Factors associated with unscheduled care use by cancer decedents: a systematic review with narrative synthesis

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ABSTRACT

Background People who die from cancer (cancer decedents) may experience unpleasant and distressing symptoms which cause them to present to unscheduled care. Unscheduled care is unplanned care delivered by general practitioner out-of-hours and emergency departments. Use of unscheduled care can disrupt treatment plans, leading to a disjointed patient care and suboptimal outcomes.

Objectives This systematic review aimed to identify factors associated with unscheduled care use by cancer decedents.

Method Systematic review with narrative synthesis of seven electronic databases (PubMed; Medline; Embase; Cochrane Database of Systematic Reviews; Cochrane Central Register of Controlled Trials; Web of Science; Cumulative Index to Nursing and Allied Health Literature) from inception until 01 January 2020. All observational and experimental studies were included, irrespective of their research design.

Results The search yielded 238 publications included at full-text, of which 47 were included in the final review and synthesis. Unscheduled care use by cancer decedents was influenced by multiple factors, synthesised into themes: demography, clinical and patient, temporal, prescribing and systems. Cancer decedents who were older, men, had comorbidities, or lung cancer, were most likely to use unscheduled care. Unscheduled care presentations were commonly due to pain, breathlessness and gastrointestinal symptoms. Low continuity of care, and oncology-led care were associated with greater unscheduled care use. Access to palliative care, having an up-to-date palliative care plan, and carer education were associated with less unscheduled care use.

Conclusion The review identifies multiple factors associated with unscheduled care use by cancer decedents. Understanding these factors can inform future practice and policy developments, in order to appropriately target future interventions, optimise service delivery and improve the patient journey.

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INTRODUCTION

During their illness, people who die from cancer may experience unpleasant and distressing symptoms which cause them to present to unscheduled care. Unscheduled care is the use of services that are available to the public without prior appointment or arrangement, and is used to address medical needs which arise outwith core hours. 1 While unscheduled care arrangements vary significantly by country and healthcare system, they are largely comprised out-of-hours primary care (OOH), and hospital emergency departments (ED). While there is no agreed terminology in published literature, which encompasses the full spectrum of people who live with and going on to die from cancer, the term ‘cancer decedents’ will be used in this publication. Unscheduled care use in ‘cancer decedents’ will refer to unscheduled care use, up to a year before death, of people who die from cancer.

Because of the nature of unscheduled care, consultations focus on addressing episodic, acute or emergency needs, often by providing the most expedient or readily available treatment. Unscheduled care contacts are often with clinicians who are not known to the patient, in clinical settings they may not be familiar with or may struggle to attend, and occur at anti-social times. All of these factors can mean that unscheduled care
contacts can be distressing to patients and families, may disrupt planned treatment and can trigger potentially unwanted and avoidable hospital admission. This lack of joined-up care planning has led some experts to suggest that having significant contact with unscheduled care may therefore be a marker of poor patient care. In spite of this, relatively little is known about why cancer decedents present to unscheduled care. The aim of this systematic review was to identify factors that are associated with use of unscheduled care by cancer decedents. This review specifically seeks to address the following research questions: (1) what factors are associated with greater use of unscheduled care use by cancer decedents? (2) what factors are associated with less use of unscheduled care use by cancer decedents? In addition, we asked: (3) what are the temporal trends, geographical distribution, research designs, cancer types examined and unscheduled care setting in which these papers have been published? Understanding these factors may allow researchers, policymakers and clinicians to target these elements in future research, policy development and clinical practice. By targeting modifiable factors that are associated with greater unscheduled care use we can minimise potentially avoidable unscheduled care visits and their sequelae. By identifying non-modifiable factors that are associated with greater unscheduled care use we can more appropriately target resources and support to people for whom it would confer the most benefit. This would allow optimisation of unscheduled care delivery and improve the patient journey for people who go on to die from cancer.

**METHODS**

**Selection criteria**

Studies were eligible for inclusion if they identified at least one factor that was associated with use of unscheduled care by adults with cancer in their palliative or terminal phase of illness. No limits were applied for date of publication, country of origin, type of unscheduled care service examined or study design. Due to available resources, articles published in languages other than English were excluded. Studies conducted in specific populations, for example, for one specific type of cancer only, were included but this was noted in synthesis and quality analysis. We excluded studies for which there was no abstract or full text available. We also excluded review articles and any papers reporting duplicate data.

**Search strategy**

Electronic databases (Medline; Embase; PubMed; Cochrane Database of Systematic Reviews; Cochrane Central Register of Controlled Trials; Web of Science; Cumulative Index to Nursing and Allied Health Literature (CINAHL)) were searched from inception to 1 January 2020, for all relevant titles. The search terms used were:

1. [cancer OR malignant OR malignancy OR tumour OR neoplastic OR neoplasm OR neoplasia].
2. [Palliative OR palliation OR palliating OR palliate OR palliat* OR terminal* OR ‘End of Life’ OR end-of-life OR hospice OR ‘life support’ OR dying OR death OR ‘last year’ OR ‘final year’ OR ‘last 12 (twelve) months’ OR anticipatory].
3. [unscheduled OR after-hours OR out-of-hours OR OOH OR emergency OR urgent OR ER OR ‘Emergency Department’ OR night OR emergency OR pre-hospital OR ‘General Practice’ OR ‘primary care’].
4. 1 AND 2 AND 3.

Additional records were identified through searching references of included articles. Hand searching of key journals from 2010 to present was conducted. Journals included for hand searching were any journal that had published more than one of the papers included in this systematic review. These were as follows: American Journal of Hospice and Palliative Care, BMC Palliative Care, British Journal of General Practice, Journal of Pain and Symptom Management, Journal of Palliative Medicine and Palliative Medicine.

**Data extraction and analysis**

Title and abstract screening and full text review to determine inclusion were independently conducted by two reviewers (SEEM, LJG) with good concordance. Disagreements were resolved through discussion, with third reviewer arbitration where consensus could not be reached (DB or BHS). The following data were extracted using a standardised form adapted from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses checklist: title, country of origin, year, author, sample size, methods, design, setting (eg, primary care or ED), cancer type, medication given, interventions, factors associated with greater use of unscheduled care, factors associated with less use of unscheduled care, factors associated with either greater and less use of unscheduled care, conclusions and key concepts.

**Narrative synthesis**

Two reviewers (SEEM, LJG) independently identified factors from each study that were associated with greater or less use of unscheduled care. Narrative synthesis was used to summarise and describe the findings of the included studies. Factors were compared, and similar factors were grouped together under unifying themes, with decision on grouping and identification of themes agreed by all authors.

**Assessment of quality**

Risk of bias was independently assessed by two reviewers (SEEM, LJG) using tools appropriate to the study design. There is no consensus on which tools are best for analysing quality of research and reporting in population health research. In order to evaluate which tool best fit the papers analysed in this review, available tools were each compared with the

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criteria set out by the Agency for Healthcare Research and Quality. Each tool was assessed on its merits to determine which was the best fit for each type of study. The tools that were selected for use were: SIGN Methodology 3 (cohort studies); SIGN Methodology 4 (case–control studies); ROBINS tool (descriptive studies); CASP Tool (qualitative studies); Cochrane Risk of Bias Tool (controlled trials). The quality of the included randomised controlled trial (RCT) was assessed through the evaluation of the risk of bias at both the study level and outcome level. Disagreements were resolved by discussion and consensus, or through arbitration by a third reviewer (DB/BHS).

RESULTS
Quality assessment
45 of the 47 included papers were assessed as having low risk of bias. One publication was assessed as having moderate risk of bias and one publication as serious risk of bias. Full details of quality assessment and ratings are available in online supplemental tables Q1–Q5. However, there were elements of relative weakness in many papers, including: small sample size, restricted demographic information reported and methods of analysis. Because neither of the two publications at higher risk of bias contributed new factors or had contradictory findings to included publications with low risk of bias, all 47 studies were included in the narrative synthesis; however, quality assessment was considered at each stage to inform the weight given to findings.

Overview of results
The search strategy identified 238 potential articles for inclusion, of which 107 full-text articles were reviewed (figure 1). Ultimately, 47 studies, totalling n=924 793 individuals, fulfilled the inclusion criteria. Detailed information for the included publications (including title, study type, setting and patient demographics) is described in online supplemental table S1.

The rate of publication of included research papers related to unscheduled care use by cancer decedents has increased over time; 33 of the 47 studies (70.2%) were published in the last 5 years. This increase was, however, only seen in studies conducted within EDs; the volume of studies examining general practitioner OOH remains small and markedly less than ED. While the only paper set in both OOH and ED was published within the last 5 years, only one of the four papers (25%) set exclusively in OOH was published in the last 5 years. Conversely, 31 of the 41 publications (75.6%) set within EDs were published in the last 5 years. Detailed rates of publication are available in online supplemental figure S1.

Most studies (44.6%, n=21/47) were carried out in North America, with the USA generating 29.8% (n=14/47) of all included publications. There were 23.4% (n=11/47) carried out in both Europe and Asia, 6.4% in Australia (n=3/47), 2.1% in South America (n=1/47) and none in Africa.

There were 30 publications which included ‘any advanced cancer’ type. The remaining papers focused on one or more specific cancer types only: seven studies focused on gastrointestinal malignancies, six on lung cancer, three on breast cancer, two on prostate cancer, two on pancreatic cancer and one each on haematological malignancies, head and neck malignancies and melanoma.

Evidence was drawn primarily from publications that were retrospective cohort (n=25, 53.2%), prospective cohort (n=4/47, 8.5%), case–control (n=6, 12.8%), descriptive (n=3, 6.4%) and qualitative studies (n=3, 6.4%). One RCT was included (single-blinded only).

Setting
The majority of the studies (41/47 studies) examined ED use only. The remainder examined primary care OOH only (4/47), OOH and ED together (1/47), or did not report the specific setting of unscheduled care use (1/47).

Factors and themes related to unscheduled care use
Factors associated with unscheduled care use were identified and were classified into factors associated with greater use of unscheduled care, factors associated with less use of unscheduled care, and factors associated with either greater or less use of unscheduled care (table 1). Because the factors used in this narrative synthesis are general categories, they contain elements which have differential effects on unscheduled care use. For example, ‘cancer type’ is associated with either greater or less use of unscheduled care depending on the specific type of cancer. Factors associated with use of unscheduled care by cancer decedents were grouped into five main themes: demographic factors; clinical
Table 1  Factors associated with use of unscheduled care

| Associated with either greater or less use of unscheduled care | Associated with less use of unscheduled care | Associated with greater use of unscheduled care |
|---------------------------------------------------------------|---------------------------------------------|----------------------------------------------|
| ► Demographic factors                                        | ► ED referrals to palliative care           | ► Reduced clinical follow-up                 |
| ► Clinical factors                                           | ► Enrolment in hospice programme            | ► Emotional distress in patient or carers     |
| ► Cancer type                                                | ► Good communication                       | ► Metastatic disease                         |
| ► Other clinical factors                                     | ► GP continuity of care                     | ► Non-business hours                         |
| ► Systems factors                                            | ► Home care nursing                        | ► Pain                                       |
| ► Availability of medication and analgesia                    | ► Home visit by GP                         | ► Cancer treatments: chemotherapy and radiotherapy |
| ► Variations in time, day and month                           | ► Greater length of time before death       | ► Multimorbidity                             |
|                                                               | ► Training or education of patients and carers | ► Previous use of unscheduled care          |
|                                                               | ► Written palliative care plans             |                                              |
|                                                               | ► Symptom management kits                   |                                              |

ED, emergency department, accident and emergency, A&E or emergency room; GP, general practitioner, primary care physician.

and patient factors; temporal factors; prescribing factors; and systems.

The number of papers providing evidence for each factors, identified as being associated with unscheduled care use by cancer decedents, and their grouping into themes, is demonstrated in box 1. Source papers for each factor are described in online supplemental table S3.

Box 1  Key themes associated with unscheduled care use by cancer decedents

Demography
⇒ Demographic factors (13/47 studies).
⇒ Gender (8/47 studies).
⇒ Socioeconomic status (7/47 studies).
⇒ Age (5/47 studies).
⇒ Living arrangements (3/47 studies).
⇒ Rurality (5/47 studies).
⇒ Race or ethnicity (4/47 studies).

Clinical and patient
⇒ Other clinical factors (16/47 studies).
⇒ Cancer type (13/47 studies).
⇒ Pain (13/47 studies).
⇒ Multimorbidity (5/47 studies).
⇒ Chemotherapy and radiotherapy (4/47 studies).
⇒ Metastatic disease (3/47 studies).
⇒ Communication and emotional (5/47 studies).

Temporal
⇒ Variations by time, day and month (5/47 studies).
⇒ Time before death (5/47 studies).

Prescribing
⇒ Medication (4/47 studies).
⇒ Other prescribing interventions (1/47 studies).

Systems
⇒ Enrolment in hospice (11/47 studies).
⇒ Clinical follow-up and continuity of care (7/47 studies).
⇒ Home care nursing (7/47 studies).
⇒ Domiciliary palliative care (4/47 studies).
⇒ Other systems factors (4/47 studies).
⇒ Previous use of unscheduled care (3/47 studies).
⇒ Systems factors (2/47 studies).
⇒ Training of patients and carers (2/47 studies).

Demography
Among patients dying from cancer, the evidence was highly consistent across multiple publications in finding an association between gender (eight studies), age (five studies), socioeconomic status (seven studies) and living arrangements (three studies) and unscheduled care use among cancer decedents. Men were more likely to attend unscheduled care than women. Older patients with cancer were more likely to use unscheduled care at the end of life than younger patients with cancer. Patients with cancer who were single or lived alone were more likely to present to unscheduled care than those who did not. Cancer decedents who lived in areas with higher levels of deprivation were more likely to use unscheduled care than those living in areas of less deprivation.

Clinical and patient
There was ample and consistent evidence of the association of cancer type (13 studies), pain (13 studies) and presenting complaints (16 studies) with greater use of unscheduled care by cancer decedents. Though fewer publications reported on the association between multimorbidity (five studies), receiving chemotherapy or radiotherapy (four studies), metastatic disease (three studies) and increased unscheduled care use, the findings were consistent.

Cancer decedents who had lung cancer presented to unscheduled care more frequently than patients with other cancer types. Pain was the single biggest clinical factor associated with
use of unscheduled care, accounting for up to 83% of presentations. After pain, breathlessness and gastrointestinal symptoms were consistently the most common reasons for visiting unscheduled care. Compared with patients without metastases, patients with metastatic disease were more likely to use unscheduled care near the end of life and had a higher number of visits. Cancer decedents who were currently receiving chemotherapy or radiotherapy were more likely to use unscheduled care than those who were not. Patients receiving radiotherapy in their last month of life were more likely to present to ED. Patients with medical comorbidities in addition to cancer were higher users of unscheduled care.

Communication and emotional factors
There were fewer and more heterogeneous studies which examined communication and emotional factors in association with unscheduled care use. Cancer decedents’ prior experience of unscheduled care affected their likelihood of future unscheduled care use. Those who had negative past experience were less likely to use unscheduled care. Fear and anxiety were found to be significant motivating factors behind presenting to unscheduled care. Loneliness and psychological distress among patients with terminal cancer were associated with higher use of unscheduled care.

Temporal
While there were some differences in terms of months specified for peak unscheduled care use, all studies reporting on temporal factors (five studies) found that unscheduled care use was lowest in the spring and highest in the winter. Patients with terminal cancer were more likely to present to ED in the evenings, overnight or at the weekends, outwith usual business hours. There was consistent evidence (five studies) demonstrating that cancer decedents who were close to death were significantly more likely to use unscheduled care than those who were not close to death.

Prescribing
Inadequate supplies of or access to of prescription medication, especially prescription analgesia, were found to be associated with unscheduled care use in three studies. One study showed that patients on higher doses of morphine were less likely to use emergency services OOH than those on lower daily doses of morphine, with another study demonstrating that provision of acute symptom management kits, with ‘just in case’ medications, reduced unscheduled care use.

Systems
Enrolment in hospice programme
There was a significant amount of consistent evidence supporting the association between hospice enrolment and unscheduled care use by cancer decedents. Being enrolled in a hospice programme was consistently associated with a lower use of unscheduled care.

Continuity of care and clinical follow-up
There was high-level consistent evidence supporting (seven studies) an association between continuity of care, clinical follow-up and unscheduled care. Unscheduled care use was significantly lower if patients had seen a GP in the preceding 3 months. Patients receiving high levels of continuity of care and clinical follow-up were significantly less likely to use unscheduled care than those who had low levels of continuity and poor follow-up. Having a primary care physician, rather than purely secondary-care led care, was associated with less unscheduled care use. Patients who experienced high levels of continuity of care by their primary care physician were significantly less likely to attend unscheduled care. This effect was dose-dependent, with one paper demonstrating that patients with poor continuity of care made up to four times as many unscheduled care visits and those with moderate continuity of care made twice as many unscheduled care visits, when compared with those with high continuity of care.

Home care nursing
There was ample consistent evidence (seven studies) supporting the association between community palliative care and unscheduled care use by cancer decedents. People with community-based access to palliative care had fewer unscheduled care attendances than those without community palliative care. This was particularly true in terms of reduction in visits for non-emergency clinical presentations ED visits; there was a greater reduction in unscheduled care use if palliative care was initiated before the last 6 months of life. The effect was dose-dependent in that the greater the number of home care nursing hours received, the greater the reduction in unscheduled care use.

Domiciliary palliative care
Four studies demonstrated an association between home-based palliative care and unscheduled care visits. The provision of home-based primary palliative care was associated with a reduction in unscheduled care use. One study found that a home visit by a GP was suggested by patients with terminal cancer as being the single biggest intervention that could possibly have prevented them from presenting to unscheduled care. This was also found to be dose dependent: the higher the number of GP home visits, the greater the reduction in unscheduled care use.
Other system factors
A few, significantly heterogeneous, papers (four studies) examined other systems factors. Having clear and accessible contact information for the unscheduled care centre was associated with increased use of unscheduled care.27 Patients with multiple previous ED visits in their last year of life were more likely to use the ED in their last month of life, when compared with those who had not used the ED previously.13 One paper suggested that being referred to a palliative care team directly from ED allowed for earlier control of symptoms and reduced subsequent attendance at and admission to hospital from unscheduled care.26

Another study found that patients who had written palliative care plans were less likely to attend unscheduled care and, when they did attend unscheduled care, were two to three times less likely to be admitted to hospital than those without a written palliative care plan.47

Training of education of patients and carers
There were few studies (two studies) which examined training and education of patients and carers; however, those that did found that having a primary care-giver who had completed a structured training programme focused on what symptoms to anticipate and how to manage these symptoms was associated with reduced use of unscheduled care.36 39 One study found that patients whose carers had undertaken such a programme showed an 80% reduction in unscheduled care use for acute symptoms.39

DISCUSSION
Summary
This systematic review summarises the current evidence on factors influencing unscheduled care use by cancer decedents. These factors were grouped into five main themes: demography, clinical and patient, temporal, prescribing and systems. Demography, clinical and patient themes, were more likely to be reported in the included papers than temporal, prescribing and system themes.

At the end of life, older cancer decedents were found to be significantly more likely to use unscheduled care than younger cancer decedents. Men were more likely to attend unscheduled care than women. Lung cancer was the most common cancer among cancer decedents attending unscheduled care. Cancer decedents with pain, breathlessness and gastrointestinal symptoms or medical comorbidities seen in unscheduled care more often than those without. Those who experienced a lack of continuity of care were significantly more likely to use unscheduled care. Good palliative care, including provision of hospice care, having an up-to-date palliative care plan, educating carers about how to expect and manage changes at the end of life, and having access to community-based palliative care, reduced unscheduled use of unscheduled care among cancer decedents.

The studies included in this systematic review were generally assessed as having low risk of bias (45/47) according to the appropriate assessment criteria. The two studies judged to have moderate or serious risk of bias did not contribute any new factors that had not been previously extracted from the higher quality publications.

This is the first systematic review to examine all locations of unscheduled care delivery, including both OOH and ED, when considering unscheduled care use in cancer decedents. Available evidence for factors associated with unscheduled care use focuses heavily on ED and tends to ignore OOH.

Implications for research and practice
Access to unscheduled care will always be an important part of community palliative care for cancer decedents; however, ensuring that such contacts are appropriate and unavoidable is important in order to minimise disruption to patients’ treatment plans and continuity of care, and to optimise cancer decedent’s mode and location of care so that it is minimally disruptive to them and their families during their palliative phase. Minimising avoidable unscheduled care contacts would also relieve the time and resource pressures that exists within the field of unscheduled care. Ensuring that unscheduled care is delivered in a less time-pressurised way due to intensity of resource use, is important both for retaining and attracting clinicians and for ensuring a positive experience and welcoming environment for those patients who use unscheduled care for unpredictable and unavoidable reasons.

One-third of included papers originated from the USA, which has a privatised system of healthcare that is significantly different to most nationalised or socialised health systems, such as the UK and the rest of Europe. The differences in healthcare systems, especially in availability of healthcare coverage and personal/individual cost of accessing healthcare, does have the potential to affect which factors influence unscheduled care use by cancer decedents. Furthermore, there are significant population and demographic differences between the USA and other countries, particularly with regards to the association between ethnicity and socioeconomic status,48 which may have confounded the association between race and unscheduled care use by failing to correct for deprivation.49 50 Having more studies conducted outside the USA would be of benefit to improving the relevance of these findings to countries with national health systems.

While the number of papers published in ED increased annually, the number of papers published in OOH settings did not show a similar trend. Given the paucity of studies examining use of OOH by cancer decedents, future research in this area is vital in order to improve our understanding of this under-researched element of unscheduled care.

In addition to primary care centred research, there is need for further research to holistically examine unscheduled care use across multiple services, in order to improve understanding of unscheduled care as a whole. Based on these findings, potential areas for future studies include: care coordination and communication across unscheduled care providers and systems, access to medication including analgesia, planned or easily organised GP or nursing home
visits, community palliative care provision, training and education of patients and carers, and improved ease of contact and access to unscheduled care services. Any trials of interventions to optimise unscheduled care use should be targeted at the groups identified as being high-risk of using unscheduled care services, including older people, men and people with lung cancer, and should ideally evaluated by RCTs where these can be ethically justified.

Strengths and limitations
To the authors’ knowledge this is the first paper using standard systematic review approaches to address these research questions. A potential limitation is due to the exclusion of non-English publications and publications for which there was no accompanying full-text (eg, abstract-only publications), this was for practical reasons only. The use of hand searching and reference searching will have minimised the number of studies missed in the review. We uncovered a diverse range of research studies carried out in many different contexts; while all included studies contained data on at least one demographic, clinical, patient, temporal, prescribing or system themes, there was wide heterogeneity in terms of the focus of individual papers. Due to the large number of studies included and diverse factors and themes we have uncovered, we believe this review to be a comprehensive overview of the literature in this field.

CONCLUSIONS
The review identifies factors associated with unscheduled care use by cancer decedents. Factors were grouped by narrative synthesis into five main themes: demography, clinical and patient, temporal, prescribing and systems. Understanding what influences unscheduled care will help future planning of cancer patient care, particularly during the last few weeks of life. Addressing modifiable factors which increase unscheduled care use can optimise the delivery of patient care, improve the patient journey by minimising unnecessary healthcare contacts, and alleviate some of the care pressure on unscheduled care services. This review found that unscheduled care use by cancer decedents can be optimised by managing pain and palliative symptoms, using anticipatory care planning, educating patients and carers, and providing access to relevant community-based professionals and palliative care services.

Correction notice
This article has been updated since it was first published. The article type has been changed to Systematic review.

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All authors are aware of and agree to the submission and that have all contributed this manuscript sufficiently to be named as authors. All persons or bodies with an interest in this manuscript are aware of its submission and agree to it.

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