

REVIEWS

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# Understanding the urgent and emergency care navigation work undertaken by people with cancer and their informal caregivers: a conceptually framed scoping review

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## Abstract

**Background** People with cancer frequently use urgent and emergency care. Reviews of research have focussed on the incidence and predictors of service use in this population, rather than how people make decisions about which service to access. Understanding what factors influence these choices will inform ways in which we might enable people with cancer to effectively access services.

**Aims** (1) Describe research undertaken about choices made by people with cancer about routes to access urgent and emergency care; (2) characterise decisions made by patients and informal caregivers to use certain services, with specific reference to work involved in navigating access; and (3) identify research priorities.

**Methods** Scoping review of qualitative and mixed methods studies. Electronic database searches (AMED, CINAHL, Embase, MEDLINE, PsycInfo) and 'berrypicking' identified 18 papers. Study, participant, and service characteristics were mapped, and Turnbull et al.'s Model of Urgent Care Help-seeking informed a directed qualitative content analysis.

**Results** Studies have involved people with advanced cancer to the relative exclusion of people with curable disease, receiving anticancer treatment, and who are multi-morbid. Six subcategories of navigation work were identified: (1) making decisions with, and seeking help from, specialists, (2) seeking safety, (3) positioning to access desired treatment, (4) negotiating tortuous pathways to help, (5) making decisions in collaboration with caregivers, and (6) managing isolation from services and social networks.

**Conclusion** There are significant knowledge gaps and a need for more research, particularly studies of how different patient groups prepare for potential deterioration and make sense of systems of urgent and emergency care.

**Keywords** Acute oncology, Cancer, Caregivers, Emergency care, Help-seeking, Patient work, Qualitative, Scoping review, Urgent care

## Introduction

Evidence suggests people with cancer use urgent and emergency care (UEC) services more than the general population [1–3], often presenting with 'high acuity, high symptom burden, and frequent need for admission' ([4], p.9). UEC use by people with cancer is expected to rise in tandem with an ageing population and increased survival [5]. Reviews of research have identified factors associated

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with UEC use by people with cancer (e.g., symptom clusters, demographic factors) [4, 6–8] and interventions which aim to prevent emergency care use by this population [9, 10]. Psychosocial factors that might influence usage, and preferences and experiences of informal caregivers, remain neglected areas of research [11]. To our knowledge, there is no overview of studies that has focussed on how people with cancer make decisions about which UEC service to access when acutely unwell. Understanding which services and patient groups have been studied, and what factors influence their choices, is needed to inform ways in which we might support patients to effectively access UEC for complications of cancer and its treatment.

Navigating UEC systems can be difficult for people with cancer [12]. The concept of ‘work’ has been used to understand the decisions, activities, and tasks undertaken by patients and informal caregivers to manage illness, the consequences of these actions, and the challenges encountered [13]. In the Model of Urgent Care Help-seeking, Turnbull et al. [14] describe how decisions about UEC service use are, in part, the product of ‘navigation work’ undertaken to make sense of the availability, accessibility, and acceptability of services. Turnbull et al.’s model [15] describes how this work is either undertaken alone (individual level navigation work) or with the support of others, such as family or friends (social network level navigation work). The model also describes how time of day and social contexts influence this workload (socio-temporal navigation work) [15]. To understand the extent to which international research has studied this phenomenon, this scoping review aimed to achieve the following: (1) describe research undertaken about choices made by people with cancer about routes to access UEC, (2) characterise how people with cancer decide to use which service in terms of ‘navigation work’, and (3) identify priorities for research.

## Methods

Scoping reviews aim to map the breadth and depth of research in a field to answer a broad research question [16]. In contrast to systematic reviews, scoping reviews aim to ‘extract the essence of a diverse body of evidence’ ([17], p.1398) and can be used to clarify key characteristics of a concept and identify knowledge gaps in an emerging field [18]. Building upon preliminary findings [19], this review aimed to answer the question as follows: *what research describes how adults with cancer and their informal caregivers navigate urgent and emergency care?* We followed Arksey and O’Malley’s [20] framework, which comprises five stages: (1) identifying a research question, (2) identifying relevant studies, (3) study selection, (4) charting the data, and (5) collating, summarising,

and reporting results. PRISMA guidelines [21] for scoping reviews were followed.

### Identifying relevant studies

We retrieved literature in two stages: (1) electronic database searching and (2) ‘berrypicking’. Our review focused on research published since 2000 due to changes in UEC delivery models that have taken place internationally since the end of the 1990s [22].

### Electronic database search

Search terms were developed from subject headings (e.g. MeSH terms) and informed by key publications, such as Mills et al. [6] and Turnbull et al. [14], to capture research describing decisions to use different UEC services. Search terms and subject headings were divided into 4 categories: (1) population (people with cancer or their informal caregivers); (2) concept (help-seeking decisions); (3) context (UEC services); and (4) study (qualitative methods). Electronic databases were searched from January 2000 to May 2021 and included the following: AMED, CINAHL, MEDLINE, PsycInfo (via EBSCO), and Embase (via Ovid). Searches were undertaken June–July 2021. An example electronic database search strategy is displayed in Additional File 1.

### Berrypicking

We drew upon Booth et al.’s [23] cluster searching method, applying ‘berrypicking’ strategies to search for potentially relevant papers co-located with or related to papers included via electronic database searching. Techniques reflected four of Bates’ [24] berrypicking strategies: (1) footnote chasing, (2) citation searching, (3) author searching, and (4) area scanning. The procedures followed for each strategy are displayed in Additional File 2.

### Study selection

We used pre-specified eligibility criteria to screen papers for relevance (Table 1). Titles and abstracts of retrieved papers were screened by the principal reviewer (J. D.); where potentially relevant, citations were imported into EndNote™ 20 (Clarivate™) and de-duplicated. Full-text papers that met the eligibility criteria were included for data extraction. Uncertainty about whether a paper met the criteria was resolved by discussion with the review team (R. W. and A. R.). The process is displayed in the PRISMA flowchart [25] in Fig. 1.

**Table 1** Eligibility criteria

	Inclusion criteria	Exclusion criteria
Language	Papers published in English	Papers not published in English
Publication date	Papers published after the year 1999	Papers published prior to the year 2000
Population	Studies that recruited patient participants as follows: with an established diagnosis of cancer (of any type) and age > 17 years. Papers that recruited informal caregivers of people with cancer meeting the criteria above	Studies that recruited patient participants as follows: without cancer only, who were diagnosed with cancer during or following the episode of UEC use studied, age < 18 years only. Studies that recruited paid or professional caregivers only
Help-seeking	Papers that report studies of the decisions made by patients and their informal caregivers to use services (or not)	Papers that report studies of the following: behaviour change interventions, healthcare professionals' views about patient and informal caregiver decision-making only, or satisfaction with, or experiences of, services only
Services	Papers that focus on patient use of urgent or emergency health-care services	Papers that report studies of the following: scheduled healthcare contacts only, use of palliative care services (i.e. hospices) only, or service contacts initiated by professionals only
Publication type	Papers that report empirical research	Papers that report the following: literature reviews, study protocols, abstracts only, theses and dissertations, discussion papers (i.e. editorials and commentaries), audit and quality improvement, or news and magazine articles
Study type	Studies that used qualitative methods or studies that used mixed methods and where the qualitative component was used to study help-seeking decisions	Studies that used quantitative methods only or studies that used mixed methods and where the qualitative component was not used to study help-seeking decisions

### Quality appraisal

As is convention in scoping reviews [18], and to ensure findings represented the breadth of research literature, no papers were excluded on the grounds of quality.

### Data extraction and analysis

Data were charted using a template developed a priori and with reference to the Model of Urgent Care Help-seeking [15]. A two-stage approach to collating and summarising data was undertaken: (1) descriptive mapping of study, participant, and service characteristics and (2) directed qualitative content analysis of data amenable to interpretation as navigation work.

#### Stage 1: mapping study, participant, and service characteristics

Data extracted and analysed in stage 1 included the following: publication details (e.g. country of origin); study design and methods (e.g. theories enrolled); patient participant characteristics (e.g. cancer stage); informal caregiver characteristics (e.g. relationship to patient participant); and services studied (e.g. ambulance).

#### Stage 2: content analysis of author and participant quotations

We used qualitative content analysis [26] to characterise the work involved in navigating access to UEC services. Author and participant quotations amenable to interpretation as 'navigation work' were extracted from the 'Results' sections of papers and treated as data. When studies also focussed on help-seeking for other

conditions, data were extracted only if clearly relevant to people with cancer. Directed qualitative content analysis was undertaken following the method described by Assarroudi et al. [27]. We theoretically defined coding rules and categories with reference to Turnbull et al. [14] and piloted the coding matrix on data extracted from five papers which studied five different UEC services. Data were managed in Excel<sup>®</sup> (Microsoft<sup>®</sup>) and analysed by the principal reviewer (J. D.); coding decisions were discussed in data analysis meetings with the review team (R. W. and A. R.). Subcategories were developed by comparing and interpreting similarities and differences in meaning across groups of codes [27] (in pursuit of the *latent* content [28]).

### Results

Searches identified 21,723 potentially relevant papers. Stage 1 (electronic database searching) identified 19,561 citations, and stage 2 (berrypicking) identified 2162 citations. After de-duplication and screening, 90 full-text papers were assessed for relevance, of which 18 studies [29–46] met the eligibility criteria and were included for data extraction (Table 2).

#### Characteristics of studies, participants, and services

Study, participant, and service characteristics are mapped in Figs. 2 and 3.

#### Study characteristics

The majority of studies were conducted in Europe ( $n = 12/18$ ) [30, 32–35, 37–39, 41–43, 46] and North

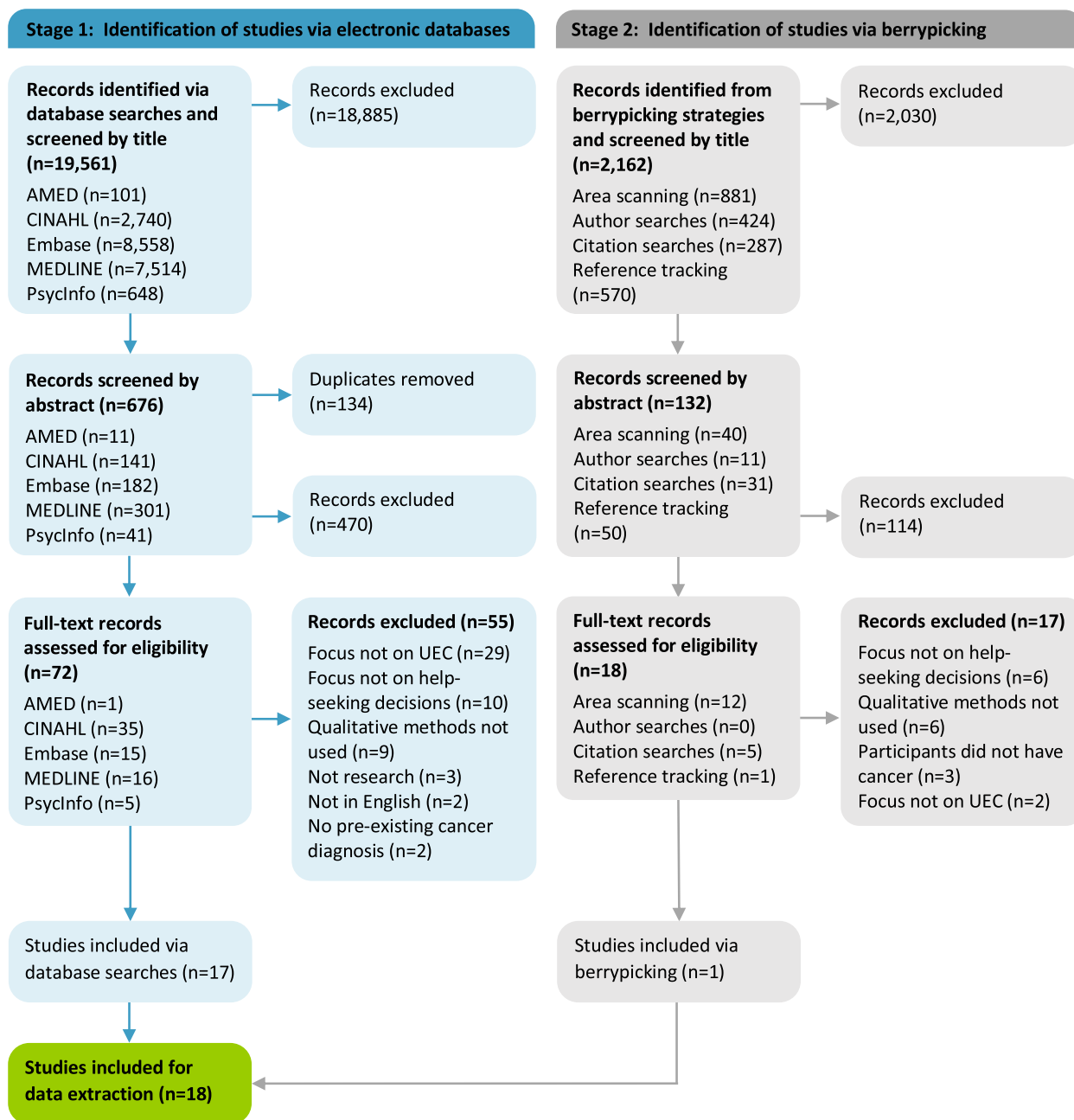


Fig. 1 PRISMA flowchart

America ( $n = 5/18$ ) [29, 31, 40, 44, 45], with one [36] originating from Australia. Most European studies ( $n = 10/12$ ) [32, 33, 35, 37–39, 41–43, 46] were conducted in the United Kingdom (UK); two studies [30, 34] originated from Denmark. North American studies were conducted in the United States (US) ( $n = 3/18$ ) [31, 44, 45] and Canada ( $n = 2/18$ ) [29, 40]. Most studies ( $n = 14/18$ ) [29–42] were published after 2014. Almost all reported qualitative studies ( $n = 16/18$ ) [29–31,

33–39, 41–46] with one [34] reporting a secondary analysis of another included paper by the same authors. The remaining papers ( $n = 2/18$ ) [32, 40] used mixed methods. Most qualitative studies ( $n = 14/16$ ) used qualitative description; one paper reported a phenomenological study [30], whereas the other [37] reported a constructivist grounded theory approach. Of the mixed methods studies, one described using a concurrent triangulation design [40], while the other [32] did not

**Table 2** Summary of included studies

Study details	Aim and objectives	Design and methods	Participants	Relevant findings
[29] Mostarac et al. (2021); Canada	Understand decisions about emergency department attendance from the perspective of patients and family members; focus on understanding causes of avoidable attendances	Qualitative descriptive study <sup>2</sup> , structured interviews, qualitative content analysis	Adults (age $\geq 21$ years) ( $n = 45$ ) with solid ( $n = 37/45$ ) and haematological ( $n = 8/45$ ) cancers; most of whom ( $n = 30/45$ ) had received anticancer treatment in the past 6 weeks	ED attendance was prompted by severe or unexpected symptoms, when alternative services were unavailable, or when self-management had failed. People often acted on the advice of cancer specialists and informal caregivers
[30] Jørgensen et al. <sup>b</sup> (2021); Denmark	Understand decisions about, factors leading to, and experiences of using a specialist cancer emergency helpline from the perspectives of patients and family members	Phenomenological hermeneutic study, semi-structured interviews, qualitative content analysis	Adults ( $n = 12$ ) <sup>c</sup> , most of whom had incurable cancer ( $n = 8/12$ ); informal caregivers ( $n = 10$ ) <sup>d</sup> , most of whom were spouses or partners ( $n = 8/10$ ), were included	Unexpected symptoms prompted help-seeking, and the helpline was used to obtain reassurance when self-managing symptoms at home. Experience of previous care delivered by call handlers influenced decisions about service re-use
[31] Kaufmann et al. (2020); United States	Examine patient perceptions of factors leading to unplanned acute care and hospital admissions; focus on understanding and preventing unnecessary acute care use	Qualitative descriptive study <sup>3</sup> , semi-structured interviews, constant comparative analysis	Adults (age $\geq 18$ years) with solid cancers ( $n = 49$ ), most of whom had advanced cancer ( $n = 27/49$ ), and had received anticancer treatment in the past 6 months	Acute hospital care was avoided where possible. Uncontrolled symptoms and patients' fears for their safety if they remained at home influenced the decision to seek help. Service use was often prompted following contact with patients' cancer specialist team
[32] Jamieson et al. (2020); United Kingdom	Describe the experiences, reporting behaviours, and management of immunotherapy-related adverse events; focus on delayed reporting and management	Mixed methods study, descriptive analysis of quantitative health record data, semi-structured interviews, content analysis	Adults with solid cancers ( $n = 13$ ) who had received immunotherapy and reported symptoms of treatment toxicity to urgent and emergency care or in scheduled clinic appointments	People delayed seeking help to report symptoms in routine appointments or because symptoms were not interpreted as treatment-related or indicative of serious illness
[33] Green et al. (2019) United Kingdom	Understand decisions about, and experiences of, attending the ED by people with palliative care needs	Qualitative descriptive study <sup>2</sup> , in-depth interviews using a narrative approach	Adults known to a specialist palliative care service ( $n = 7$ ) with cancer ( $n = 3/7$ ) or other long-term conditions (e.g. COPD) ( $n = 4/7$ ); informal caregivers ( $n = 2$ ) were included	Unclear routes to access made decision-making difficult. Knowledge of how services were organised was needed to navigate the system, and people often had multiple contacts with other services prior to attending the ED
[34] Pedersen et al. <sup>b</sup> (2019); Denmark	Explore the meaning of responsibility to people with cancer when using a specialist cancer emergency helpline	Secondary analysis of primary study [30], qualitative descriptive analysis, qualitative content analysis	Refer to Jørgensen et al. [30]	Patients used a specialist cancer emergency helpline to share the burden associated with, and feel safe when, self-managing symptoms at home. People felt responsible for being observant for, and accurately reporting, deteriorating symptoms

**Table 2** (continued)

Study details	Aim and objectives	Design and methods	Participants	Relevant findings
[35] Chen et al. (2019); United Kingdom	Understand patient and caregiver views and experiences of cancer-related emergency admissions and inpatient care; focus on avoidable and unavoidable hospital admissions	Qualitative descriptive study <sup>a</sup> , semi-structured interviews; framework analysis	Adults with cancer ( $n = 20$ ) who had received anticancer treatment; most of whom ( $n = 17/20$ ) had advanced cancer; informal caregivers ( $n = 12$ ) were included	People used emergency care for severe or unexpected symptoms, on the advice of cancer specialists, or when problems could not be resolved with self-management guided by professionals
[36] Philip et al. (2018); Australia	Explore experiences and perceptions of ED use by people with advanced cancer and their informal caregivers	Cross-sectional qualitative descriptive study <sup>a</sup> , semi-structured interviews; phenomenological approach to data analysis	Adults with advanced cancer ( $n = 19$ ), most of whom had solid cancers ( $n = 12/19$ ); informal caregivers ( $n = 10$ ), most of whom were spouses or partners ( $n = 6/10$ ), were included	Decisions to use the ED were prompted by advice from specialists; symptoms which did not respond to self-management, and as a means to secure specialist inpatient care
[37] Oakley et al. (2017); United Kingdom	Understand what factors result in delayed reporting of symptoms suggestive of neutropenic sepsis	Constructivist grounded theory study; in-depth interviews and observation; constant comparative analysis	Women with breast cancer ( $n = 13$ ) who had received anticancer treatment with chemotherapy; most of whom had curable cancer ( $n = 9/13$ ); informal caregivers ( $n = 9$ ), most of whom were spouses or partners ( $n = 3/9$ ), were included	Subconscious collusion between patients, caregivers, and clinicians contributed to delayed reporting of symptoms. Fatalism, not wishing to inconvenience helpline staff, and fear contributed to delays
[38] Henson et al. (2016); United Kingdom	Explore decisions to use the ED from the perspectives of people with advanced cancer and their informal caregivers	Cross-sectional qualitative descriptive study <sup>a</sup> , semi-structured interviews; constant comparative analysis	Adults (age $\geq 18$ years) with advanced cancer ( $n = 18$ ), most of whom had solid cancers ( $n = 11/18$ ); informal caregivers ( $n = 6$ ), all of whom were family or close friends, were included	Difficulties accessing alternative care out of hours, anxiety regarding their cancer diagnosis, and feeling safe in hospital influenced the decision to use the ED
[39] Karasouli et al. (2016); United Kingdom	Understand the symptom-related, psychological, and organisational factors that contributed to emergency hospital admission in people with lung cancer and COPD	Qualitative descriptive study <sup>a</sup> using critical incident technique; semi-structured interviews; thematic and cross-case analysis	Adults with advanced lung disease ( $n = 39$ ), including incurable lung cancer ( $n = 24/39$ ) and COPD ( $n = 15/39$ ); informal caregivers ( $n = 20$ ) and health professionals ( $n = 50$ ) were included	People with cancer and their caregivers used previous experience to self-manage symptoms and negotiate access to care. Decisions about emergency care use were influenced by uncertainty and anxiety, and hospital admission was avoided for as long as possible
[40] Nguyen et al. (2016); Canada	Describe clinical and demographic factors associated with ED use and explain, from the perspectives of older adults, reasons for attending the ED	Concurrent, triangulation mixed methods study; descriptive quantitative analysis of medical records; semi-structured interviews; qualitative content analysis	Older adults (age $\geq 70$ years) who had received anticancer treatment ( $n = 11$ ), most of whom had solid cancers ( $n = 9/11$ ) and some of whom had comorbidities ( $n = 5/11$ )	People sought help when their symptoms deteriorated or were perceived as a threat to life, when other services were not available, or when their cancer specialist team could not be contacted out of hours

**Table 2** (continued)

Study details	Aim and objectives	Design and methods	Participants	Relevant findings
[41] Clarke et al. (2015); United Kingdom	Describe the early signs and symptoms of, and the facilitators and barriers to, early help-seeking for symptoms suggestive of neutropenic sepsis	Qualitative descriptive study <sup>a</sup> , semi-structured, narrative interviews, grounded theory approach to analysis	Adults (age $\geq$ 18 years) with haematological cancers ( $n = 22$ ) who had received chemotherapy; informal caregivers ( $n = 10$ ), all of whom were spouses or partners, were included	Misinterpretation of signs and symptoms, unclear information, and denial contributed to delayed help-seeking. Informal caregivers encouraged and supported help-seeking, but attempts to access care were often confounded by non-specialists' lack of knowledge
[42] Adam et al. (2015); United Kingdom	Explore the views and experiences of patients and informal caregivers who used out-of-hours services for cancer-related pain	Qualitative descriptive study <sup>a</sup> , semi-structured interviews, framework analysis and inductive thematic analysis	Adults (age $\geq$ 18 years) with cancer ( $n = 11$ ), most of whom had advanced cancer ( $n = 10/11$ ); informal caregivers ( $n = 4$ ) were included	The interpreted cause of the pain as well as its severity influenced the decision to contact the out-of-hours service. Informal caregivers supported and facilitated help-seeking, and previous experience influenced the decision to re-use services
[43] Richards et al. (2011); United Kingdom	Explore decisions about and experiences of out-of-hours service use by people with advanced cancer	Qualitative descriptive study <sup>a</sup> , semi-structured interviews, constant comparative analysis	Adults with advanced cancer ( $n = 20$ ) <sup>c</sup> , informal caregivers ( $n = 15$ ), most of whom were spouses or partners ( $n = 11/15$ ), were included	Decisions to contact the out-of-hours service were informed by self-appraisal of the legitimacy of their need for help. Relational and informational continuity was highly valued, and previous experiences influenced reselection of services
[44] Grudzen et al. (2011); United States	Understand how and why people attend the ED for end-of-life care and patients' perceptions of their illness and of advanced care planning	Qualitative descriptive study <sup>a</sup> , interviews, grounded theory approach to data analysis	Adults with incurable diseases ( $n = 13$ ), most of whom had advanced cancer ( $n = 8/13$ )	People sought help when symptoms became severe, and help-seeking was influenced by the unavailability of alternative services and financial concerns
[45] Smith et al. (2010); United States	Explore perceptions and experiences of ED care by people with terminal illness and their informal caregivers	Qualitative descriptive study <sup>a</sup> , semi-structured interviews, grounded theory approach to analysis	Adults with terminal illnesses ( $n = 14$ ), most of whom had cancer ( $n = 12/14$ ); informal caregivers ( $n = 7$ ) were included	Uncertainty, anxiety, and feeling unprepared to self-manage symptoms at home influenced decisions to attend the ED towards the end of life
[46] Worth et al. (2006); United Kingdom	Explore decisions about, and experiences of, using out-of-hours services by people with cancer, their informal caregivers, and primary care clinicians	Qualitative descriptive study <sup>a</sup> , in-depth interviews and focus groups, constant comparative analysis	Adults with advanced cancer ( $n = 39$ ), informal caregivers ( $n = 67$ ), and health professionals ( $n = 50$ ) were included	The legitimacy of need, including concerns about inconveniencing clinicians, influenced the decision to seek help. People attempted to bypass aspects of the system perceived to block access to care, and people often delayed seeking help to access familiar clinicians in-hours

ED emergency department, COPD chronic obstructive pulmonary disease

<sup>a</sup> Papers were categorised as reporting a qualitative descriptive study if the research design was not explicitly aligned to a specific tradition of qualitative research methodology.<sup>b</sup> To avoid duplication, patient and caregiver participant characteristic data were extracted from Jørgensen et al. [30] as the primary study and not from Pedersen et al. [34] as the secondary analysis. <sup>c</sup>Data were extracted about the characteristics of patient participants whose decisions to use UEC were explored in interviews with caregiver participants alone or were not described as an informant but participated in joint interviews. <sup>d</sup>Data were extracted about the characteristics of caregiver participants who were not described as an informant but participated in joint interviews

STUDY	PARTICIPANT CHARACTERISTICS					
	Authors	Focus on specific health problem	Cancer type	Cancer stage	Anti-cancer treatment	Co-/multi-morbidity
<b>GROUNDED THEORY STUDIES</b>						
Oakley et al	NS	△	◆◆	****		●
<b>PHENOMENOLOGICAL STUDIES</b>						
Jørgensen et al		△	◆◆	** <sup>b</sup>		●
<b>QUALITATIVE DESCRIPTIVE STUDIES</b>						
Mostarac et al		△▲	◆◇	** <sup>a</sup>		●
Kaufmann et al		△	◆◇	***		
Green et al		△☀	◆◇	* <sup>b</sup>		○●
Pedersen et al		△	◆◆	** <sup>b</sup>		●
Chen et al		△△	◆◆	** <sup>a</sup>		○
Phillip et al		△▲	◆	* <sup>b</sup>		●
Henson et al		△▲△	◆			○
Karasouli et al		△☀	◆	* <sup>a</sup>		○●
Adam et al	Pain	△	◆◇			○
Clarke et al	NS	▲	◇	****		●
Richards et al		△	◆	* <sup>a,b</sup>		●
Grudzen et al		△	◆			
Smith et al		△☀	◆			○●
Worth et al		△	◆	* <sup>b</sup>		○●
<b>MIXED METHODS STUDIES</b>						
Jamieson et al	IO	△	◇	****		
Nguyen et al		△▲	◇	***	Co	

**NS** neutropenic sepsis, **IO** immune checkpoint inhibitor toxicity, △ solid cancer, ▲ haematological cancer, △ unspecified cancer type, ☀ studies which included people without cancer, ◆ early or curable cancer, ◆ advanced or incurable cancer, ◇ prognosis unclear or unspecified, \* incidental focus on anti-cancer treatment with (a) minority of participants described as receiving treatment or (b) minor focus in qualitative findings, \*\* anti-cancer treatment not study focus but (a) majority of participants described as receiving treatment or (b) significant focus in qualitative findings, \*\*\* anti-cancer treatment focus of study but treatments not specified, \*\*\*\* anti-cancer treatment focus of study and treatments specified, **Co** patients with comorbidities included, ● patient-informal caregiver relationship specified, ○ patient-informal caregiver relationship unspecified

**Fig. 2** Map of participant characteristics

make the design explicit. Both used qualitative descriptive methods in the qualitative component [32, 40]. Many of the papers ( $n = 13/18$ ) did not explicitly enrol theory; theories and conceptual frameworks enrolled

by the remaining ( $n = 5/18$ ) studies were the following: ‘Model of Healthcare Utilization’ [29], ‘Burden of Treatment Theory’ [33], ‘Cumulative Complexity Model’ [35], ‘Model of Emergency Department Use’ [38], and the ‘Utilization Process Model’ [40].



STUDY Authors	URGENT AND EMERGENCY CARE SERVICE CHARACTERISTICS					
	Ambulance and pre-hospital care	Emergency Department	Specialist emergency cancer care	Out-of-hours service	Community pharmacy	Urgent and Emergency care system
<b>GROUNDED THEORY STUDIES</b>						
Oakley et al		*	**			
<b>PHENOMENOLOGICAL STUDIES</b>						
Jørgensen et al			***			
<b>QUALITATIVE DESCRIPTIVE STUDIES</b>						
Mostarac et al		***				
Kaufmann et al		***				
Green et al		***		*		
Pedersen et al			***			
Chen et al	**		**			
Phillip et al		***				
Henson et al	*	***				
Karasouli et al	**	**				
Adam et al				***		
Clarke et al	*		**			
Richards et al						***
Grudzen et al		***				
Smith et al		***				
Worth et al				***		
<b>MIXED METHODS STUDIES</b>						
Jamieson et al		**	**		*	
Nguyen et al		***	*			

\* Decisions about using service was minor focus of study or described incidentally, \*\* Decisions about using service was described but was not study aim, \*\*\* Decisions about using service was main study aim

**Fig. 3** Map of service characteristics

**Participant characteristics**

Characteristics of 339 people with cancer who had used UEC were described by the 18 studies [29–46]. Type of cancer was specified for over two-thirds of patient participants ( $n = 230/339$ ) [29–42]. Most patient participants had solid cancers ( $n = 192/230$ ) [29–40, 42]; over one-third ( $n = 67/192$ ) [29, 31, 32, 35, 36, 38, 39] had lung cancer, with breast ( $n = 32/192$ ) [29–31, 34, 37, 40, 42] and lower gastrointestinal tract ( $n = 19/192$ ) [29, 30, 34, 35, 40, 42] cancers being the next most common diseases.

Only 38 patient participants across five studies [29, 36, 38, 40, 41] had haematological malignancies. Cancer stage was made explicit for all participants in 11 studies [30, 34–39, 43–46] representing approximately two-thirds of patient participants ( $n = 233/339$ ); almost all ( $n = 217/233$ ) had advanced cancer [29–31, 33–39, 42–46]. A minority were described as receiving anticancer treatment ( $n = 161/339$ ) by half of studies included [29, 31, 32, 35, 37, 39–41, 43]. Treatment provided was specified for more than half ( $n = 101/161$ ) of these participants

[29, 32, 35, 37, 39, 41, 43]; however, only five studies [31, 32, 37, 40, 41] explicitly focussed on patients' decisions and experiences during anticancer treatment. Where specified, chemotherapy was the dominant ( $n = 81/101$ ) treatment modality [29, 35, 37, 39, 41, 43]; 13 patient participants had received immunotherapy [32], and seven had received radiotherapy [29]. For one paper [35], data extraction about anticancer treatment modality was limited by the way participant characteristics were reported. One study [40] recruited participants ( $n = 5/339$ ) with comorbidities; however, this was not the focus.

Most studies ( $n = 14/18$ ) [29, 30, 33–39, 41–43, 45, 46] recruited informal caregivers ( $n = 166$ ). For three papers [33, 39, 45], it was largely unclear whether participants were informal caregivers of people with cancer or other diseases; this limited data extraction from these papers. Four studies did not recruit informal caregivers [31, 32, 40, 44]. Informal caregivers' relationships to patient participants were specified for fewer than half ( $n = 76/166$ ) of caregivers about whom data were extracted [29, 30, 33, 34, 36, 37, 39, 41, 43, 45, 46]. The most frequently reported relationship to patients was spouses or partners ( $n = 55/76$ ) [29, 30, 33, 34, 36, 37, 39, 41, 43, 45, 46], followed by grown-up children ( $n = 8/76$ ), [29, 30, 34, 36, 43], and parents ( $n = 5/76$ ) [29, 36, 37]. There were no dedicated studies of the help-seeking experiences of informal caregivers.

#### Service characteristics

Most studies ( $n = 12/18$ ) [29–31, 33, 34, 36, 38, 40, 42, 44–46] focussed on decisions to use a single UEC service. The majority ( $n = 8/12$ ) [29, 31, 33, 36, 38, 40, 44, 45] studied help-seeking from emergency departments (ED); a smaller number focussed on specialist emergency helplines ( $n = 2/12$ ) [30, 34] and out-of-hours primary care services ( $n = 2/12$ ) [42, 46]. Two studies [35, 39] focussed on the events leading up to emergency hospital admission from various routes; however, most participants had used a single service: a specialist emergency helpline [35] or an ED [39]. Three studies [32, 37, 41] focussed on the decision to report symptoms suggestive of anticancer treatment toxicity without specific focus on individual UEC services. Of UEC services used by patients in these studies, most had contacted [32, 41], or discussed decisions with reference to [37], a specialist emergency helpline. None focussed on non-use of services, and only one paper [43] studied help-seeking from a UEC system.

#### Directed qualitative content analysis

Six subcategories reflecting the navigation work undertaken at individual ('Subcategory 1: making decisions with, and seeking help from, specialists', 'Subcategory 2: seeking safety', 'Subcategory 3: positioning to access

the desired treatment', 'Subcategory 4: negotiating tortuous pathways to help'), social network ('Subcategory 5: making decisions in collaboration with caregivers'), and socio-temporal ('Subcategory 6: managing isolation from services and social networks') levels were identified. Included papers have been cited as source documents from which data were extracted, condensed, and interpreted to develop groups of codes for each subcategory.

#### Subcategory 1: making decisions with, and seeking help from, specialists

People preferred to be guided by specialists whom they knew and trusted [31, 35, 37, 38, 43]. Familiar clinicians from cancer and palliative care were consulted as part of the decision to use UEC [31, 38, 40, 45]. People with cancer were directed to UEC on the advice of specialists whom they contacted in the first instance [29, 31, 33, 35, 38, 40, 45] or used prior verbal and written instructions from their cancer centre to choose which service to use [30, 34, 36, 38, 39]:

*All these instructions are basically on the card I've got. It tells you to go to emergency once your temperature gets up over 38. (Patient participant; ED [36], p.442)*

They often considered specialists the only safe option from whom to seek help [30, 33, 34, 43], with a perceived lack of cancer-related expertise deterring many from using non-specialist UEC [31, 46]. Familiarity with their specialist team meant that some deferred seeking help until routine clinic appointments, even when specialist emergency helplines were available [32, 37]. Ultimately, attending the ED was a last resort when they failed to reach specialists for advice [29, 40], when community care was deemed unviable [36, 38, 39, 44], or when cancer-specific UEC was unavailable [29, 33, 36].

#### Subcategory 2: seeking safety

Fear and anxiety (provoked by uncontrolled symptoms or uncertainty about which course of action to take) influenced which services were selected [31, 40, 46]. People with cancer chose to attend ED when faced with severe symptoms [33, 40, 44], and many were motivated by the comfort and safety they found in the hospital environment [31, 36, 38, 46]:

*Here [in the hospital], I'm safe [if] something happens. (Patient participant; ED [31], p.e1295)*

Feeling safe at, and trust in, the cancer centre where they received treatment provoked help-seeking from UEC aligned to these institutions [36, 38]. Services were chosen to share the burden of responsibility for self-management [34, 38], and people sought reassurance from

specialists to feel safe when working to manage deteriorating symptoms at home [30, 31, 34].

### **Subcategory 3: positioning to access the desired treatment**

People with cancer sought help from services with clear objectives in mind; services were selected to support symptom self-management [31, 32, 34, 35] or, when faced with deterioration, to provide rapid symptom control [29, 38, 39, 42]. Previous experiences of cancer-related UEC influenced re-use (or not) of services [37, 39, 40, 42, 46]. Symptoms and previous supportive treatment guided service reselection with the intention of receiving specific interventions again [29, 45]. Seeking help from services that involved multiple stages and re-explanation to multiple professionals was burdensome and avoided where possible [33, 38, 42, 43, 46]:

*... they would have to go through someone else to go through someone else (Researcher: Mmm) do you know what ... I wouldn't want anything like that. (Patient participant; ED [38], p.7)*

People bypassed parts of the UEC system that would result in unnecessary work, either because utilising alternative services was perceived as futile [38, 46] or to seek help from specialists via unofficial channels [38, 43]. Indeed, they positioned their help-seeking to achieve onward care as much as initial symptom control; people with cancer chose to attend ED as a way of brokering access not only to a hospital admission [29, 36, 38] but also to cancer wards [29, 36].

### **Subcategory 4: negotiating tortuous pathways to help**

Action was taken following careful appraisal of a range of options [33, 38, 39, 43]. For many, the path to obtaining help was convoluted and characterised by clusters of escalating contacts with (often multiple) services [33, 34, 36, 38, 43]:

*I phoned the daughter up and told her what had happened ... she said 'oh, hold on I'll be round' ... so she said 'I better ring up, 111, just to get a bit of advice,' so, she phoned them ... they said 'well we think he better go to the local hospital,' so that's how they got the ambulance (Patient participant; ED [33], p.4)*

Contacting one service often resulted in being given more navigation work to do, either by being asked to select another service from which to obtain onward treatment [35, 39, 45] or to 'phone back in the morning' ([32], p.7) if telephone-delivered services could not manage the problem out-of-hours [32, 46]. Over time, many people with cancer had to learn how UEC services were

organised to negotiate their way through the system effectively [33, 46].

### **Subcategory 5: making decisions in collaboration with caregivers**

People with cancer and their informal caregivers often worked together [31, 37, 39] but deciding when to use, and initiating contact with, UEC was often led by caregivers [31, 33, 38, 39, 42, 43, 46]. Navigation work was sometimes a collaborative effort between patients, their caregivers, and community [38] or pre-hospital [39] practitioners. In the event of serious illness or brisk deterioration, decisions were taken by caregivers on patients' behalf [34, 35, 46]. However, decisions about the need to use UEC often precipitated patient-caregiver conflict; caregivers applied increasing pressure if patients minimised symptoms or delayed seeking help [31, 37, 38]. Indeed, caregivers sometimes overrode patients' decisions by initiating contact with UEC services against their wishes if perceived to be making an unwise choice [31, 41, 43]:

*The sicker he gets the less he wants any intervention, but I now know that I have to quickly overrule him. (Caregiver participant; specialist emergency helpline [41], p.2690)*

### **Subcategory 6: managing isolation from services and social networks**

Deciding which service to use was influenced by the isolation people with cancer felt when facing deterioration alone [30, 43]. Distant family members were contacted and converged on patients to reduce the burden of accessing UEC [31, 33]. For caregivers however, the potential negative impact on patients that travelling to obtain help may incur was carefully considered when deciding which service to use but also constituted a burden [34, 43, 46]:

*She's suffering the pain and I am stressing, and I am thinking do I get in the car? Do I create more pain? You know, it's all these sorts of things that go through your mind. (Caregiver participant; out-of-hours service [43], p.174-175)*

Unfamiliarity with out-of-hours systems made decision-making harder; the unavailability of specialists made deciding which service to use more difficult [40, 43]. During this period, people weighed up whether to wait until in-hours services resumed [40, 46] and accessed emergency care overnight and at weekends when no alternative remained [29, 40].

## Discussion

This scoping review aimed to map what qualitative research exists about decisions to use UEC by people with cancer. It identified a small body of research, homogenous in terms of the following: (1) design and methods used, (2) patient populations recruited, and (3) services studied. The review also sought to characterise the ‘navigation work’ undertaken by people with cancer and their informal caregivers. It has also identified areas that would benefit from further research.

The focus of research to date has been about help-seeking by people with advanced cancer, not people receiving anticancer treatment. A minority of studies [32, 37, 41] focussed on and were explicit about the anticancer treatment received for all participants, the majority of whom were treated with chemotherapy. This is significant as the processes of care associated with planning and delivering anticancer treatment, and symptoms and trajectories of complications, differ by treatment modality. Our understanding of how these factors might influence decisions to use UEC (or not) is limited by the evidence. Furthermore, there is a surprising lack of focus on the sequelae of advanced cancer known to necessitate emergency care. For example, we could only identify one instance [45] where a patient was explicitly described as seeking help for metastatic spinal cord compression. No studies focussed on the decisions to use UEC by people with cancer who were multi-morbid. Evidence suggests this population perceive healthcare systems to be fragmented and difficult to navigate [47] and experience convoluted pathways through acute care [48]. Further research that focuses on the decisions and experiences of these patient groups is needed.

### Individual level navigation work

Findings from the content analysis suggest navigating UEC entails different types of work for people with cancer compared to other groups of patients (‘Subcategory 1: making decisions with, and seeking help from, specialists’, ‘Subcategory 2: seeking safety’, ‘Subcategory 3: positioning to access the desired treatment’, ‘Subcategory 4: negotiating tortuous pathways to help’). Our findings show people with cancer prefer to seek help from cancer and palliative care services to whom they are known and work hard to access these via UEC. This contrasts with previous research [49] which has shown people with long-term conditions (excluding cancer) select services for their perceived technological capability rather than care delivered by familiar clinicians. Studies continue to demonstrate the importance of trusting relationships with care providers to people with cancer [50–52], and the findings of our review suggest the concept of ‘being in

safe hands’ ([53], p.1538) during scheduled cancer treatment may influence which UEC service is selected when acutely unwell. In comparison with the Model of Urgent Care Help-seeking [15], our findings suggest acceptability of services is more important than their availability, with acceptability contingent on feeling safe at, and trust in, services’ ability to meet the unique needs of people with cancer.

Similarly to Turnbull et al. [14], decisions about which service to use were ‘recursive’ (i.e. shaped by prior help-seeking experiences). Findings from our review suggest decisions are informed by experiences since a diagnosis of cancer; however, recent evidence [54, 55] suggests frequent ED attendances prior to a cancer diagnosis are associated with increased ED use following diagnosis. Further qualitative work is needed to explore which experiences, both prior to and following cancer diagnosis, influence decisions about future UEC use and why. In contrast to the Model of Urgent Care Help-seeking [15], our findings show decisions made by people with cancer are predicated on detailed appraisals of their clinical need rather than convenience. Seeking help from the ‘right’ service constitutes hard work; people with cancer are keen to avoid, but often face, burdensome access procedures, which they attempt to circumvent by bypassing parts of the system. This is significant as international evidence has largely described ‘bypassing’ in terms of avoiding primary care when choosing secondary care [56–58] and suggests systems, and the work required to navigate them, may be more complex for people with cancer. However, our understanding of how people with cancer make sense of the UEC landscape is limited by a literature that has largely studied services in isolation.

### Social network level navigation work

Our review shows how informal caregivers perform a dual role in help-seeking (‘Subcategory 5: making decisions in collaboration with caregivers’). Caregivers not only *support* people with cancer to navigate UEC but often *take charge* of this workload. This finding contrasts with those of Turnbull et al. [15] who describe how navigation work by the general population predominantly takes place at an individual level, with relational network members consulted as part of, but not responsible for, decision-making. It also contrasts with findings from studies of help-seeking for complications of long-term conditions in which caregivers are largely described as fulfilling encouraging and facilitative roles [59–61]; acting without patients’ permission was rarer [62]. It is therefore significant that this phenomenon has been captured by the small body of research identified by this review. Evidence suggests informal caregivers of people with cancer act as both ‘advocate’ and ‘protector’ ([63],

**Table 3** Research priorities

<b>Anticancer treatment</b>	Studies which explore how decisions to use UEC (or not) might differ for people treated with curative intent and comparative studies of help-seeking by people receiving different anticancer treatments
<b>Understudied populations</b>	Studies of people with complications of advanced cancer known to often require UEC (e.g. metastatic spinal cord compression), people with haematological cancers, and people with cancer and multimorbidity
<b>Roles of social networks</b>	Studies that explore the roles undertaken by informal caregivers when navigating UEC and how help-seeking might differ for those living alone or with fragile social networks
<b>System-level help-seeking</b>	Studies which explore how people make sense of UEC systems and how the availability, accessibility, and acceptability of (differently organised) specialist and non-specialist services might influence help-seeking
<b>Contingency planning</b>	Studies of how people prepare for complications of cancer and its treatment (including fine-grained understanding of how people use information about UEC) and how this might influence service use

p.803), assuming responsibility for decisions about [64] and negotiating access to care [65] on patients' behalf. However, support for informal caregivers to learn how to navigate cancer health systems is lacking [66]; further, dedicated exploration in relation to UEC is needed.

#### Socio-temporal contexts

Navigation work by people with cancer also appears to be influenced by both time of day and social contexts ('Sub-category 6: managing isolation from services and social networks'). Unfamiliarity with the UEC system out of hours and unavailability of usual support structures made deciding whether to seek help, and which service to use, more difficult. Difficulty relating to prior information at the point of deterioration confounded decision-making, a finding echoed by wider literature [12, 67]. A decade ago, a report from the UK [68] highlighted the need to embed personalised contingency planning into the routine care of people at risk of complications of cancer and its treatment. To the best of our knowledge, how people with cancer and their informal caregivers prepare for complications that necessitate contact with UEC remains an area that has been unexplored by dedicated research. Our findings reinforce the need to understand how preparing for acute illness might influence the work of navigating UEC.

#### Recommendations for research

This scoping review has identified a small body of literature and significant knowledge gaps. Although policy and practice would benefit from high-quality, theory-led studies that explore any aspect of UEC use by people with cancer, based on findings from this review, we have outlined five areas which should be prioritised in Table 3.

#### Limitations

Scoping reviews are time-consuming, resource-intensive projects and involve collating and interpreting large

volumes of data [69]. For pragmatic reasons, the process of identifying, selecting, and extracting data from studies was undertaken by a single reviewer (J. D.). Multiple reviewers may have mitigated against potentially relevant papers and data being excluded, a commonly reported limitation of scoping reviews [70]. Time and funding constraints precluded translation of articles not published in English, which may also have resulted in relevant articles being excluded. The relatively small number of, and the richness of data amenable to interpretation as navigation work from, studies published outside of the UK precluded a comparative analysis by country. In addition, no studies from low- or middle-income countries were eligible for inclusion. As such, our findings and research recommendations may not be relevant to all international contexts.

#### Conclusion

This review scoped research studies pertaining to decisions about using UEC by people with cancer and their informal caregivers that have used qualitative and mixed methods. It has identified and summarised a small amount of narrowly focussed research, namely studies of decisions to use EDs by people with advanced cancer who are not receiving anticancer treatment. This review suggests navigating UEC constitutes hard work and is qualitatively different for people with cancer. Our understanding about ways in which we might prepare and support patients to effectively access these services is constrained by the evidence base. There is a need to progress research in this area.

#### Abbreviations

UEC	Urgent and emergency care
ED	Emergency department
UK	United Kingdom
US	United States

## Supplementary Information

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**Additional file 1.** Electronic database search strategy for MEDLINE. Table describing the search terms and subject headings used to search the MEDLINE database via EBSCO.

**Additional file 2.** Berrypicking strategies. Table describing the berrypicking strategies and procedures followed.

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### Authors' contributions

The project was conceived and review designed by J. D., R. W., and A. R. Literature searching and data extraction was undertaken by J. D.. Data analysis, data interpretation, and manuscript writing were undertaken by J. D., R. W., and A. R. The authors read and approved the final manuscript.

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### Availability of data and materials

Data collated and summarised from this review are available from the corresponding author upon reasonable request.

### Declarations

#### Ethics approval and consent to participate

Ethical approval was not required for this work.

#### Consent for publication

Not applicable.

#### Competing interests

The authors declare that they have no competing interests.

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