Systematic review

Symptom appraisal and help-seeking for complications of cancer and its treatment: a systematic review and qualitative synthesis

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ABSTRACT

Background Complications of cancer and its treatment can be life-threatening, disrupt cancer treatment and negatively impact health-related quality of life. While we understand how people appraise symptoms prior to a cancer diagnosis, little is known about how people decide to seek help for complications during cancer treatment.

Aim Characterise how patients and informal caregivers appraise symptoms suggestive of, and decide whether to seek help from urgent and emergency care (or not) for, complications of cancer and its treatment.

Methods Systematic review and qualitative synthesis. Six electronic databases (ASSIA, CINAHL, Embase, MEDLINE, PsycInfo and Web of Science) were searched for papers using qualitative methods published since 2000 (last search performed on 11 October 2024). Supplementary and cluster searches were performed. 7120 records were identified and 22 papers (representing accounts of over 300 people with cancer) were included following the application of the ‘appraisal prompts’ criteria. Data were synthesised using abductive analysis.

Findings A conceptual map was developed to articulate how five analytic constructs interact and influence the ‘patient work’ of detecting, interpreting and responding to complications. Findings show that appraising symptoms is iterative and informed by knowledge, skills and perceptions developed prior to treatment through experiences of complications, and following contact with urgent and emergency care.

Conclusion This is the first review to characterise how patients and informal caregivers make decisions about cancer-related complications. Findings show preparation for complications should be treated as a process (rather than an event), and poor experiences of services contribute to delayed help-seeking and risk avoidable harm.

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WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ People with cancer frequently need to seek help from urgent and emergency care services for symptoms caused by complications of treatment or their cancer itself.

WHAT THIS STUDY ADDS

⇒ How patients and informal caregivers make sense of uncertainty and risk in the context of complications of cancer and its treatment informs how they detect, interpret and respond to symptoms.

⇒ Symptom appraisal and help-seeking decisions for complications are influenced by fear of cancer progression, the burden of accessing urgent and emergency care and pre-treatment preparation.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ To prevent delays in help-seeking, services need to support patients and informal caregivers to develop anticipatory action plans, pay attention to caregivers’ concerns about patient deterioration and ensure positive experiences of urgent and emergency care services.

⇒ Further research is needed to test our conceptual map, and before interventions to support symptom appraisal and timely help-seeking can be suggested.

BACKGROUND

Modern cancer care is increasingly provided on an ambulatory basis, meaning that serious complications that arise will occur at home and necessitate a response from urgent and emergency care (UEC) services.[1] Globally, the number of people with a new cancer diagnosis is projected to rise to 35 million by 2050,[2] with growing numbers of patients eligible for increasingly effective anticancer treatments expected to place substantial burdens on UEC systems worldwide.[3] People with cancer are at risk of multiple complications related to their disease and treatment; many of these complications can be life-threatening,[4] interrupt and limit the effectiveness of treatment regimens,[5 6] and negatively impact patients' health-related quality of life.[7 8] Prompt symptom recognition[4] and early help-seeking[9] are crucial to prevent avoidable harm. However, we do not have a thorough understanding of the factors people with cancer consider when deciding to access UEC (or not).[10]

Reflecting an international focus on improving early cancer detection, the literature is replete with studies[11 12] and reviews of research[13 14] focused on how patients appraise possible cancer symptoms. By comparison, research exploring symptom appraisal for complications of cancer and its treatment is scarce; studies and reviews of research have described demographic and clinical factors associated with emergency care use,[15–17] rather than how patients appraise symptoms as potentially needing intervention from UEC. Much research has been preoccupied with identifying the 'preventable' use of UEC,[18 19] despite difficulties defining avoidable care in this population[10 20 21] and evidence to suggest clinicians frequently disagree about what constitutes a preventable episode of care.[22] Without a better understanding of how people with cancer make decisions about new or deteriorating symptoms, clinicians and service managers will be unable to take informed decisions about the best ways to promote access to the right service at the right time.

To the best of our knowledge, there is no dedicated synthesis of studies using qualitative methods to explore symptom appraisal and decisions about help-seeking in this context. This review aims to address this gap by answering the following question: *how do patients and their informal caregivers appraise symptoms suggestive of, and identify the need to seek help from urgent and emergency care (or not) for, complications of cancer and its treatment?*

Conceptual framework

This review forms the first part of a multiphased programme of qualitative work which aims to build theory and explain how acutely unwell people with cancer and informal caregivers appraise symptoms and access UEC. Access to healthcare, as described by theoretical frameworks,[23 24] begins with patients perceiving a need to seek help. In this review, we use symptom appraisal to conceptually frame our qualitative synthesis. In a narrative synthesis of extant theory,[25] symptom appraisal has been characterised as a multistaged, iterative process comprising: (1) detection, (2) interpretation and (3) response. In their review, Whitaker *et al*[25] define the end point of symptom appraisal as the decision to consult a health professional (or not). By enrolling symptom appraisal, this review focuses on patients' and informal caregivers' decisions about the need to access UEC, rather than why they choose a specific service from which to seek help (a subject explored in our prior scoping review[26]).

This review draws on wider literature related to help-seeking and psychosocial theory to explore how patients' emotional responses and their social networks might influence symptom appraisal. Our synthesis incorporates aspects of Liberati *et al*'s[27] extension to the candidacy framework[24] of access, which highlighted how help-seeking decisions are influenced by patients' perceptions of their 'deservingness' for care at the point of symptom interpretation. We also refer to Leventhal *et al*'s[28] Common-Sense Model of Self-Regulation to explore how patients' reactions to symptoms (such as fear and anxiety) and their perceptions of risk might interact to shape symptom appraisal. Similar to our previous work, which aimed to explore (in part) how social network members navigate access to cancer-related UEC,[26] this review also draws on the Model of Urgent Care Help-seeking[29] with the aim of articulating informal caregivers' role in the 'work' required to appraise deteriorating symptoms.

As such, our objective was to explore not only how people with cancer appraise acute symptoms, but also to characterise how patients and informal caregivers judge the 'appropriateness' of accessing UEC as part of making decisions about help-seeking. In doing so, we aimed to develop a conceptual map, grounded in empirical and theoretical literature, and to progress understanding of the considerations, preferences and experiences that influence patients' and informal caregivers' decisions in this context.

METHODS

In a review of approaches to qualitative meta-synthesis, Kinn *et al*[30] argued that taking an abductive approach might enhance how 'the synthesiser 'puzzles together' an interpretive account of multiple qualitative studies' (p. 1285).[30] Despite the numerous methods of conducting qualitative evidence synthesis,[31] a dearth of approaches that explicitly enrol abductive reasoning to identify literature, analyse data and situate findings in relation to theory exists. In conducting this review, we combined systematic review procedures familiar to many qualitative literature review methods and an approach to collecting, analysing and theorising from data rooted in abductive analysis.[32] A summary of the review protocol was registered with the International Prospective Register of Systematic Reviews (PROSPERO). Enhancing Transparency in Reporting the Synthesis of Qualitative Research reporting guidelines[33] were followed.

Table 1 Key definitions

Cancer treatment	This review focuses on non-surgical cancer treatments, including radiotherapy, systemic anticancer therapy, endocrine therapy and targeted therapy (including immunotherapy). For the purpose of this review, we included treatments for haematological cancers (such as bone marrow transplantation and cellular therapies) and supportive interventions for cancer-related symptoms (such as pharmacological therapy for pain) in this definition.
Urgent and emergency care services	This review focuses on services designed to provide care for health problems needing immediate or same-day treatment, acknowledging that the boundaries between UEC services (and their roles) are inconsistently defined in policy and research.[79] In addition to specialist urgent and emergency cancer services, we included the following services in our definition: urgent telephone and digital advice services, out-of-hours services, urgent treatment centres, community pharmacies, ambulance services and emergency departments.

UEC, urgent and emergency care.

Identifying relevant studies

Searches were undertaken in three phases: (1) electronic database searches, (2) supplementary searches and (3) cluster searches. We did not search for unpublished studies or grey literature. Due to significant changes to UEC systems[34] and targeted anticancer treatment availability[35] that took place internationally at the end of the 1990s, we limited our review to studies published after 1999. Key definitions (table 1) informed the development of eligibility criteria and search terms.

Phase 1: electronic database searches

We refined the search strategy from our prior scoping review[26] to comprehensively search for potentially relevant studies. Subject headings and free-text terms were divided into three sets: (1) population terms (people with cancer), (2) phenomenon of interest (symptom appraisal and help-seeking decisions about using UEC services) and (3) study methods (qualitative and mixed methods). Six electronic bibliographic databases were searched: (1) ASSIA (via ProQuest), (2) CINAHL (via EBSCO), (3) Embase (via Ovid), (4) MEDLINE (via Ovid), (5) PsycInfo (via EBSCO) and (6) Web of Science Core Collection (Clarivate). Databases were searched from January 2000 to the present; the initial search was conducted on 2 May 2023 (and updated on 11 October 2024). No additional limiters were applied. Search strategies for each electronic database are displayed in online supplemental file A (base search) and online supplemental file B (updated search).

Phase 2: supplementary searches

We drew on the concept of ‘area scanning’—the search for records physically collocated with papers already selected for inclusion[36]—to identify digitally collocated papers. The ‘related articles’ and ‘similar articles’ functions in Google Scholar and PubMed respectively were applied to the included papers. For pragmatic reasons, only the first 20 records were retrieved for screening. Potentially relevant papers included in our prior scoping review[26] and literature reviews of potentially related topics retrieved in phase 1 were hand-searched; the base search was conducted between June and October 2023 (and updated in December 2024).

Phase 3: cluster searches

We enrolled the cluster searching procedure described by Booth *et al*[37] to structure iterative searches for contextually and theoretically related papers. Papers included in phases 1 and 2 were treated as key citations; the procedure followed is displayed in online supplemental file C. Theory and concepts identified by cluster searches also informed our abductive synthesis. We separately reviewed the reference lists of included papers, screening citations by title and abstract; the base search was conducted between July and December 2023 (and updated between December 2024 and January 2025).

Study selection

Potentially relevant records were imported into the bibliographic management software EndNote V.20 (Clarivate) and deduplicated. Records were screened against prespecified eligibility criteria, with one criterion added after protocol registration but before screening commenced (table 2). In phase 1, deduplicated records were imported into the systematic review management application Rayyan (QCRI).[38] Records were independently screened by title and abstract by the principal reviewer (JD) and another reviewer (RW or JT) with good concordance. Screening of records in phase 1 was conducted between May and June 2023 for the base search (and between November and December 2024 for the updated search). In phases 2 and 3, records were screened by title and abstract by the principal reviewer (JD), and independently screened by full text by the principal reviewer (JD) and another reviewer (JT). Screening of records in the base searches was conducted between June and October 2023 for phase 2 and between July and December 2023 for phase 3. Updated searches were conducted in December 2024 for phase 2 and between December 2024 and January 2025 for phase 3. The process is displayed in a Preferred Reporting Items for Systematic Reviews and Meta-Analyses flowchart[39] (figure 1).

Quality appraisal

Relevance of full-text papers was prioritised over methodological quality. Quality assessment of full-text papers was undertaken using the ‘appraisal prompts’ described by Dixon-Woods *et al*.[24] Papers were deemed

Table 2 Eligibility criteria

Criteria	Inclusion	Exclusion
1. Publication type	Papers that report empirical research papers.	Papers that report: study protocols; conference proceedings or abstracts; dissertations or theses; quality improvement projects or audits and other non-research papers.
2. Publication date	Papers published after the year 1999.	Papers published before the year 2000.
3. Language	Papers published in English.	Papers not published in English.
4. Study type	Papers that report: qualitative studies; or mixed-methods studies that studied symptom appraisal or help-seeking decisions as part of the qualitative component.	Papers that report: studies that used quantitative methods only; or mixed-methods studies that did not study symptom appraisal or help-seeking decisions as part of the qualitative component.
5. Concepts	Papers that report findings amenable to interpretation as symptom appraisal or decisions about help-seeking.	Papers that report studies of the following only: behaviour change; supported self-management interventions; digital symptom monitoring interventions or patient satisfaction with services.
6. Population	Papers that report studies that recruited: patient participants with an established cancer diagnosis (of any type); adults ≥18 years old or informal caregiver participants of patient participants meeting the criteria above.	Papers that report studies that recruited: patients diagnosed with cancer as a result of the episode of care studied; patients without cancer (and their informal caregivers) only; children <18 years old (and their informal caregivers) only; health and social care professionals only or paid caregivers only.
7. Services	Papers that report studies about symptom appraisal or decisions about help-seeking in the context of urgent or emergency care services.	Papers that report studies of: evaluations of new services; specialist palliative and end-of-life care services (eg, hospices) only; ambulatory delivery of cancer treatment; non-urgent use of community pharmacies and cancer information and support services.
8. Data extractability*	Papers that report study samples comprising: a majority of patient participants with cancer; or a minority of patient participants with cancer but participant quotations or author comments relevant to this review could be identified for extraction.	Papers that report study samples comprising a minority of patient participants with cancer and participant quotations or author comments relevant to this review could not be identified for extraction.

*Criterion added after protocol registered (but prior to record screening).

'fatally flawed' and excluded if one or more of the five appraisal prompts could not be answered with a 'yes' response. Otherwise, papers were not excluded on the grounds of quality. Quality assessment was undertaken independently by two reviewers (JD and RW). Uncertainty or disagreement was resolved by discussion with the wider review team (JT and AR).

Data extraction

A bespoke data extraction template was used. Data extracted included: (1) publication details, (2) author details, (3) project details, (4) study design, methods and findings, (5) participant and health service characteristics, (6) theories or conceptual models enrolled and (7) relevant participant and author quotations. Data extraction was undertaken by the principal reviewer (JD); an independent cross-check of extraction of participant and author quotations from six included papers was undertaken by a second reviewer (RW or JT). Authors' comments and participant quotations amenable to interpretation as symptom appraisal and help-seeking decisions were extracted from 'findings' sections of papers and published supplementary materials. Data were not extracted from 'discussion' sections to ensure that synthetic findings were grounded in participants' views. Only data attributable to participants with cancer or their informal caregivers were extracted from studies in which the views of patient participants without cancer and healthcare professionals were also studied.

Data analysis

Data were imported into the qualitative data analysis software NVivo (Lumivero) V.20. Data analysis followed the method of abductive analysis described by Timmermans and Tavory.[32] Open coding—guided by questioning 'who did what, when, where, how and with what consequences?'[32] (p. 73)—was undertaken first. Focused coding—using 'index cases' (ie, salient participant quotations, author comments or themes presented by papers) to anchor analytic arguments as they developed—followed open coding. Focused coding was undertaken by iteratively working between (and comparing) open codes from across included papers and concepts drawn from the review's conceptual framework and extant theoretical literature. Data were analysed by the principal reviewer (JD); coding decisions were discussed in data analysis meetings with the review team (RW, JT and AR). Visual representations were developed to 'test' the analytic domains of the conceptual map as they developed, and how they interacted to influence symptom appraisal and help-seeking decisions.

RESULTS

Searches identified 7120 potentially relevant records: phase 1 (electronic database searches) identified 2642 records, phase 2 (supplementary searches) identified 932 records and phase 3 (cluster searches) identified 3546 records. After de-duplication and screening, 71 full-text papers were assessed for relevance, of which

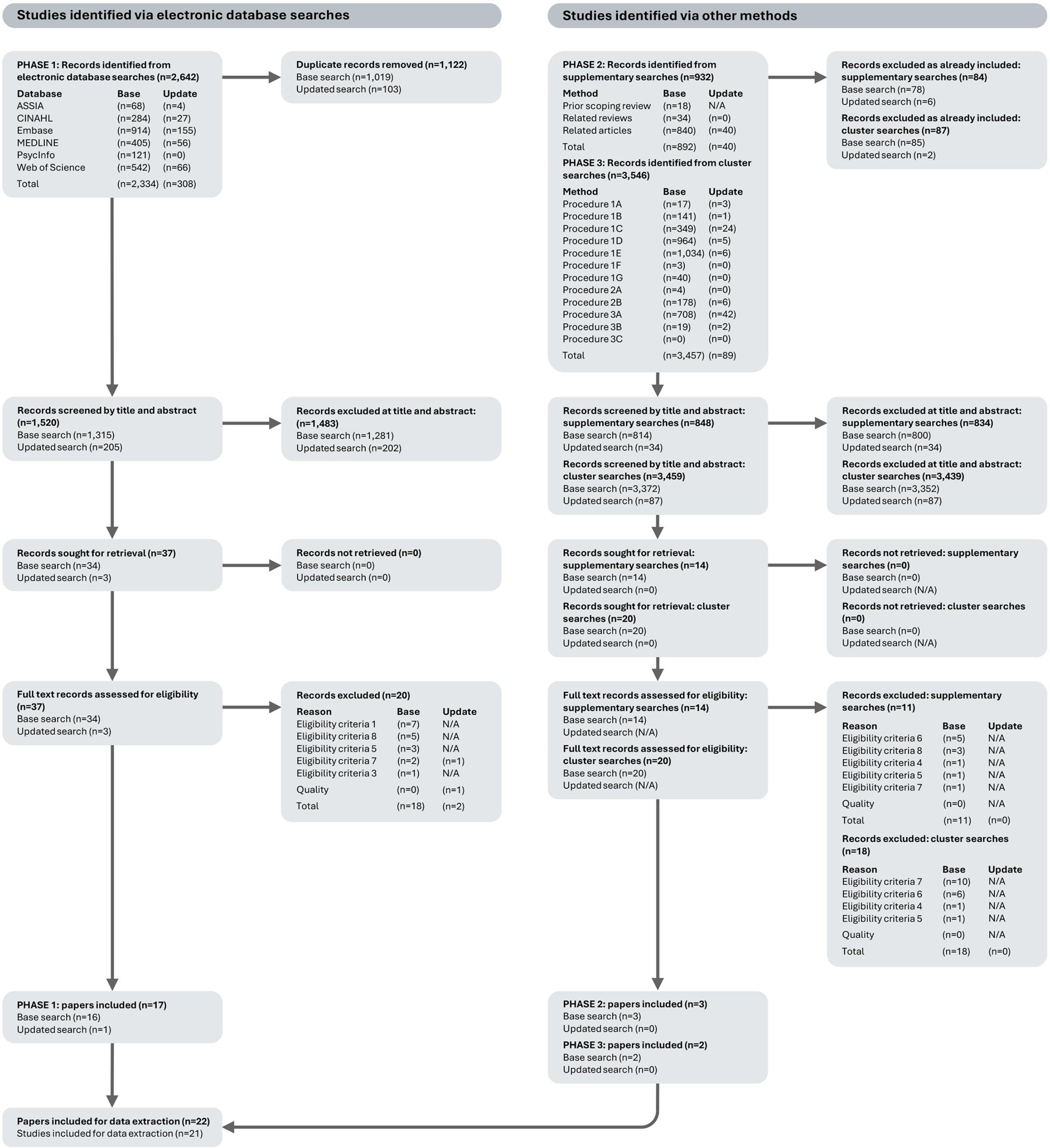

Figure 1 PRISMA flowchart. PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

23 papers (representing 22 studies) met the eligibility criteria.

Quality of eligible papers

One paper was excluded on the grounds of quality (table 3); as such, 22 papers (representing 21 studies) were included for data extraction after quality appraisal. A summary of the included papers is available in online supplemental file D.

Study characteristics

Included papers (n=22)[40–61] were published between 2006 and 2024. One study cluster was identified, which included a primary qualitative interview study[43] and a secondary qualitative analysis[50] (conducted by the same research team). The majority of papers originated from the UK (n=12/22) or the USA (n=3/22). Most papers (n=20/22) report qualitative studies; the remainder (n=2/22) report mixed-methods studies. The majority of papers report studies which used retrospective methods only (n=19/22) and semistructured interviews (n=18/22) to collect qualitative data and did not explicitly enrol theory (n=16/22). Of the theories or models enrolled, none were specific to symptom appraisal. Study characteristics are summarised in table 4.

Table 3 Quality appraisal

Included paper	Prompt 1	Prompt 2	Prompt 3	Prompt 4	Prompt 5
Geddie and Loerzel[80]	Yes	Yes	Yes	No	Yes
Dufton *et al*[40]	Yes	Yes	Yes	Yes	Yes
Ejem *et al*[41]	Yes	Yes	Yes	Yes	Yes
Kutzleben *et al*[42]	Yes	Yes	Yes	Yes	Yes
Jørgensen *et al*[43]	Yes	Yes	Yes	Yes	Yes
Mostarac *et al*[44]	Yes	Yes	Yes	Yes	Yes
Ream *et al*[45]	Yes	Yes	Yes	Yes	Yes
Jamieson *et al*[46]	Yes	Yes	Yes	Yes	Yes
Kaufmann *et al*[47]	Yes	Yes	Yes	Yes	Yes
Chen *et al*[48]	Yes	Yes	Yes	Yes	Yes
Green *et al*[49]	Yes	Yes	Yes	Yes	Yes
Pedersen *et al*[50]	Yes	Yes	Yes	Yes	Yes
Philip *et al*[51]	Yes	Yes	Yes	Yes	Yes
Oakley *et al*[52]	Yes	Yes	Yes	Yes	Yes
Henson *et al*[53]	Yes	Yes	Yes	Yes	Yes
Karasouli *et al*[54]	Yes	Yes	Yes	Yes	Yes
Nguyen *et al*[55]	Yes	Yes	Yes	Yes	Yes
Adam *et al*[56]	Yes	Yes	Yes	Yes	Yes
Clarke *et al*[57]	Yes	Yes	Yes	Yes	Yes
Leydon *et al*[58]	Yes	Yes	Yes	Yes	Yes
Richards *et al*[59]	Yes	Yes	Yes	Yes	Yes
Smith *et al*[60]	Yes	Yes	Yes	Yes	Yes
Worth *et al*[61]	Yes	Yes	Yes	Yes	Yes

Appraisal prompts:[24] (1) Are the aims and objectives of the research clearly stated?, (2) Is the research design clearly specified and appropriate for the aims and objectives of the research?, (3) Do the researchers provide a clear account of the process by which their findings were reproduced?, (4) Do the researchers display enough data to support their interpretations and conclusions? and (5) Is the method of analysis appropriate and adequately explicated?

Most papers reported studies that recruited both patient and informal caregiver participants (n=17/22); a smaller number recruited informal caregiver (n=2/22) or patient (n=3/22) participants only. Most papers reported studies that recruited patient participants with solid cancers only (n=11/22), samples in which most or all participants had advanced disease (n=14/22), and interviews about help-seeking from emergency departments (n=8/22). Fewer papers reported studies which recruited patient participants with haematological cancers (n=6/22) or recruited a majority of people with curative disease (n=2/22). Only one paper[55] described whether patient participants had comorbidities. Most papers did not state whether (or how many) people were receiving anticancer treatment (n=12/22); of those that did (n=10/22), four focused on help-seeking for suspected neutropenic sepsis (n=2/10) or immunotherapy toxicity (n=2/10).

Qualitative synthesis

From our synthesis, we have characterised how people with cancer and their informal caregivers appraise symptoms and make decisions about seeking help from UEC services. Using Whitaker *et al*'s[25] model as a framework, we describe five analytic constructs which articulate the considerations, preferences and experiences that influence symptom appraisal in this context: (1) preparation for complications, (2) sense-making: uncertainty, (3) sense-making: risk, (4) burden of help-seeking and (5) experience of complications. Here, included papers have been cited as source documents from which data were coded and analytic constructs developed. How these five analytic constructs stand in tension with one another as patients and informal caregivers make decisions about symptoms is presented as part of our findings.

Preparation for complications

The extent to which people with cancer and their informal caregivers felt prepared for complications of cancer or its treatment shaped their interpretation of, and response to, deteriorating symptoms. Patients' self-management and help-seeking responses were often guided by prior verbal or written instructions provided by professionals about specific symptoms,[42 43 47 50 51 53 54 56 57 61] but the need to seek help was also informed by the extent to which their symptoms were 'known' to their specialists:[44 47]

> I felt pretty good about handling problems at home. I had tools. I had instructions, 'You might feel like this… This might feel like that. That's normal. That's

Table 4 Study characteristics

Participants	
Patients and informal caregivers	17/22[40,42–44,48–54,56–61]
Patients only	3/22[46,47,55]
Informal caregivers only	2/22[41,45]
Studies which included people without cancer	4/22[49,54,58,60]
Cancer type	
Solid cancers (all participants)	11/22[41–43,45–47,49,50,52,54,56]
Solid and haematological cancers	5/22[40,44,51,53,55]
Haematological cancers (all participants)	1/22[57]
Not explicitly stated	5/22[48,58–61]
Cancer stage	
Advanced cancer (all participants)	9/22[41,42,51,53,54,58–61]
Advanced cancer (most participants)	5/22[43,47,48,50,56]
Curable cancer (most participants)	2/22[45,52]
Not explicitly stated	6/22[40,44,46,49,55,57]
Non-surgical cancer treatment	
Chemotherapy (all or most participants)	6/22[40,44,45,48,52,57]
Immunotherapy (all or most participants)	2/22[42,46]
On treatment (unspecified)	2/22[47,55]
Not explicitly stated	12/22[41,43,49–51,53,54,56,58–61]
Health problems	
Neutropenic sepsis	2/22[52,57]
Immunotherapy toxicity	2/22[42,46]
Other specific health problems*	2/22[41,56]
Heterogenous or not explicitly stated	16/22[40,43–45,47–51,53–55,58–61]
UEC services studied	
Emergency departments	8/22[40,44,47,49,51,53,55,60]
Multiple services	5/22[46,48,52,54,59]
Specialist emergency cancer care	4/22[43,45,50,57]
Other services†	5/22[41,42,56,58,61]

*Includes studies of help-seeking decisions for seizures in people with primary malignant brain tumours[41] and cancer-related pain.[56]

†Includes papers which present findings about decisions to seek help from out-of-hours services[56,58,61] and pre-hospital emergency care.[41,42]

UEC, urgent and emergency care.

> not normal. If that happens then you take this.' With the [new] GI stuff, I don't feel very capable of being able handle the stuff at home because I don't think they are sure what's going on yet either. ((p. e1295);[47] patient participant)

For many, the need for reassurance—either to check that 'nothing was very wrong' (p. 2077)[50] or to have proposed self-management actions sanctioned—underpinned their decision to seek help.[48,50,61] However, difficulty interpreting and applying prior instructions complicated decisions about whether to seek help or not,[43,52,57] and many patients and informal caregivers sought information from social networks comprising peers with cancer to help interpret unfamiliar symptoms at the point of deterioration.[46,47,57] Alongside the severity[44,47,48,53,60,61] and rapidity[44,47–49,52,56,61] of their deterioration, it was symptoms for which patients and informal caregivers felt unprepared that influenced their decisions to seek help from UEC services.[41–43,47,50,52,55,60] However, rushed and mechanical clinic appointments[40,42,52] and the overwhelming nature of being newly diagnosed with cancer[41,42,52] confounded preparation for complications:

> We didn't even have time to look and see what we were, I mean, you don't have time to research anything. You're just agreeing to these surgeries. You know they're relieving the pressure and putting shunts in before you can digest anything because it's such an emergency situation. So, I think that's a lot to deal with. I think seizures kind of fall down low on the totem pole. ((p. 321);[41] informal caregiver participant)

Sense-making: uncertainty

How patients make sense of their symptoms as either a complication of cancer or its treatment influences how they respond to acute deterioration in their health. Patients' interpretation of new or changing symptoms was framed by their knowledge of anticancer treatment side-effects (and their implications)[42,46,47,50,57] and the spread of their cancer.[53,56] The 'process of elimination' (p. 6)[46] undertaken to decide whether symptoms represented a complication of their cancer or its treatment not only proved difficult for patients[42,46,50] but took place amid considerable fear and anxiety.[43,50,54,55,61] Much of this anxiety (and the decision to seek help) was precipitated by patients' uncertainty about the cause of their symptoms, and driven by a fear that their cancer had progressed:[43,53,56]

> I don't like being in pain… I didnae understand why, you know, if I get pain, I didnae understand why I'm getting it and what's happening so em, I kind'a worry about it in case the cancer's spread. ((p. e756);[56] patient participant)

Interpreting and deciding how to respond to deterioration was confounded by difficulty interpreting the significance of fluctuations in chronic symptoms,[54,56] challenges distinguishing between side effects of supportive medications and other problems,[43,46,57] and nebulous symptoms associated with early anticancer treatment toxicity.[42,45,52,57] Complications of anticancer treatment often went undetected or were misinterpreted due to limited knowledge of common symptoms, their significance and expected trajectories.[40,42,43,46,52] The combination of 'mild' symptoms[40,46,48,52,53] and the absence of other warning signs[40,46,52,57] resulted in many patients underestimating the level of risk, with symptoms often framed with reference to common ailments.[40,42,43,46,52] On detecting signs and symptoms of febrile neutropenia, however, many adopted maladaptive coping strategies—such as choosing to ‘ignore’ fevers (p. 2690),[57] having a ‘cold bath’ (p. 1508)[52] or masking symptoms with antipyretic medication[47]—influenced by fear and denial.[52 57]

Sense-making: risk

At the onset of symptoms, people with cancer engaged in watchful waiting[47 48 50 58] and used (often tried-and-tested[54]) self-management strategies[44 46 48 54 55] to lessen the burden of acute illness. For many, this was the default response and continued in the face of severe symptoms[40 47 54 58] which patients often endured for days and despite deterioration.[44 47 53 55] For some patients, hoping their symptoms would spontaneously improve delayed early help-seeking.[40 47] As symptoms worsened, the decision to seek help from UEC services was prompted when patients’ and informal caregivers’ capacity to self-manage was exceeded.[43 47 48 50 51 54 56 60] As such, patients often sought help at the point symptoms developed into crises,[40 44 47 48 51 55 59] or because the risk of not seeking help was deemed by patients or informal caregivers to be unacceptably high:[43 47 50 59 60]

> We feel most safe by calling you… when I know that it is cystitis, he has to start treatment immediately, because I am afraid that he does not get his chemotherapy [on time]. ((p. 101);[43] informal caregiver participant)

Informal caregivers contributed significantly to the assessment and management of risk as patients’ health deteriorated. Patients’ decisions about self-management and seeking help were often made in partnership with informal caregivers,[40 46 49 54 56] who both used knowledge of what was ‘normal’ (in terms of patients’ baseline health) to interpret the severity of deterioration.[46 50 54] The significance of symptoms and urgency of obtaining help was often first appreciated by informal caregivers;[40 44 47 55 57] in response, informal caregivers encouraged and sanctioned decisions to seek help,[53 56 59] becoming more insistent on this course of action as the patient’s condition worsened.[47 52] Tensions between patients and informal caregivers emerged when informal caregivers’ advice was not heeded,[47 52–54 59] with evidence this conflict burdened both parties.[53 59] For some patients, the burden of symptoms limited their capability to respond effectively as they deteriorated,[48 49 57] with the decision to seek help (and when) often made emergently by informal caregivers at the point a patient’s condition became unmanageable:[40 47–50 52 54 58 59]

> He got to the top of the stairs, couldn’t breathe at all. And I said to him, we’re going to have to ring… because you can’t go on like this. Anyway, I got him back downstairs and um he wasn’t any better and I rang the ambulance. ((p. 5);[54] informal caregiver participant)

Burden of help-seeking

Receiving anticancer treatment came with an expectation that patients (and informal caregivers) monitor, manage[50 52 57] and seek help for new and deteriorating symptoms.[43 48 52 57] Although this workload was undertaken diligently by many, it was not without burden;[50] indeed, the anticipated ‘rigmarole’ (p. e757)[56] of using services out-of-hours,[47 58 61] or the prospect of being (re)admitted to hospital,[47 54 57 58] contributed to many persisting with self-management at the expense of seeking help sooner. On detecting a serious problem, many patients felt conflicted by the expectation of following professionals’ advice about contacting UEC services and their wish to carry on with self-management at home,[47 52 57] pointing to a burden of (repeated) help-seeking:

> … It’s just the side-effects… I can't keep ringing… every time I feel ill. ((p. 1509);[52] patient participant)

At the point of deterioration, patients and informal caregivers also found it challenging to determine whether their concerns were urgent[40–42 45 56 58 61] or represented a legitimate need to access UEC services.[41 43 56 58 59 61] Difficulty deciding whether to seek help (or not) was compounded by fears of being a burden, either in terms of contributing to the workload experienced by overstretched health systems[56–58] or concerns about ‘bothering’ (p. e1296)[47] health professionals unnecessarily (despite often severe or debilitating symptoms):[43 45–47 50 56 58 59 61]

> … you can page a registrar if it’s urgent but we weren’t sure if it was a problem or if it was urgent, so that was probably the most stressful thing, not knowing whether you should phone them in the middle of… it was only like 11pm but whether just to… so we just waited until the morning. ((p. 6);[45] informal caregiver participant)

Decisions about help-seeking were also influenced by concerns for ‘others’; acutely unwell people with cancer were concerned that, by seeking help, attention would be diverted from other, more deserving patients.[47 56–58] As such, deciding to seek help took courage on the part of patients and informal caregivers, contributed to the stress of responding to acute symptoms,[41 43 47 50 58 61] and often resulted in delayed help-seeking.[45 50] Decisions to delay (and suffer burdensome symptoms longer) were often regretted, and both patients and informal caregivers blamed themselves for not having the ‘courage to call’ (p. 419)[58] sooner.[54 58]

Experience of complications

Previous experiences of complications of cancer and its treatment influence how both people with cancer and their informal caregivers detect, interpret and respond to symptoms. Patients and informal caregivers better understood ‘what to look out for’ (p. 6)[45] with prior experience of complications[43 45 53 54 57] and drew on these episodes of deterioration to interpret the cause of, and urgency of seeking help for, acute symptoms.[41 45 47 53 54 57] However, this experience often came at the cost of learning the hard way. Identifying the need to seek help was grounded in past experiences of using UEC services for life-threatening emergencies since being diagnosed with cancer:[40 52 54 55 57 60]

> At first, you think, 'oh, [chemotherapy] isn't that strong', and then, the second lot, you think, 'oh my God, his neutro-things are down, will he catch anything? Have I got a cold?', because you realise then that that's it, that's how powerful it is. I mean, it could kill you. ((p. 2690);[57] informal caregiver participant)

Experience of serious treatment-related complications re-shaped informal caregivers' management of risk, manifesting as increased vigilance,[57] deeper understanding of what to do if a similar problem were to recur[52] or persistent concern about the threat of complications.[45] Although knowing what to expect and how to respond often developed over time and with experience,[43 45 47 57] this was not universal[45] and past experiences did not always result in effective symptom appraisal. For better or for worse, people receiving immunotherapy used prior experiences of chemotherapy and radiotherapy to interpret new symptoms; some were able to use these experiences to recognise patterns in their symptoms,[42] whereas others misinterpreted acute toxicity as a 'legacy' (p. 6)[46] of previous treatments.

Conceptual map

From the qualitative synthesis, we developed a conceptual map (figure 2) which explains how 'analytic constructs' derived from our analysis (described above) influence the 'process constructs' (detection, interpretation and response) derived from the model of symptom appraisal described by Whitaker *et al*.[25] Unlike the model presented by Whitaker *et al*,[25] we contend patients' and informal caregivers' actions might move bi-directionally between response to interpretation (eg, people may reevaluate their interpretations following self-management actions without detecting new somatic information).

In our conceptual map, we show that preparation informs how people make sense of uncertainty (path A) and risk (path B) related to complications. Knowing the cause of (and the uncertainty generated by) newly detected symptoms influences how potential consequences of those symptoms are perceived which, in turn, shapes how people respond (path C). The risk people attach to symptoms—either as direct health threats (eg, infection as a serious threat to health) or indirect health threats (eg, infection as a threat to their anticancer treatment schedule)—influences the 'work' undertaken to appraise new or acute symptoms (path D).

Decisions about responding to symptoms by using UEC services (or not) are also shaped by the burden of help-seeking (path E); acutely unwell people with cancer have to resolve tensions between conflicting priorities when making decisions about help-seeking, weighing the perceived legitimacy of their UEC needs

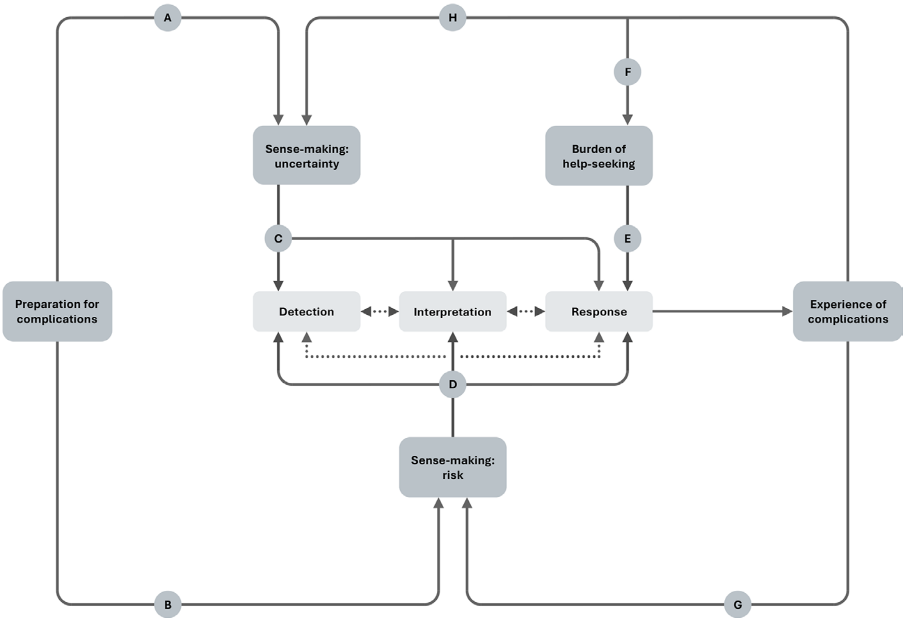

Figure 2 Conceptual map of symptom appraisal and urgent and emergency care help-seeking for complications of cancer and its treatment. Dashed arrows represent progress through the phases of symptom appraisal (eg, from 'detection' to 'interpretation'); solid arrows represent relationships between analytic constructs developed by our qualitative synthesis (eg, 'preparation for complications') and how these influence the process of symptom appraisal.

against perceived risks to themselves and others. How people perceive burdens of help-seeking (which might accumulate over time) (path F), as well as how people make sense of risk (path G) and uncertainty (path H), is also influenced by past experiences of complications (and other acute illnesses). As such, our findings suggest the work of detecting, interpreting and responding to symptoms of complications is not only an iterative process at the point of deterioration, but informed by knowledge, skills and perceptions developed and reappraised with experience.

DISCUSSION

To the best of our knowledge, this is the first review (systematic or otherwise) to synthesise data from studies using qualitative methods to characterise how patients and informal caregivers appraise symptoms suggestive of complications of cancer or its treatment. In doing so, we have integrated the accounts of over 300 people with cancer and over 200 informal caregivers—and abductively drawn on theoretical and conceptual work relating to risk and uncertainty, burdens of illness and treatment and health literacy and sense-making—to develop the conceptual map (figure 2). We discuss how the analytic constructs interact with the process of appraising symptoms and making help-seeking decisions via the eight pathways below and suggest priorities for future research.

Influence of preparation on uncertainty and risk: paths A and B

Findings suggest the 'novelty rule'—interpreting symptoms as incompatible with an expected or recognisable pattern of illness[62]—strongly motivates decisions to seek cancer-related UEC. Rather than being influenced by a 'universal somatic experience' (p. 346)[63] accrued over a lifetime, the 'novelty' of health problems in this context appears to be the product of a poor fit between acute symptoms and those for which patients were prepared by specialists. Understanding what symptoms to expect and how to self-manage their illness are important[64] but often unmet[65] information needs which are reported by people with cancer. Our findings suggest that preparation shapes how people make sense of uncertainty (path A), with unexpected symptoms often perceived as a threat (and prompt help-seeking from UEC) in this context.

The volume of new information received prior to, and the psychological burden of, starting cancer treatment influences how people prepare for future potential health threats (path B). To date, the concept of 'cancer information overload' has not been applied to study how people process information about potential complications during cancer treatment.[66] Nonetheless, studies from the field of health literacy indicate patients' understanding of toxicity can be negatively impacted by being given 'too much information at once' (p. 9)[67], and patients' fears result from, and contribute to, poorer understanding of cancer information.[68] However, studies focusing on how people plan ahead for complications are lacking;[26] as such, our understanding of how pre-treatment (and other) information is used to prepare for risks, and how preparation informs action during deterioration (or not), is limited.

Making sense of uncertainty and risk: paths C and D

For many, the uncertainty generated by new symptoms (path C) contributed to concerns that symptoms represented cancer progression. These findings are significant as, to the best of our knowledge, this is the first review to link symptom appraisal and decisions about seeking help from UEC services during treatment to the fear of cancer progression. Defined as 'fear, worry, or concern about cancer returning or progressing' (p. 3266),[69] fear of cancer recurrence or progression—terms which are often used interchangeably but appear to be distinct constructs[70]—have been linked to greater use of emergency care by cancer survivors.[71] A deeper understanding of which factors might contribute to the fear of cancer progression in this context is needed.

How people with cancer and their informal caregivers make sense of the risk of complications appears to inform the work they undertake to appraise and manage symptoms in this context (path D). Although self-management—which was often initiated, facilitated and re-appraised by informal caregivers—appears to be the default response to deterioration, existing evidence lacks granularity in terms of what actions are taken prior to help-seeking decisions, when and by whom. Considering the decision to seek help is informed by the work and outcomes of self-management as much as how symptoms are interpreted,[62] this knowledge gap needs to be explored via research before interventions can be developed.

Burden of (repeated) help-seeking: paths E and F

Although evidence suggests people with cancer are frequently admitted to hospital from emergency care,[15] our findings show this group to be deeply concerned about seeking help inappropriately. To date, the concept of 'self-perceived burden' has been applied to describe patients' perceptions of how their illness negatively impacts informal caregivers;[72] it has not been extended to understand how patients might perceive their health needs as a burden on professionals, services and systems. This is important as some evidence suggests those with more complex cancer-related supportive care needs (and are, arguably, more likely to need UEC) appear to report higher levels of self-perceived burden.[73]

Furthermore, our synthesis suggests many patients are burdened by the tension between the wish to be a 'good' patient (and follow specialists' advice) and the desire to avoid UEC (and the potential disruption associated with accessing services). The notion of good patienthood, from the perspectives of people with cancer, appears to involve following 'unpleasant or seemingly burdensome' (p. 2228)[74] instructions from specialists and a potential 'moral obligation' to self-care (p. 286)[75]. At the point of deterioration, resolving this tension appears to burden people with cancer (path E).

Burdensome access procedures—both perceived and (as demonstrated by our previous work[26]) experienced—influence decisions about (and contribute to delayed) help-seeking, as does a desire to avoid recurrent service use (path F). Understanding which processes contribute to or reduce the burden of accessing cancer-related UEC, and how these might differ by service delivery model, is an important objective of future research. Although the included papers were drawn from international literature, we did not find evidence to suggest financial burdens significantly contributed to UEC help-seeking decisions; this deserves further study, as health systems with different insurance, payment and funding arrangements might influence patients' decisions in this context.

Impact of experience on future sense-making: paths G and H

Similar to studies of people seeking general urgent care[29] and those with long-term conditions,[76] our findings show previous experiences influence how people with cancer make sense of risks and assess the urgency of help-seeking (path G). To date, studies have largely focused on patients' decisions prior to a single episode of help-seeking, rather than how people make sense of symptoms over time. This is important as symptoms associated with toxicity not only change over the course of treatments, but differ significantly by modality. Indeed, how people appraise symptoms suggestive of complications of (progressive) disease, and how these might interact with comorbid illness, is likely to change across the life course with cancer. Our understanding of how approaches to symptom appraisal might change after transitional events (such as commencing second-line treatment or developing a new site of metastatic disease) would benefit from research.

The experience of symptoms, and the outcomes of self-managing and seeking help, influences the level of uncertainty perceived if similar problems are encountered in the future (path H). For example, familiarity with clusters of symptoms which fluctuate as cycles of anticancer treatment progress may reduce the uncertainty (and risk) perceived by patients and informal caregivers, particularly if confidence and capacity to self-manage develop over this time. Equally, uncertainty about the significance of feverish symptoms may diminish after hospital admission with febrile neutropenia, but the risk attached to similar symptoms may increase after an episode of sepsis. Whether these experiences influence preparation for future episodes of deterioration (and how) is, however, unclear. Future work should explore how patients and informal caregivers might recursively shape their preparatory actions over time (or not) and identify opportunities to support self-management and timely help-seeking.

Implications for practice and policy

These findings point to the complexity of supporting patients to prepare for, and appraise symptoms of, complications of cancer and its treatment. Numerous papers[41 53 56 57 60] have made recommendations about the content and importance of information to facilitate help-seeking, avoid service use or support 'better' self-management. On the basis of our synthesis, we suggest how clinicians work to transform this information into action plans, and how these plans are reappraised with patients and their experiences of complications, shapes decisions about seeking help. Furthermore, our findings show informal caregivers frequently lead the work of detecting, interpreting and responding to symptoms, but studies suggest the concerns of informal caregivers of people with cancer are not always recognised by UEC clinicians.[57 59] As such, the concerns of informal caregivers could be a 'red flag' indicative of significant deterioration and a means to inform decisions about the urgency of assessment and interventions. Finally, this review suggests a close relationship exists between (poor) experiences of care and (delayed) future help-seeking; in this context, the experience of cancer-related UEC is a matter of patient safety.

Strengths and limitations

This is the first review to draw together findings from international qualitative research to characterise how people make decisions about symptoms suggestive of complications of cancer and its treatment. Due to resource constraints, included studies were limited to those published in English. Nevertheless, we only excluded one potentially relevant paper in full text for this reason. This review used multiple search strategies in addition to electronic database searching. Title and abstract screening were undertaken by a single reviewer for supplementary and cluster searches, which may have resulted in relevant papers being excluded. However, this approach was in line with established systematic review procedures and similar to the approach taken by a systematic review comparing single and double screening procedures.[77]

No study included in this review explicitly enrolled the concept of symptom appraisal and, in line with a critique of help-seeking literature generally,[78] data included in our analysis were extracted from mostly atheoretical studies. By drawing on the method of abductive analysis,[32] however, we were able to anchor findings to extant theoretical literature. That said, our conceptual map should be tested in future research; explanatory approaches to qualitative and mixed methods research, underpinned by findings from this review, might develop and extend the dimensions of our map and progress theory-building specific to this context. Underrepresented patient groups, including people with cancer and multimorbidity and those receiving radical or curative treatment, should be recruited to future studies.

CONCLUSION

This systematic review and qualitative synthesis has developed a conceptual map which for the first time characterises how patients and their informal caregivers appraise acute symptoms and make help-seeking decisions about complications of cancer and its treatment. Our findings suggest the work undertaken to appraise symptoms in this context is complex, changes across courses of treatment and disease trajectories, and (repeatedly) burdens people with cancer and informal caregivers. This review demonstrates the need for interventions which better prepare people for complications, as well as the importance of developing models of care that reduce the burdens faced by patients seeking urgent and emergency cancer care.

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