1 cancer.mp. or Neoplasms/ (1978858)
2 onco*.mp. (548891)
3 oncology.mp. or Oncology Nursing/ or Medical Oncology/ (123715)
4 Carcinoma/ or carcinoma.mp. (846173)
5 Palliative Care/ or Terminal Care/ or palliat*.mp. (118536)
6 palliative medicine.mp. or Palliative Medicine/ (2337)
7 end of life.mp. (24780)
8 end stage.mp. (72932)
9 dying.mp. (35571)
10 primary care.mp. or Primary Health Care/ (152827)
11 General Practice/ or General Practitioners/ or general practi*.mp. (92972)
12 Family Practice/ or family practi*.mp. or Physicians, Family/ (82650)
13 primary care practi*.mp. (7806)
14 Community Health Services/ (31882)
15 community care.mp. or Home Care Services/ (38292)
16 After-Hours Care/ (1889)
17 'Continuity of Patient Care'/ or continuity.mp. (51639)
18 1 or 2 or 3 or 4 (2716003)
19 5 or 6 or 7 or 8 or 9 (223083)
20 10 or 11 or 12 or 13 or 14 or 15 or 16 (330693)
21 18 or 19 (2877785)
22 17 and 20 and 21 (787)

Papers relating to the perspectives of adults (>18 years) with advanced cancer and/or their close persons about continuity with GPs in primary palliative care were included.

Terms such as 'involvement', 'collaboration', 'coordination', 'abandonment' and 'fragmentation' were used to discuss issues relating to continuity.[15,20]

The primary focus of the review was continuity with GPs. Of course, it must be acknowledged that GPs work in teams, therefore, studies that discussed

Table 3 Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
• Perspectives of adults (>18 years) with advanced cancer and/or their close persons about continuity with GPs in primary palliative care • All types of original research published in full • Any country of publication • Published in English • No date limits	• No mention of GP • No mention of continuity (or other relevant terminology) • Secondary care only • Paediatric patients • Patients with cancer in diagnostic or survivorship stages only • Not published in English • Review articles • Poster abstracts

the complex, multidisciplinary organisational environment of primary care were included if they enabled contextualisation of the GP's role. The intention of later work would be to widen the lens to explore the role of allied healthcare professionals in continuity (Table 3).

Data collection

The software 'Covidence' was used to screen references (at title, abstract and full-text stages).[21] EC screened all references independently, and a second reviewer (CG) also screened five percent of titles and abstracts selected at random to ensure the selection criteria were applied with good agreement. Two further reviewers (SEM, SM) then each reviewed five papers at the full-text stage to determine inclusion and ensure consistency. (The rest of the full-text papers were single-reviewed by EC). If there were discrepancies in opinion regarding the eligibility of particular studies, discussion took place, and consensus was achieved. This approach was deemed feasible by the review team given time and resource constraints.

Data were extracted from included studies and tabulated into a bespoke table by EC (Appendix 1). Quality appraisal was conducted using Gough's 'Weight of Evidence framework'[22] and Pluye's 'A scoring system for mixed methods research and mixed studies reviews'[23] (Appendices 2 and 3). The quality appraisal process helped the authors to gain a full understanding of the existing evidence base. Debate remains as to whether mixed methods reviews should exclude certain studies based on their quality appraisal. This review excluded no studies based on their quality assessment as it was felt that relevant studies might be illuminating even if they were of low quality.[24–26]

Analysis and synthesis

Data were extracted and synthesised using iterative, thematic content analysis.[27] This resulted in a data-based convergent approach, given that the findings across all included studies were amenable to categorisation within consistent themes. The findings were presented as a narrative synthesis. The primary studies included in the review were not conducted specifically to answer our compound research question, therefore, a layered analysis was required.[28]

Results

Seventeen studies met the inclusion criteria (Appendix 4).

Four themes were developed from the data:[1] the role of GPs in facilitating continuity;[2] the role of patients and/or close persons in facilitating continuity;[3] changing needs throughout the disease trajectory; and[4] the organisational context in primary care.

Barriers to and facilitators of continuity in primary palliative care for people with advanced cancer were identified across all four themes. In summary, common barriers included: an 'uninterested' GP; a GP's lack of time; poor understanding among patients of healthcare professional roles; geographical role variation; poor communication between secondary and primary care; patients wanting disease-specific needs to be met by their specialist; increased multidisciplinary working reducing GP involvement; increased part-time GP working; staff shortages; and diagnostic delay resulting in distrust of GP.[5,9,12,14,15,20,29–34] Common facilitators included: GP empathy and proactivity; effective GP communication skills; flexible and accessible GP; having a longstanding temporal relationship with GP; and role clarification of multidisciplinary team members.[5,9,12,20,29–34]

Key themes

The four key themes will now be presented in turn. The facilitators and barriers within each theme will be presented at the start of each section and highlighted in bold within subsequent paragraphs.

- The role of GPs in facilitating continuityThe patients and carers did not expect primary care staff to be experts in cancer, but valued their ongoing support.[12]

The key facilitators within this theme include: GP proactivity; flexible, responsive GP; timely action of GP; and GP character traits such as empathy.

The key barriers include: uncertainty of the GP's role; patient preference for specialist to provide care; GP dependent on effective information exchange across healthcare settings; and a lack of initiative among GPs.

GP involvement in palliative cancer care was categorised into three patterns: sequential; parallel; and shared care. In shared care, GPs were involved in a patient's cancer care; in parallel care, GPs were in contact with patients but were involved only with non-cancer issues; and in sequential care, patients were largely cared for by their oncologist after their diagnosis.[12] The main reason suggested for these different patterns of care was related to uncertainty of the GP's role. Participants expressed a preference for their specialists to be responsible for disease-specific medical decision-making, and GPs were considered solely responsible for administrative tasks such as ensuring repeat prescriptions are processed.[5,30,31,35] Shared care often started with a statement of intent to be involved in a patient's cancer care made by a proactive GP. GP proactivity was said to permit a true partnership style of care, and was important to patients.[12] Key time points were identified at which GPs could check in with patients so as to clarify their healthcare preferences, facilitating this approach.[33] Proactive GPs were felt to be in a position to clarify the level of contact and follow-up preferred by a patient, thereby enhancing the collaborative, patient-centred element of the relationship.[33]

The ability of a GP to respond flexibly and in a timely manner to changes in a patient's condition, taking into account other factors such as the level of family support received by each patient, was deemed particularly important in the context of advanced cancer.[9,33] For GPs to respond appropriately to gaps in their patients' care, they required an understanding of how patients' needs may or may not be met by other healthcare professionals or services.[9] This 'overseeing' approach, with a need for a 'focus on the patients' entire pathway of care', depended on effective and uniform information exchange across healthcare settings, so as to achieve successful 'cancer care coordination'.[15] GPs were considered to be advocates, a role that is reliant, however, on 'excellent communication between specialists and GPs', which further emphasises the need for effective informational and managerial continuity.[30] In complex and fragmented healthcare systems, the idea that a single individual can coordinate patient may be unrealistic.[31]

Continuity was viewed as 'an important task and/or attitude' of GPs. The individual character of the GP was said to determine whether continuity occurred or not. For example, the identification of barriers such as 'GP's lack of initiative' reflects the perception of continuity as an attitude rather than a task.[14] Relational continuity was less important to patients if a GP had good interpersonal skills and was supported by informational continuity. A GP's character was important to patients, who felt that they had a strong doctor–patient relationship when their GP showed their 'human' side.[5] In one large survey study, participants expressed a wish for support with their psychosocial needs from their GP, with empathy from the GP resulting in a better doctor–patient relationship. 'Strong empathy' was perceived if the GP initiated contact, reiterating the importance of the 'proactive' trait among GPs.[34]

- The organisational context in primary care … there seemed to be no typical standard of what could or should be provided for terminally ill patients.[29]

The key facilitators within this theme include: unity between primary and secondary care health professionals; and secondary care professionals advocating role of GP to patients.

The key barriers include: variable structure of general practice; bureaucratic organisational factors; uncertainty of roles of healthcare professionals and services; and lack of informational and relational continuity in out-of-hours context.

The organisational context of a healthcare system may present challenges to continuity.[5] Michiels et al. suggested that there may not be a 'one size fits all' approach that works across the board, rather that various systems will be required depending on how each practice functions on a day-to-day basis, and how it interacts with its wider healthcare context. The authors proposed various solutions depending on the structure of a general practice. In a multi-handed GP practice, for example, a buddy system may be effective. Alternatively, continuity may be facilitated by specific follow-up sessions that the GP could manage directly with patients depending on clinical need. Such approaches were portrayed as being 'physician-friendly', which may of course have a positive impact on a GP's job satisfaction and lead to lower rates of burnout.[14] Jarrett et al. suggested that as individuals, healthcare professionals often wanted to provide continuity, but that bureaucratic organisational factors hindered their ability to do so. For example, the fixed allocation of shifts to community nurses limited their ability to be flexible and to provide complete episodes of care to their patients based on clinical need.[29]

Halkett et al. advised that uncertainty of the roles of healthcare professionals may lead to inappropriate service use, particularly in acute situations, which may have financial implications for health services. Explicit information for patients regarding where to seek help in certain circumstances that may be anticipated during their disease trajectory was advocated.[30] Johnson et al. compared the expectations and reality of various themes that exemplify optimal end of life care for patients with cancer in the context of rural general practice. If the GP was found to meet their needs sufficiently, patients would be more likely to decline the involvement of other healthcare professionals, for example specialist nurses. GP involvement therefore clearly has a significant impact on service use.[9]

Patients were more likely to report effective continuity where they perceived unity between primary and secondary care health professionals, facilitating GP involvement with cancer care.[30,36,37] If GPs echoed the information provided by secondary care, patients felt supported.[37] If patients felt that oncologists and GPs were communicating well with one another, they seemed more likely to consult with their GP about cancer-related issues, and had more confidence in their GP's availability and ability to manage cancer-related concerns.[36] It was suggested that oncologists could facilitate a strong link between the patient and their GP, by reiterating the importance of the GP's role and involvement in cancer care.[30,36] Thus, consistency, facilitated by informational and managerial continuity[15], improved healthcare experience and resulted in patients having positive attitudes towards their care.[37]

Internationally, out-of-hours (OOH) primary care is delivered outside of 'normal working hours', and increasingly tends to be operationally independent from daytime services.[38,39] For example, the 'GP cooperative' model is prevalent in the OOH context of the healthcare systems included in this review, since the 'rationalisation of 24-hour availability of GPs'.[6] Common features of service provision include telephone consultations, home visits and face-to-face appointments at a designated base (often not a patient's usual GP practice). Nursing or non-clinical staff are often responsible for triaging calls.[6] Richards et al. explored the experiences of seeking OOH care in terminal illness.[40] GPs working in the OOH setting do not have routine access to full medical records, and are unlikely to experience relational continuity with patients. Patients expected informational continuity to extend to the OOH context, yet it did not. They did not expect relational continuity, but would have liked it. Patients reported preferring to have direct access to oncology wards as they perceived continuity and felt secure in the specialist knowledge they provided.[40]

- The role of patients and/or close persons in facilitating continuityPatients who proactively took control of their care were more able to influence continuity than those who were disengaged and/or depended on the medical professionals to take charge of their illnesses.[32]

The key facilitators within this theme include: empowerment of patient / close person; involvement of close person in patient's care; effective health administration; shared decision-making; proactive patient personality trait; GP awareness of family dynamics; and provision of patient information to support navigation of local healthcare services.

The key barriers include complex multidisciplinary care context; and passive patient personality trait.

There was limited evidence on the role of patients and/or their close persons in facilitating continuity, with only two studies by the same team explicitly mentioning this.[20,32] Nazareth et al. outlined four main facilitators to perceptions of good continuity: 'patients' actions; the engagement of people close to them; the ability to share treatment decisions; and the effectiveness of health administrative systems.'[32] The palliative care context was thought to be particularly challenging for GPs to maintain their position as the central coordinator given the often-complex multidisciplinary team approach to care. The authors suggested that supporting and empowering patients to influence continuity of their own care, or to identify individuals who may be able to advocate on their behalf, would go some way to surmount this hurdle.[32]

King et al. suggested that a patient's personality, whether 'proactive' or 'passive', can influence their perception of continuity and their ability to influence the level of continuity they experience. They also acknowledged the impact that a patient's personality has on preferences for care and their ability to cope. It was suggested that communication with healthcare professionals was more effective, and a patient's ability to make difficult decisions enhanced; if their family members were involved. It was recommended that GPs should pay close attention to family dynamics and close person involvement in the patient's healthcare journey, so as to understand patient needs in relation to continuity and how best to facilitate this.[20]

Other studies referred to the role of patients and/or close persons in continuity, but this concept was not a key focus of such articles. For instance, Jarrett et al. suggested that the provision of information booklets to patients, highlighting the roles of local healthcare professionals they may encounter within their multidisciplinary care, may manage expectations and also empower patients to make appropriate decisions with regards to navigation of the healthcare system.[29]

- Changing needs throughout the disease trajectorySpecialists should actively endorse the role of the GP in order to ensure that the patient has an additional or alternative source of support throughout the cancer journey.[30]

The key facilitators within this theme include: taking disease trajectory into account when assessing the need for continuity; and a long-term GP-patient relationship.

The key barrier includes a loss of contact with GP during the specialist treatment phase of the illness.

The level of continuity a patient requires may be dependent on factors such as their diagnosis or disease trajectory. For example, patients with cancer may need an entirely different approach to continuity, as their diagnosis is often shrouded in fear given its potential to threaten life. King et al. support the idea that continuity is a spectrum rather than a binary concept.[20]

The needs of patients changed, and often increased, as their disease progressed.[9] The capacity of a patient's GP to meet their needs was also found to vary greatly depending on their stage of illness.[30] Patients seemed to gravitate back to their GP as their cancer progressed, but if the GP had not maintained an ongoing relationship with the patient throughout their cancer care, then it was difficult for the GP to resume responsibility.[41] The connection between patients with cancer and their GPs was often lost by the time patients reached the terminal phase of their illness,[12,41] meaning that patients often sought additional support from their specialist at such times.[30] GP involvement was deemed important from diagnosis, so that their knowledge of the patient's illness and the doctor–patient relationship had been well-established by the final weeks of life.[33] Long-term relationships, and consequently a GP's increased non-medical knowledge of a patient, were said to facilitate difficult discussions.[9]

Discussion

Main findings of the study

Throughout all four themes, was a sense that each individual patient's context, preferences and priorities must be appreciated in order to provide the appropriate level and type of continuity.

Continuity is difficult to define given its complexity; its multiple inter-relating components and dependency on contextual factors.[42] Terms such as 'involvement', 'collaboration' and 'coordination' were used in included studies that discussed issues relating to continuity. Further, the terms 'abandonment' and 'fragmentation' were used to reflect a lack of continuity.[15,20] Informational and managerial continuity are often viewed as overlapping concepts, and many studies in this review presented them as such.[14,31,40] Muddying the waters even further was the finding that participants viewed continuity as a 'task and/or attitude of their GPs', which supports the ongoing struggle to describe continuity and its outcomes.[14]

The issue of individual roles and responsibility in continuity of care was a recurring theme, approached from various angles. Only two of the 17 included studies directly considered the role of patients, and their close persons, in facilitating continuity of care.[20,32] Dalsted et al. suggest that a single individual (GP) assuming a coordination role for patient care across the entire healthcare system is unrealistic.[31]

Strengths and limitations of the review

The fact that studies with diverse methodological approaches have yielded similar findings, highlighted by the data-based convergent approach, adds confidence to this review's conclusions.[43] Differences in the organisation of healthcare internationally mean some findings may not be relevant outside of their country of origin.[44] For example, in both Germany and Belgium, patients can freely consult with specialist healthcare professionals, so the GP does not have the 'gatekeeper' role as they do in systems like the UK's.[14,15] Due to time and resource constraints, a small proportion of papers at full-text stage were dually reviewed and EC independently constructed themes. Further, only studies written in English were included, therefore, findings may not be generalisable internationally. Handsearching was not undertaken as location bias did not seem a particular issue during the search process. No date limit was applied to the search strategy, which may have implications given the dynamic context of primary care over the years.

What this study adds

The review question is grounded in the current UK clinical context. Previous research has demonstrated the 'effectiveness' and 'appropriateness' of continuity: it benefits, is suitable for, and is valued by patients with cancer and palliative care needs.[2,5] Therefore, this review instead focussed on the facilitators and barriers to its delivery.[45]

King et al. stated their intent to measure the patient-centred outcome of 'experienced continuity', rather than describe the process of continuity at the service provision level, as proposed by healthcare professionals.[20] This disparity was not identified in other studies, yet the clear delineation has a significant impact on how findings are interpreted. The authors highlighted that measuring continuity in this way resulted in wider issues being raised, not just whether patients see the same healthcare professional at each consultation. The authors recommended that to achieve 'experienced continuity' requires the development and encouragement of self-management skills to facilitate coping among patients and their close persons. They, therefore, acknowledged an additional element to continuity alongside the relational and informational components: that 'patients are enabled to cope between service contacts'.[20]

Despite the emphasis on patient-centred healthcare in the UK and internationally, the active role of the patient (and of their social circle) remains underexplored and inadequately facilitated by professionals.[44,46,47] Multiple factors are known to affect a patient's ability or willingness to assume an active role in partnership with their healthcare professional. These are very much dependent on context but may include elements such as demographic characteristics; illness severity; health literacy; and healthcare setting. A 'patient's perception of their role and status as subordinate to clinicians' has been identified as a barrier to patient engagement. Such impediments could be lessened by educational and cultural shifts, advocating the partnership approach to healthcare among both patients and healthcare professionals.[48]

Little research focuses on the patient's (and close person's) responsibility and capacity for action regarding continuity. Two studies originating from the same institution discussed how services users might facilitate continuity.[20,32] Nazareth et al. suggested that a realistic approach to continuity in the increasingly multidisciplinary primary palliative care context was to empower and support patients to facilitate their own continuity.[32] Close persons may have more capacity than unwell patients to influence continuity of care[49]. King et al. suggest that a GP's awareness of a patient's social context may facilitate more effective self-management among patients and their close persons. This is particularly poignant in the context of advanced cancer.[20]

Continuity has long been thought of as something to be achieved; an outcome. However, King et al. suggest it is 'less a package that professionals can offer and more an interaction between the care offered, the context and the patient's beliefs and attitudes about those close to them'.[20,50] Michiels et al. reported that participants viewed continuity as either a 'task and/or attitude of their GPs'.[14] An attitude is described as one's posture or the way of carrying oneself; whereas a task is something to be accomplished. One's attitude to continuity is, therefore, a highly personal thing and raises the question as to whether continuity is something that can be taught or learned.[51] Could continuity be considered as an aspect of a healthcare professional's character, entwined with their personality and professional interest? For example, patients may perceive better continuity and proactive care if they engage with a practice that has a GP with a special interest in palliative cancer care, and recognises the importance of continuity for this patient group.[12] A more formal recognition of subspecialisation among GPs may allow doctors' characteristics and skills to better align with patients' needs.[5] Such an approach may also have a ripple effect on factors such as GP recruitment. By taking an outcome-focussed, organisational-level approach to continuity, we may be bypassing the root of the problem and, therefore, also the source of the solution. In such a complex subject area, attitude surely plays a larger part that we have previously acknowledged, particularly within the UK healthcare system which has limited flexibility and capacity for change in its current state. It is therefore unsurprising that guidance on how to provide continuity is so hard to articulate.

The UK NHS has undergone significant change since its conception, leading to changes in practice structure, OOH services, IT infrastructure and GP contracts which in turn influence continuity.[1,52–55] This resonates internationally, for example, the Canadian primary care context has a reducing overall number of GPs, who are increasingly working part-time, relocating frequently, and withdrawing from hospital work.[12,13] Dalsted et al. suggest that a single individual assuming a coordination role for patient care across the entire healthcare system is unworkable. Perhaps we are asking too much of GPs if we expect them to view the whole patient pathway, and then also take responsibility for coordinating patient care across the entire healthcare system. There may be scope for an independent healthcare professional to take on this huge task, for example, the emerging clinical navigator role.[31]

While some evidence suggests that patients felt a greater sense of continuity from their hospital specialist given their allocation to a named team[5], prescriptive and one-dimensional initiatives attempting to implement relational continuity in primary care have not been well-received. For example, one study found that the 2014 UK requirement for all patients aged 75 years or over to have a 'named accountable GP' failed to improve longitudinal continuity of care over a 9-month period. Reflections suggest that such initiatives require a more comprehensive understanding of the primary care context and pre-emptive support to change existing systems (for example, appointment booking) prior to implementation. This initiative had no way of facilitating increased continuity in practice despite a 'named GP' on paper.[56]

Many studies in this review suggested that the boundaries of informational and managerial continuity are becoming increasingly blurred.[14,31,40] Electronic records may increasingly facilitate multidisciplinary working across service boundaries. Handover forms for patients with palliative or other complex needs were identified as a potentially helpful document in supporting continuity across healthcare settings but were not often used.[40] Various other similar handover methods exist, but if these are not engaged with in terms of both entry and receipt, they are redundant. It must be recognised that each handover tool requires a GP to complete extra work, unless they can be automatically populated from the patients' records. Further, individual GPs may sometimes not understand the wider healthcare context. For example, the inner (and outer) workings of a multidisciplinary primary care team are rarely focussed on at medical school or in GP training, particularly given the wide geographical variation of healthcare structure. Also, OOH shifts for GPs are no longer mandatory in the UK,[1,4] thus GPs may not appreciate the benefit of completing such tools if they do not practice as an OOH clinician. The concept that oncologists encourage their patients to engage with GPs, again depends on the character and attitude of the oncologist, and their ability to see the bigger picture and think about the patient's experience of the healthcare system as a whole.[30,36]

Implications and suggestions for future research, policy, and practice

In reality, there will always be tension between ideal and feasible continuity of care within the wider organisational constraints and variation. To find the right balance, in a way that does not compromise patient care, requires further study. It is essential to understand the situation in each practice (and its wider healthcare service context) before being able to develop an intervention to improve continuity,[57] an approach advocated by the UK 'RCGP Continuity of Care Toolkit'.[58] Dalsted et al. suggest further research on organisational interfaces to improve coordination, rather than viewing healthcare settings as islands between which a single GP should sail.[31] Abel et al. emphasise that focussing on the clinical aspects of care alone is unlikely to result in successful continuity. They suggest that an optimal model would constitute 'a public health approach based on a close partnership between clinical services and communities/civic institutions'.[59] Abel's 'compassionate communities' concept advocates extension across boundaries between healthcare teams, services and institutions in order to overcome challenges of palliative care such as numerous comorbidities and limited accessibility.[60] In future, a realist approach may result in more useful practice and policy suggestions, as it would facilitate comprehension of 'what works for whom, in what circumstances, in what respects, and how'.[61,62]

This review illuminates the still fairly novel discussion of the role of patients and their close persons in achieving continuity of care for themselves. Research has previously been undertaken on continuity from the healthcare professional and service provider perspective; and it seems that current studies now focus more so on service user perspectives. However, little research focuses on the patient's (and close person's) responsibility and capacity for action regarding continuity, despite emerging evidence suggesting the potential value of this. Society's emphasis is increasingly on a more patient-centred healthcare system, but certain issues remain quite doctor-led and inflexible. Can patients facilitate their own continuity of care if they are empowered with relevant knowledge to make appropriate decisions? And if so, is it appropriate to ask this of patients with palliative care needs, or is it too much a burden on them and their close persons? Further research is required regarding where the responsibility lies on the doctor–patient spectrum, and how, for whom and in what circumstances this would be effective and appropriate. Bandura's 'social learning theory' is highly relevant in understanding how service users learn from each interaction in the healthcare context; manage resources and change their behaviour in a desirable way. Its application may facilitate further exploration of this issue.[63]

Conclusion

This review identifies facilitators of and barriers to continuity with GPs in primary palliative care for patients with advanced cancer and their close persons. It reveals a gap in the literature regarding the work required of service users to achieve their desired level of continuity, and their capacity for action in this context needs further attention.

Previous research has demonstrated that continuity reduces mortality and hospital use, improves clinical outcomes and medication compliance, and is cost-effective.[1] Such factors could be labelled as policy-directed, so further characterisation of the meaningful outcomes for patients is required. For example, patient outcomes regarding continuity may result in a patient feeling understood, cared for, and listened to in relation to their quality of life and death. Given the currently limited evidence base, further research is needed to measure the intangible components of the doctor–patient relationship within the context of continuity that drive the process by which we achieve both patient and policy outcomes.

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Disclaimer statements

Contributors EC led this review. All authors were involved in study design. CG independently screened five percent of titles and abstracts selected at random to ensure the selection criteria were applied with good agreement. All authors then screened the same five papers at the full-text stage to ensure consistency. EC conducted the analysis and led on writing the paper. All authors provided comments on drafts. All authors consent to submission.

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Appendices

Appendix 1: Data extraction tool

Data Extraction Tool	
Details of publication	
Publication type	
Author(s)	
Title	
Source	
Year / volume / pages	
First author's institution and country	
Ethical approval	
Introduction	
Aim(s)	
Research questions / hypotheses	
Study participants	
Setting	
Target population	
Inclusion criteria	
Exclusion criteria	
Recruitment	
Characteristics of participants: - Total n° - Age - Sex - Social class - Ethnicity - Geographical location - Other information	
Methods	
Date/timeframe of fieldwork	
Research methods / tools used	
Analysis	
Quantitative analysis	
Qualitative analysis	
Key findings relevant to review	
Meaningfulness	How is continuity in primary palliative care experienced by patients? How is continuity in primary palliative care experienced by close persons?
Feasibility	What are their perceived facilitators of continuity in primary palliative care? What are their perceived barriers to continuity in primary palliative care?
Quality assessment	
Using Pluye's 'A scoring system for mixed methods research and mixed studies reviews'[24] and Gough's Weight of Evidence framework[23]	
Other	
Strengths/limitations	
Notes	
Papers picked up from reference list	

Appendix 2: A scoring system for mixed methods research and mixed studies reviews[24]

A scoring system for mixed methods research and mixed studies reviews

Types of mixed methods study components or primary studies in a 'Systematic Mixed Studies Reviews' context (a)	Methodological quality criteria (b)
1. Qualitative	Qualitative objective or question Appropriate qualitative approach or design or method Description of the context Description of participants and justification of sampling Description of qualitative data collection and analysis Discussion of researchers' reflexivity
2 Quantitative experimental	Appropriate sequence generation and/or randomisation Allocation concealment and/or blinding Complete outcome data and/or low withdrawal/drop-out
3 Quantitative observational	Appropriate sampling and sample Justification of measurements (validity and standards) Control of confounding variables
4 Mixed methods	Justification of the mixed methods design Combination of qualitative and quantitative data collection-analysis techniques or procedures Integration of qualitative and quantitative data or results

Caution notice: Outside quantitative experimental studies, the implication of clustering primary studies or study components by quality score has not been critically examined. With respect to systematic reviews of quantitative experimental studies, the clustering of primary studies and the weighting of quantitative results by quality score are discouraged.

(a) Potential applications: *With respect to mixed methods research in general:* Appraisal of the methodological quality of qualitative, quantitative and mixed methods components. With respect to systematic mixed studies reviews: Concomitant appraisal of the methodological quality of primary qualitative, quantitative and mixed methods studies.
(b) Procedure for planning, reporting and assessing mixed methods research or mixed studies reviews. For each type of study component or primary study, describe the methodological quality by criterion. Score presence/absence of criteria respectively 1/0 (complement the retained publication with related documents, and contact authors when more information is needed). Calculate a 'quality score' [(number of 'presence' responses divided by the number of 'relevant criteria') x 100]. Use this score as a rationale for excluding 'poor quality' study components or primary studies. Use the criteria for describing the quality of retained components or studies (qualitative quality appraisal).

Appendix 3: Gough's weight of evidence framework[23]

Weight of Evidence A (WoE A). This is a generic and thus non-review-specific judgement about the coherence and integrity of the evidence in its own terms. That may be the generally accepted criteria for evaluating the quality of this type of evidence by those who generally use and produce it.
Weight of Evidence B (WoE B). This is a review-specific judgement about the appropriateness of that form of evidence for answering the review question, that is, the fitness for purpose of that form of evidence. For example, the relevance of certain research designs such as experimental studies for answering questions about process.
Weight of Evidence C (WoE C). This is a review-specific judgement about the relevance of the focus of the evidence for the review question. For example, a research study may not have the type of sample, the type of evidence gathering or analysis that is central to the review question or it may not have been undertaken in an appropriate context from which results can be generalised to the answer the review question. There may also be issues of propriety of how the research was undertaken such as the ethics of the research that could impact on its inclusion and interpretation in a review.[60]
These three sets of judgements (graded as low, medium or high) can then be combined to form an overall assessment Weight of Evidence D (WoE D) of the extent that a study contributes evidence to answering a review question.

Appendix 4: Descriptive data table

Author, year	Country of origin	Method	Focus	Cancer diagnoses	Patients	Close persons	Healthcare professional perspective explored	Gough's weight of evidence	Pluye score	Further detail about quality appraisal
King et al., 2006	England	Mixed methods 1. Cross-sectional qualitative study 2. Quantitative and qualitative prospective longitudinal study	To understand patient/carer/healthcare professional views of continuity in cancer care; to formulate a quantitative research tool for continuity; to identify associations between continuity and satisfaction	Breast, lung, colorectal	1. n = 28 2. n = 199 (quant) 2. n = 3 (qual)	1. n = 18 2. n = 145 (quant) 2. n = 2 (qual)	Yes	High	100%	King et al. adopted several phases in their mixed methods study to address their compound research questions and acknowledged the complexity of their research context. Despite small participant numbers in the final qualitative phase, the thought that went into study design and analysis was transparent and thus the overall study scored highly in terms of quality.
Lundstrom et al., 2011	Denmark	Mixed methods Cross-sectional questionnaire study: quantitative logistic regression and qualitative analysis of written comments	To investigate cancer patients' experiences of contact with GP and GP/hospital cooperation	Head and neck, gastrointestinal, lung, gynae, prostate, urinary, breast, lymphoma, leukaemia, other, unknown	n = 1490	n = 0	No	High	100%	This study was presented as 'mixed methods' by the authors, though they did not employ a qualitative approach to data collection; only at analysis stage were the free-text comments of the survey data analysed qualitatively. Though a validated survey, the cross-sectional nature made it impossible for authors to imply causality between various patient experiences.

Continued

Continued

Author, year	Country of origin	Method	Focus	Cancer diagnoses	Patients	Close persons	Healthcare professional perspective explored	Gough's weight of evidence	Pluye score	Further detail about quality appraisal
Nielsen et al., 2003	Denmark	Quantitative experimental longitudinal survey RCT, participants completed questionnaires at baseline, 3m and 6m	To determine effect of shared care programme on cancer patient attitudes towards healthcare system and reports on contacts with GP	Breast, gastrointestinal, germinal cell, head and neck, urinary, gynaecological, sarcoma, melanoma, brain, lung, other	n = 248	n = 0	No	Medium	100%	The study was well-reported and comprehensive, thus scored highly on Pluye's score, but the solely quantitative approach was deemed inadequate to fully address the research questions. Findings must be interpreted with caution, given that the study was not blinded. Oncologists may therefore have altered their practice for patients in the control group, having completed paperwork for 'intervention group' patients previously.
Barnes et al., 2007	Canada	Quantitative observational cross-sectional survey	To assess patient perspective of FP involvement in cancer care follow-up & facilitators/barriers	Lung, breast, prostate, gastrointestinal, renal, bladder, other (all metastatic)	n = 365	n = 0	No	Low	33%	The solely quantitative approach of this study resulted in a low quality appraisal score.
Aubin et al., 2010	Canada	Quantitative observational longitudinal survey Prospective, longitudinal, survey (every 3–6 months for 18 months)	To assess patient perspective of FP involvement in cancer care follow-up	Lung	n = 395	n = 0	No	Medium	66%	This study experienced a high dropout rate, which was comparable with other studies involving participants with a life-limiting illness, but only a small proportion of participants were in the terminal phase of their illness. Also, only patients with lung cancer were included, but given the diverse demographic characteristics of participants, findings may be applicable to other cancer contexts.

Continued

Continued

Author, year	Country of origin	Method	Focus	Cancer diagnoses	Patients	Close persons	Healthcare professional perspective explored	Gough's weight of evidence	Pluye score	Further detail about quality appraisal
Druel et al., 2020	France	Quantitative observational cross-sectional survey	To explore coordination that exists within the 3-way relationship between GP/patient/ oncologist	Not stated	n = 403	n = 0	No	Medium	66%	The quantitative nature of the study was perceived as insufficient to entirely answer research questions.
Nazareth et al., 2008	England	Qualitative case study analysis	To develop ideas of cancer care continuity from patient/carer/ healthcare professional perspectives	Colorectal, breast	n = 7 (28 participants total as each patient identified a carer and 2 HCPs)	n = 7	Yes	High	83%	This study achieved high scores; its qualitative case study analysis provided in-depth, triangulated data from four simultaneous angles, which appropriately addressed the research questions.
Kendall et al., 2006	Scotland	Qualitative action research framework Serial discussion groups	To involve cancer patients/carers/ healthcare professionals in designing framework for effective primary cancer care	Bowel, breast, lymphoma, testis, prostate, haematological, lung, unknown	n = 14	n = 2	Yes	High	83%	This study used appropriate qualitative methods to answer their research questions, justifying and reporting their approaches comprehensively.
Michiels et al., 2007	Belgium	Qualitative prospective longitudinal interview study (2 interviews 3 months apart)	To explore palliative patient/carer perspectives of GP's role in end-of-life care continuity & facilitators/ barriers	Metastatic solid cancer	n = 17 (17 patients in 17 interviews)	n = 8 (joined patient for interview)	No	High	83%	The qualitative design of this study seemed to provide comprehensive understanding of the GP's role in continuity at the end of life from patient perspectives, and was well-reported, thus scoring highly.
Couchman et al., 2020	England	Qualitative interview study	To explore patient views of the FP's role in palliative cancer care & facilitators/barriers	Bladder, colorectal, breast, ovarian, gastric, atrial sarcoma, lung, prostate, pancreatic	n = 15	n = 0	No	High	100%	The qualitative design of this study seemed to provide comprehensive understanding of the GP's role in continuity at the end of life from patient perspectives, and was well-reported, thus scoring highly.

Continued

Continued

Author, year	Country of origin	Method	Focus	Cancer diagnoses	Patients	Close persons	Healthcare professional perspective explored	Gough's weight of evidence	Pluye score	Further detail about quality appraisal
Norman et al., 2009	Canada	Qualitative interview study	To explore palliative patient perception of factors that affect GP/patient relationship and of GP's role in cancer care	Breast, lung and 9 other sites	n = 25	n = 0	No	High	83%	This study used appropriate qualitative methods to answer their research questions, justifying and reporting their approaches comprehensively.
Johnson et al., 2020	Australia	Qualitative interview study	To explore patient/carer/GP views of characteristics of optimal end-of-life care in rural general practice	Lung, prostate, breast, pancreatic, melanoma	n = 6	n = 3	Yes	Medium	83%	Johnson et al. experienced issues with achieving a heterogenous sample and the study had to be stopped early due to difficulties recruiting patients approaching the end of life. Therefore, data saturation was perhaps not achieved.
Jarrett et al., 1999	England	Qualitative interview study	To explore terminally ill patient/carer perspectives of community-based services	Prostate, lung, bladder, tongue, glioma (1 patient had motor neurone disease)	n = 12 (15 interviews in total)	n = 12 (15 interviews in total)	No	Low	50%	This qualitative interview study was part of a wider study including the perspectives of healthcare professionals. Authors state their concerns about likely selection bias, and the small sample size confined by limited time and resources.
Halkett et al., 2015	Australia	Qualitative interview study	To explore patient perspectives on the role of their GP after diagnosis of advanced cancer	Lung, throat, adrenal, oesophageal, breast, prostate, lymphoma, colorectal, renal (all metastatic)	n = 21	'Carers provided input if present at the time'	No	High	83%	This study used appropriate qualitative methods to explore the views and experiences of their participants. It was well-reported, thus scoring highly.

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Author, year	Country of origin	Method	Focus	Cancer diagnoses	Patients	Close persons	Healthcare professional perspective explored	Gough's weight of evidence	Pluye score	Further detail about quality appraisal
Dalsted et al., 2011	Denmark	Qualitative interview study	To explore patient/ healthcare professional views of the FP's coordinating role in cancer care	Colorectal, lung, prostate	n = 12	'Spouses often participated'	Yes	Medium	33%	This study adopted qualitative methods to explore the views and experiences of their participants. It's score was lower than other studies employing similar methods, given inadequate reporting of justification of methodological decisions.
Kamradt et al., 2015	Germany	Qualitative focus group study	To explore patient/ healthcare professional perspectives of challenges in colorectal cancer care	Colorectal	n = 12 (and 2 patient support group representatives in 3 focus groups)	n = 0	Yes	Low	50%	This study was designed and conducted by a multidisciplinary research team; a concept that the authors replicated in the segmented recruitment strategy for their homogenous focus groups including patients, patient representatives and HCPs.
Richards et al., 2011	England	Qualitative interview study	To explore experiences of advanced cancer patients/carers about accessing OOH care	Not stated	n = 13 (20 interviews in total)	n = 15 (20 interviews in total)	No	Medium	66%	The authors acknowledge that a lack of ethnic diversity among participants may limit the generalisability of these findings. Another limitation of this study, as is common with this patient population, is the likely selection bias resulting from clinician recruitment of patients who might be 'sufficiently well enough' to participate.

Appendix 5: Definition of terms

Primary care	In the UK, 'primary care services provide the first point of contact in the healthcare system, acting as the 'front door' of the NHS.'[61] For the purpose of this review, we will focus on the care provided by general practitioners and allied health professionals in the community for patients with advanced cancer. It must be acknowledged that the structure, and therefore definition, of primary care practice varies internationally in terms of the background and role of providers, and the nature of services provided to patients.[62] A variety of internationally recognised terms, such as 'general practitioner', 'general practice', 'family physician', 'family practice', 'primary care' and 'primary care physician' will be included in the search strategy to capture all relevant studies. The terms 'general practitioner' and 'general practice' will be used throughout the report, and are to be considered synonymous with the terms 'family physician', 'family practice', 'primary care', 'primary care physician'.
Close person	Informal care is the unpaid care provided by someone with whom the patient has a social relationship. For example, 'a spouse, parent, child, other relative, neighbour, friend or other non-kin' may be an informal carer.[63] However, as has been discussed by King et al. previously, the term 'close persons' is used throughout this review, given that the term 'carer' may not be applicable at all stages of the patient's disease trajectory.[21]
Healthcare professional	A healthcare professional is qualified in a particular speciality or discipline, and is regulated by a professional body in their provision of healthcare service to patients.[64]
Palliative care	Palliative care involves treatment and support for people with any life-threatening condition, and those important to them.[11]
Specialist palliative care	'Palliative care provided by healthcare professionals who specialise in palliative care and work within a multi-disciplinary specialist care team'.[65]
Generalist palliative care	'Palliative care provided by the patient and family's usual professional carers as a vital and integral part of their routine clinical care'.[65]
End-of-life care	The General Medical Council define end-of-life care as support in the last 12 months of someone's life.[66] Given their usual prognosis, most people with mesothelioma could be considered to be at the end of their life. As a result, the terms 'palliative care' and 'end-of-life care' will be used interchangeably throughout this protocol. It must be acknowledged, though, that palliative care is much more than solely end-of-life care, and that the needs of patients and their informal carers may vary throughout the illness trajectory. The involvement of healthcare professionals and services may therefore also fluctuate.[67] Further, the term 'end-of-life' is often associated solely with specialist palliative care services. Though likely to play a role in the care of people with mesothelioma, such services are not the focus of this review, which concentrates on generalist palliative care provided by general practitioners (GPs) and allied health professionals.[68]
Continuity	Continuity is typically defined as 'the extent to which a person experiences an ongoing relationship with a clinician and the coordinated clinical care that progresses smoothly as the patient moves between different parts of the health service'.[8] It can be considered in terms of: • Relational continuity – the same professional seeing the same patient over a period of time. • Informational continuity – professionals having access to accurate, up-to-date patient records. • Managerial continuity – a system which enables timely and efficient handovers of care between clinicians, teams, and organisations.[1] Terms such as 'involvement', 'collaboration' and 'coordination' have been used in studies that discuss issues relating to continuity. Further, the terms 'abandonment' and 'fragmentation' were used to reflect a lack of continuity.[6,21]