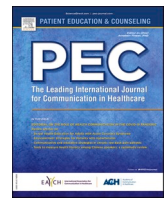




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The information and communication needs of patients with advanced incurable cancer: A rapid review

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ABSTRACT

Objectives: This review aimed to collate evidence on the key information and communication needs of patients with advanced incurable cancer and their caregivers. It also sought to identify barriers and facilitators to communicating, understanding and receiving information, with the view of influencing improvements to future practice.

Methods: This study used a rapid review methodology. Databases were searched on the Ovid platform to identify relevant qualitative data. Methodological quality was assessed, and data extraction was completed. A thematic synthesis approach was used for data analysis.

Results: Findings from 42 articles highlighted that key information should be communicated in accordance with individual needs, including tailoring when and how information is provided. It also highlighted the need for healthcare professionals to provide adequate time, openness, and sensitivity to facilitate understanding of prognosis, treatment and care options. Barriers to receiving, communicating and understanding information relating to healthcare professionals and healthcare systems focus on inadequate time in consultations and a lack of specified point of contact. Patient level barriers included difficulties engaging with and processing challenging information, and inadequate health and death literacy. Facilitators included incremental information provision and early access to palliative care specialists.

Conclusions: Key communication and information needs identified in the review's synthesised findings should be considered when developing communication strategies alongside the barriers and facilitators.

Practice implications: HCPs should provide patients and caregivers with bespoke support to improve their health and death literacy, and a direct point of contact. Health service training could focus on personalised and empathetic information delivery.

1. Introduction

Patients with advanced incurable cancer and their caregivers are confronted with challenging psychological, physical, practical, and existential issues. These include physical and emotional pain, uncertainty and complex decision making relating to treatment, dying and end of life. Despite this, they often experience unmet information and communication needs. [1,2] Information suitable for their needs is regularly unavailable or inappropriately communicated. [3] Insufficient information and communication provision can lead to unnecessary distress, inappropriate decision making or resource use, and poorer quality of life. [4,5] Inadequate cancer and health literacy among

patients with advanced cancer and caregivers can inhibit information comprehension. [6,7] Thus, there is a need to improve information and communication between patients, their caregivers and health services to ensure that they are appropriately equipped to understand their disease trajectory and come to terms with its implications.

Prior research illustrates that effective health and care communication approaches, including shared decision making, can enhance quality of life (QoL),⁵ improve patient satisfaction, decrease non-beneficial medical care, facilitate care consistent with patient goals and wishes, and are cost effective. [5,8,9] It is also recognised that appropriately communicated information can help patients gain control, reduce anxiety, create realistic expectations, promote self-care and participation,

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⁵ QOL = Quality of life

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and generate feelings of safety and security. [10,11] However, healthcare professionals' (HCPs)⁶ perceptions of what information is needed and how it is best communicated often contrasts with those of patients and their caregivers. [12].

There is a need to address gaps in understanding what key information is needed, and how it is provided in different contexts, including how and when this information is preferred according to patients and their caregivers. [13,14].

2. Materials and methods

This rapid review was conducted using modified systematic review methods, informed by rapid review methods outlined by the Palliative Care Evidence Review Service (PaCERS).⁷ [15] The PaCERS methodology was used in order to provide a review of relevant literature to inform policy and practice within a short timeframe. The process involved literature screening conducted independently by one reviewer and then checked by another. This modified method is restricted to literature from the previous 10 years, Organisation for Economic Co-operation and Development (OCED)⁸ countries only and uses limited databases and sources. The Data Extraction (DE)⁹ and Qualitative Appraisal (QA)¹⁰ are divided between the reviewers and then checked by a second reviewer. Data analysis was completed using thematic synthesis. [16] This review is reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)¹¹ statement 2020. [17] A protocol was registered and published on the PROSPERO database. https://www.crd.york.ac.uk/PROSPERO/display_record.php?RecordID=434023.

2.1. Aims

This review aimed to collate recent peer reviewed research evidence on the key information and communication needs of patients with advanced incurable cancer and their caregivers. It also aimed to identify barriers and facilitators to communicating, understanding and receiving information, with the view of influencing improvements to future practice.

Research Question.

What are the key information and communication needs of patients with incurable cancer and their caregivers?

Objectives.

- To understand the key information and communication needs of patients with advanced incurable cancer and their caregivers.
- To identify patients' and caregivers' preferences for information and communication when they have an incurable cancer diagnosis, including:
 - What information do patients and caregivers want to receive?
 - How and when do patients and caregivers prefer to be communicated with?
- To identify barriers and facilitators to receiving, communicating and understanding information
- To understand how information and communication can be improved and made more inclusive for patients and their caregivers.

2.2. Search strategy

In April 2023 an initial scoping review was conducted to identify relevant literature and refine the scope of the review. A search strategy was iteratively developed for the rapid review between April 2023 and June 2023 by the systematic reviewer with the support of two researchers. A final search strategy was agreed upon on 8 June 2023 and an updated search was conducted on the 1 August 2024 (Supplement A).

Comprehensive searches were conducted across multiple databases, restricted to English language articles published after 2013: MEDLINE, EMBASE, and PsycINFO on the Ovid platform. Scopus via Elsevier and the Cochrane Central Register of Controlled Trials (Cochrane Library, Wiley). Due to the vast number of studies identified via the database search and time constraints, no supplementary searches were carried out to identify additional papers.

2.3. Researcher reflexivity

All authors were currently working within the field of palliative and end of life care. The lead author is a social scientist with a background in exploring the qualitative experiences of people with cancer, with particular interest in healthcare communications. The second author is a psychologist and social researcher with experience of researching caregivers' experiences relating to end of life and bereavement. The third author is a GP academic trainee currently researching patients' needs towards end of life. The systematic reviewer co-created the PaCERS methodology and oversaw its methodological application during this review.

2.4. Study selection

The study selection process is presented in a PRISMA diagram (Fig. 1). In the initial search 3089 texts were identified and imported into Endnote v20, where 1740 duplicates and irrelevant papers were removed by the Systematic Reviewer (SR).¹² Then, 1349 sources were exported to Rayyan web application (a screening tool), [18] and screened separately by three researchers in accordance with inclusion and exclusion criteria (Table 1). Only studies from OECD countries were included due to these countries having a similar types of economy and, therefore, the studies would be more comparable. Any disagreements were resolved through discussion, or with a third reviewer. Then, 74 full texts were retrieved and screened between the researchers and the SR with a further 20 removed, resulting in 54 texts for data extraction. In the updated 2024 search, 375 texts were retrieved, with 272 non-compliant texts and duplicates removed. Then, 103 studies were exported to Rayyan web application. These were screened by two researchers. Four full texts were retrieved for data extraction.

2.5. Data extraction

Data extraction forms were developed by the researchers and the SR based on the research question and objectives and used to collate information from papers. Disagreements were resolved by consensus with all team members. A further 10 papers were removed leaving 44 papers, as they were found to be mixed qualitative and quantitative methods, lacking relevant content or describing the wrong patient population e.g., describing caregivers of children. Data extraction was completed on an additional four texts in the updated search. A summary of the data extraction from the studies is available in Table 2.

2.6. Quality Appraisal

(QA) was conducted on 44 papers in 2023 and on a further four

⁶ HCP = Healthcare Professional

⁷ PaCERS = Palliative Care Evidence Review Service

⁸ Organisation for Economic Co-operation and Development = OCED

⁹ DE- Data Extraction

¹⁰ QA = Quality Appraisal

¹¹ PRISMA = Preferred Reporting Items for Systematic Reviews and Meta-Analyses

¹² SR = Systematic reviewer

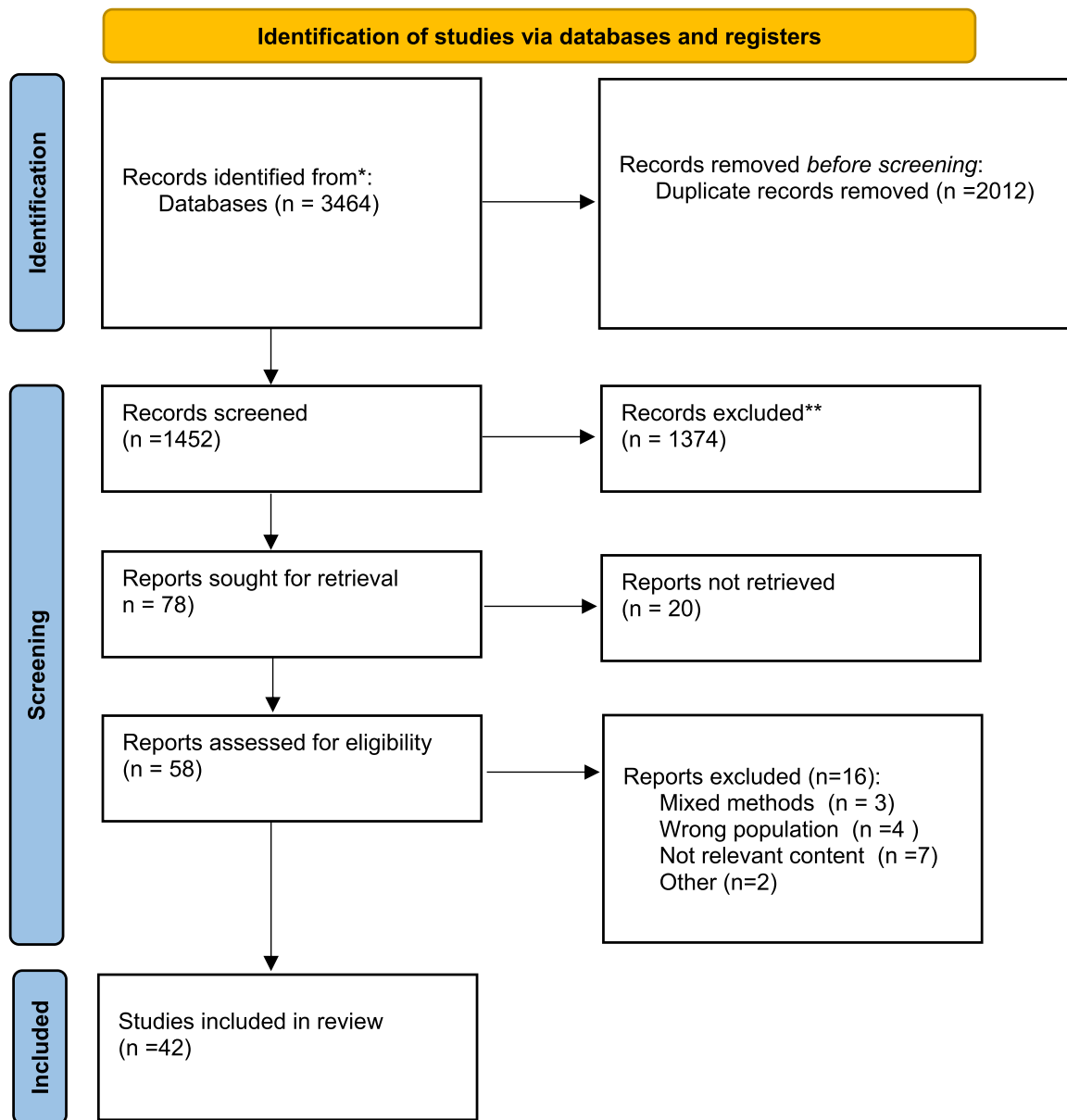


Fig. 1. PRISMA flow diagram.

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Table 1

Inclusion and exclusion criteria.

Inclusion criteria
<ul style="list-style-type: none"> ● Discusses information and/or communication needs or preferences from the perspectives of patients with advanced incurable cancer and/or caregivers. ● Discusses barriers to or facilitators of effective communication or information-giving in the context of an incurable cancer diagnosis (including inequalities). ● Journal articles. ● Includes primary data. ● Includes qualitative data with direct quotations from patients with advanced incurable cancer or caregivers. ● Organisation for Economic Co-operation and Development (OECD) countries.
<p>Exclusion criteria</p> <ul style="list-style-type: none"> ● Does not discuss information or communication needs/preferences or barriers/facilitators of effective communication or information-giving. ● Discusses the views of HCPs rather than those of patients/ or caregivers. ● Discusses the views of children or caregivers of children (aged under 16 years old). ● Is a trial registration, protocol, book chapter or conference document. ● Is based only in non-OECD countries. ● Is not available in English. ● Only includes quantitative data. ● Mixed qualitative and quantitative studies.

Table 2

Data extraction table.

Article	Settings and study design	Aims	Participants	Main findings
1. Ahmed et al. [23]	2 Cancer centres, Canada Semi-structured interviews. Six-phase thematic analysis. PCC framework was used to guide the analysis.	To identify experiences of patients living with advanced colorectal cancer and their caregivers to inform the development of an early palliative care pathway.	15 patients 7 caregivers	<ul style="list-style-type: none"> ● Patients and caregivers needed clarification of the roles and responsibilities of the different HCPs involved in their care (including their family physician's (GP's) role) and better explanations of the meaning of palliative care. ● Some described poor communication of their initial diagnosis (e.g. over the phone or overheard). ● The importance of a respectful patient-HCP relationship was highlighted with patients feeling fully informed and engaged in shared decision-making as an equal member of the care team. ● Preferences for the timing of ACP conversations were highly individualised (early on vs. nearer to end of life). ● Symptom checklists were seen as helpful conversation openers but follow-up by the HCPs was important.
2. Ahmed et al. [55]	2 Cancer centres, Canada. Semi-structured interviews with two cohorts of patients and caregivers with advanced colorectal cancer before and after implementation of an early PC pathway. Thematic analysis guided by a Person-Centred Care Framework.	To understand the experience of patients with advanced colorectal cancer and family caregivers who received early PC support from a specialist palliative care nurse and compared those experiences with participants who experienced standard oncology care prior to implementation of early PC.	7 patients 5 caregivers	<ul style="list-style-type: none"> ● Visits from the early PC nurse were seen as helpful and improved patients' and caregivers' understanding of PC. ● Participants greatly appreciated the PC nurse's role in facilitating and coordinating communication with and between healthcare providers and supporting access to care, helping patients feel well supported. ● Participants developed a close relationship with their PC nurse which they experienced as patient-centred, supportive and respectful. The nurse's resourcefulness, empathy, kindness and holistic understanding of the patients'/carers' situations were highlighted, as well as their comfort and skill in facilitating end of life conversations. Most preferred their family physician to be kept informed about their cancer treatment and involved.
3. Back et al. [56]	Seattle Cancer Care Alliance, a tertiary cancer centre USA. Semi-structured interview participants commented on the audio recordings of oncology fellows discussing goals of care. Constant comparison analysis method.	To elicit patient and family views on commonly used communication practices (reactions to clinician's goals of care conversations).	37 Patients 20 family caregivers	<p>Three preferred communication practices were identified by patients and caregivers regarding stages of their cancer pathway:</p> <ul style="list-style-type: none"> ● A necessary disruption of the patient's expectations about "trying another chemo" (e.g. "We're in a different place"). ● Offering actionable responses to the disruption (e.g. "Here's what we can do now"). ● To find a new place that acknowledges death is closer yet still allows for "living forward" (e.g. "Use your inner wisdom").
4. Bergqvist et al. [39]	Karolinska University Hospital, Solna, Sweden. Semi-guided interviews. Qualitative conventional content analysis.	To explore breast cancer patients' preferences and perceptions of patient-doctor communication regarding continuous late lines of palliative chemotherapy, in a Swedish context.	20 patients	<ul style="list-style-type: none"> ● All patients knew they had incurable breast cancer but expressed hope for cure. ● Patients' definition of a good compassionate doctor was one who gives positive but honest news and leaves room for hope. ● Ongoing chemotherapy, positive news from the doctors, and support from relatives encouraged hope. ● The women often expressed they accepted chemotherapy to please their doctor and relatives. ● Over time, women stopped asking questions afraid of getting bad news, and left more treatment decisions to the doctor.
5. Borland et al. [49]	Known to Hospice nurses. Northern Ireland. Semi-structured interviews. Thematic content analysis.	To retrospectively explore partners' understandings and experiences in relation to caring for a loved one with a terminal illness, with a particular focus on the role of the hospice nurse specialist (HNS).	7 caregivers	<ul style="list-style-type: none"> ● All patients knew they had incurable breast cancer but expressed hope for cure. ● Patients' definition of a good compassionate doctor was one who gives positive but honest news and leaves room for hope. ● Ongoing chemotherapy, positive news from the doctors, and support from relatives encouraged hope.

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Table 2 (continued)

Article	Settings and study design	Aims	Participants	Main findings
6. Brom et al. [25]	University hospital within the outpatient clinic of either neuro-oncology or medical oncology, Netherlands. Longitudinal interview and observational study. Open coding analysis.	To examine whether and how the steps of SDM can be recognised in decision making about second- and third-line chemotherapy.	12 Patients	<ul style="list-style-type: none"> ● The women often expressed they accepted chemotherapy to please their doctor and relatives. ● Over time, women stopped asking questions afraid of getting bad news, and left more treatment decisions to the doctor. ● Patients felt to reach SDM in daily practice, physicians should create awareness of all treatment options, including forgoing treatment with chemotherapy, and communicate the risk of benefit and harm. ● Open and honest communication is needed in which patients' expectations and concerns are discussed.
7. Cameron et al. [64]	Regional cancer centre, North Island of New Zealand. Ethnography, four short conversations with patients, and observational fieldnotes in which humour was a major topic of the conversation. Thematic analysis.	To explore patients' experiences of extended palliative chemotherapy and determine what under lying coping strategies patients use when 'life as normal' means living with chemotherapy over a long period of time (greater than 12 months).	10 patients	<ul style="list-style-type: none"> ● The importance of interpersonal relationships with HCPs positively affected the patients' experiences of treatment, for example being referred to by their first name and having their preferences respected. ● Positivity was a key coping strategy that also has negative implications as patients may not reveal their concerns and needs. ● Trying to stay proactive and be independent and healthy was important to the participants.
8. Collins et al. [26]	A tertiary metropolitan hospital in Melbourne, Australia. Semi-structured interviews. Qualitative inductive analysis approach.	To explore patient views surrounding communication about palliative care and their responses to its discussion.	30 patients	<p>Patient barriers to understanding PC, EOL and dying included:</p> <ul style="list-style-type: none"> ● Death was expressed using only implicit, ambiguous or technical terms and perceived to be outside the parameters of medical interactions. ● The term 'palliative care' was perceived to be used by HCPs as a tool to talk about dying and understood by patients as a euphemism for death. ● 'Palliative care' was personified by patients to mean not just death, but "my death", in turn, also becoming unspeakable.
9. Collins et al. [53]	A tertiary metropolitan hospital in Melbourne, Australia. A prospective, exploratory qualitative design, involving narrative-style interviews and underpinned by an interpretative phenomenological framework.	To investigate cancer caregivers' communication experiences and potential impact on patient and caregiver outcomes.	25 caregivers	<ul style="list-style-type: none"> ● Caregivers preferred routinely available written resources about PC, supplemented by conversations that are staged overtime. ● They felt that education about the tasks of PC should be separated from referral process, allowing time for gradual adjustment, and re-visiting discussion to enable patients and families to take some control in the process of transition. ● Once death is imminent, carers wanted health professionals to clarify how much they want to know about the dying process; provide spoken acknowledgement when death is close; use direct language (e.g. use the terms 'death' and 'dying'); avoiding euphemisms; and communicate about death with the patient present.
10. Dillon et al. [27]	A multi-specialty group in Northern California which launched outpatient PC. USA. Interviews. Grounded theory analysis.	To obtain in-depth information on how patients with advanced cancer and the oncology and palliative care (PC) HCPs who care for them discuss goals of care (GoC).	25 patients	<ul style="list-style-type: none"> ● Patients' preferences for prognostic communication varied but they appreciated how PC teams facilitated and enhanced conversations including changing GoC conversations. ● Timing was challenging; some patients desired earlier conversations and PC involvement, others wanted to wait until things were "going downhill". ● Patients and clinical teams acknowledged the complexity and importance of GoC conversations. ● The frequency, quality, and content of GoC conversations were shaped by patient receptivity, stage of illness, clinician attitudes and predispositions toward PC, and early integration of PC.
11. Dionne-Odom et al. [44]	Outpatient oncology clinics of a large tertiary care academic medical centre. USA.	To describe the roles of family caregivers in assisting community-dwelling advanced	18 patients 20 caregivers	<ul style="list-style-type: none"> ● Caregivers have a role in ensuring family and HCPs have a common understanding of the patient's treatment plan, condition and

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Table 2 (continued)

Article	Settings and study design	Aims	Participants	Main findings
	Semi-structured interviews. Thematic analysis.	cancer patients with healthcare decision-making across settings and contexts.		<p>posing “what if” scenarios about current and potential future health states and treatments.</p> <ul style="list-style-type: none"> ● Caregivers also have a role in originating healthcare-related decision points, including decisions about seeking emergency care, and making healthcare decisions for patients who preferred to delegate healthcare decisions to their family caregivers. ● Family members would seek out, gather, and elicit information pertaining to the cancer diagnosis, its assessment including diagnostic and lab tests, and any proposed or potential treatments. ● Family caregivers would often encourage a positive reframing of the illness. In addition to helping patients reframe their current situation, they also facilitated conversations about prospective decisions at end-of-life.
12. Durieux et al. 2022 [42]	Two academic medical centres in the Northeastern USA. Semi-structured interview study informed by a relativist ontological and (social) constructivist epistemological position. Template analysis.	To understand caregivers’ perceptions about patients’ care experiences, the extent to which care was perceived as goal-concordant, and the factors that contextualised the end-of-life care experience.	19 caregivers	<ul style="list-style-type: none"> ● Caregivers described the importance of clear communication, inadequate prognostic communication and information gaps that undermined caregiver confidence in decision making. ● Patient-clinician relationships enriched care and were considered higher-quality when felt to be humanistic. ● Care transitions jeopardised goal-concordant care if they were associated with a need to establish relationships with new providers, inadequate information transfer between providers and poor care coordination.
13. El-Jawahri et al. [50]	Massachusetts General Hospital Cancer Centre, USA. Semi-structured interviews. A framework approach for data analysis.	To assess perceptions about hospices among patients with metastatic cancer and their caregivers (i.e., family and/or friends).	16 patients	<ul style="list-style-type: none"> ● All patients showed variable gaps in understanding about hospices, including who would benefit from hospice care and the extent of services provided. They all needed more information about hospices yet were mixed regarding the optimal timing of this information. ● Participants’ attitudes about hospices reflected their concerns about suffering, loss of dignity, and death and of hospice services. These attitudes, psychological barriers and lack of knowledge were all perceived as important barriers to hospice utilisation.
14. Fenton et al. [28]	Dana-Farber Cancer Institute (DFCI) in Boston, Massachusetts, USA. Semi structured interviews. Template analysis.	To investigate cancer caregivers’ communication experiences and potential impact on patient and caregiver outcomes.	19 caregivers	<ul style="list-style-type: none"> ● Caregivers described fulfilling many important communication roles including information gathering and sharing, advocating, and facilitating and coordinating communication for patients. ● Prognosis and EOL were the most challenging topics communicated because of caregivers’ and patients’ discordant communication needs, limited opportunity for caregivers to satisfy their personal communication needs, uncertainty regarding their communication needs and responsibilities, and feeling unacknowledged by the care team. ● These challenges negatively impacted caregivers’ abilities to satisfy their patient-related communication responsibilities, which shaped many outcomes including EOL decisions, care satisfaction, and bereavement.
15. Fliedner et al. [52]	3 cancer centres. Switzerland. Semi-structured interviews. Qualitative content analysis	To explore advanced cancer patients’ experiences with a structured early palliative care intervention, its acceptability and impact on the patients’ life including influencing factors.	20 patients	<ul style="list-style-type: none"> ● Patients highlighted the importance of mutual trust, empathy and feeling listened to in their interactions with HCPs. ● They appreciated open and honest discussions to obtain a realistic understanding of their future but wanted the tone of such discussions to be positive. ● Patients preferred the timing of early PC conversations to be based on individual patients’ needs and a close relationship with the HCP.

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Table 2 (continued)

Article	Settings and study design	Aims	Participants	Main findings
16. Fox et al. [29]	3 Australian metropolitan melanoma treatment centres. Semi-structured interviews. Grounded theory analysis.	To explore bereaved carers' experiences of immune and targeted therapy treatment options towards end of life for patients with metastatic melanoma.	20 caregivers	<ul style="list-style-type: none"> ● The structured early PC intervention was seen as helpful in stimulating family discussions and understanding PC. ● Patients and caregivers had unrealistic perceptions and expectations about treatment options related to advancing immune and targeted therapies options as they were left unprepared for treatment failures and end of life after discussions with HCPs. ● Caregivers searched for information to clarify possible treatment outcomes and prognosis. ● Caregivers pointed to HCP's difficulties with communicating bad news and expressed a need for honest and upfront communication about what can happen, including the 'worst-case scenario', and how to cope. ● After long-periods of life-sustaining treatment, patients and caregivers were not prepared for conversations about PC which they associated with diminished hope and end of life.
17. Fraterman et al. [30]	1 comprehensive cancer centre. Netherlands. Semi-structured interviews. Thematic analysis.	To explore the supportive care and information needs of high risk and advanced melanoma patients, and how these needs can be supported by eHealth applications.	13 patients	<ul style="list-style-type: none"> ● Nearly all patients experienced unmet information needs during and after treatment and would like: ● Information about melanoma, systemic therapies, other treatments, and prognosis. ● Information regarding self-management (i.e., cancer-related anxiety, sleep problems, nutrition, physical activity, and fatigue), managing work, cancer, and supportive care. ● Information concerning employment, income, housing, fertility, and talking to their children about cancer. ● Most would like interventions concerning physical activity, relaxation and mindfulness. ● The majority would like to read about experiences of fellow patients (peers) or directly communicate with them. ● Patients expected to value eHealth applications that facilitate information gathering, wellbeing interventions, and symptom management. ● eHealth applications should allow for a layered structure of information, allowing the patient to decide whether they want to view additional information.
18. Heckel et al. [38]	Regional cancer centre and University hospital. Germany. Semi-structured interviews. Thematic analysis	To identify and compare experiences, perceived burdens, and needs during home care of informal caregivers of brain tumour patients and informal caregivers of non-brain tumour patients.	28 caregivers	<ul style="list-style-type: none"> ● Caregivers in the brain tumour group required more information including where to find information, knowing what information they would require and a point of contact. ● They sought comprehensive explanations and early information about symptoms and changes that might arise in the future. ● Caregivers wanted information about the prospective care trajectory, medication on demand, useful medical aids and health and care services available, claiming benefits and practical information about dealing with challenges in daily life.
19. Jeon et al. [31]	5 hospitals, 2 bereavement charity centres. Korea. Semi-structured interview. Qualitative content analysis.	To describe the end-of-life communication experiences of bereaved families of cancer patients.	10 caregivers	<ul style="list-style-type: none"> ● Caregivers desired specific information regarding diseases, prognosis, and symptoms, and a supportive attitude from HCPs. ● Family caregivers who had not honestly informed the patients of their physical condition regretted not providing the patients a chance to prepare for their death. ● The families with sufficient information and knowledge on death applied their experiences to the process of EOL communication with the patients, which facilitated their communication.
20. Kitta et al. [32]	1 PC unit of the Medical University of Vienna. Austria.	To examine patients' experiences of end-of-life (EOL) discussions and to shed light on	12 patients	Patient interviews highlighted three themes regarding communicating EOL and PC:

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Table 2 (continued)

Article	Settings and study design	Aims	Participants	Main findings
	Semi-structured interviews. Thematic analysis.	patients' perceptions of the transition from curative to palliative care.		<ul style="list-style-type: none"> ● Medical EOL conversations contributed to the transition process from curative to PC. ● Patients' information preferences were ambivalent and modulated by defence mechanisms. ● The realisation and integration of medical EOL conversations into the individual's personal frame of reference is a process that needs effort and information from different sources coming together.
21. Lindhardt et al. [46]	1 university hospital Dept. of Oncology. Denmark. Semi-structured interviews. Thematic analysis.	To explore how the information provided by the HCPs affect and is experienced by older patients with incurable cancer receiving palliative chemotherapy.	11 patients	<p>Patients' interviews identified three main themes regarding experiencing the information about palliative chemotherapy:</p> <ul style="list-style-type: none"> ● Hope of being cured, hearing but not comprehending information, and focus on desired milestones to reach. ● Patients hid their feelings and avoided talking about the disease with HCPs due to fear of being told the truth. ● Receiving information about their incurable cancer was an ongoing dilemma for the patients.
22. McClelland et al. [46]	1 cancer centre (Breast Oncology Programme at the University of Michigan Comprehensive Cancer Centre). USA. Semi-structured interviews. Thematic analysis.	To examine patients' descriptions of resources needed to support their sexual quality of life in palliative care.	32 patients	<ul style="list-style-type: none"> ● Patients wanted more information about how treatments and surgeries would affect their bodies. ● Information about Sexual Quality of Life (SQoL) from sexual health experts, including normalcy of their sexuality, balanced with the need for privacy. ● Male partners needed more extensive information about the sexual changes that patients were experiencing. ● Information from other women with metastatic breast cancer rather than women who had curative disease. ● Comprehensive pamphlets, which explicitly discuss potential SQoL issues associated with various treatments.
23. Mohammed et al. [54]	1 cancer centre in Toronto, Ontario, Canada. Semi-structured interviews. Grounded theory analysis.	To describe bereaved caregivers' experiences of providing care at home for patients with advanced cancer, while interacting with home care services.	61 caregivers	<p>Caregivers identified key information and communication needs:</p> <ul style="list-style-type: none"> ● Help with navigating the complexities of the healthcare system. ● Advocating for their own needs as well as for those of their family member. ● Understanding what to expect at the end of life. ● Preparing in advance for tasks after death.
24. Moss et al. [43]	Cancer Centre in the midwestern USA. Semi-structured interviews. Content and thematic analyses.	To examine interpretations of the meaning of health-related decision-making terminology such as QOL and EOL.	10 caregivers	<ul style="list-style-type: none"> ● Caregivers were uncertain about the meaning of end-of-life-related terminology. ● Improvements to information and decision support interventions are needed to better support caregivers and subsequently patients towards informed cancer care decisions.
25. Ohlén et al. [24]	1 oncology clinic in a university hospital. Sweden. A phenomenological life-world approach, narrative interviews and supplementary observations. analysed phenomenological-hermeneutically in 3 interrelated phases.	To interpret how patients diagnosed with advanced gastrointestinal cancer make sense of receiving palliative treatment.	14 patients	<ul style="list-style-type: none"> ● To enhance patients' sense making of receiving palliative treatment for advanced gastrointestinal cancer, HCPs need to go beyond just communicating information and explore existential and spiritual dimensions. ● This process may involve confronting shifting expectations and awareness and struggling and easing distress.
26. Ólafsdóttir et al. [61]	1 outpatient oncology clinic at the University Hospital. Iceland. Semi-structured interviews. Thematic analysis.	To explore patients newly diagnosed with advanced lung cancer and their family members' experiences of engaging in a person-centred and structured ACP * ** * discussion facilitated by palliative care nurses in an outpatient oncology clinic.	7 patients	<ul style="list-style-type: none"> ● The timing of the ACP discussion and booklet was seen as helpful by patients and families. ● While the approach was structured, it was also flexible enough to be sensitive to individual patients' needs and readiness for the discussion. ● It fostered a discussion that many patients found somewhat difficult to engage in nevertheless helpful.
27. Pedrosa et al. [59]	1 Dept. of Oncology Phillips University Marberg, 1 oncology rehab centre, 1 community PC team Marburg-Biedenkopf, Germany.	To evaluate the novel collaborative advance care planning-approach by synthesising cancer patient and carer perspectives on communicational and relational effects.	12 patients, 13 caregivers	<ul style="list-style-type: none"> ● Psycho-oncological access to ACP strengthens readiness for ACP discussions by contributing to a comprehensive preparation of patients and relatives for EoL decisions.

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Table 2 (continued)

Article	Settings and study design	Aims	Participants	Main findings
	Semi-structure Interviews. Inductive content analysis.			<ul style="list-style-type: none"> ● It may help to explore psychological barriers, but also to differentiate between therapeutic support needs and autonomous decisions that hinder readiness to engage in end-of-life decision-making.
28. Pini et al. [21]	1 regional cancer centre, 1 hospice. UK. Semi structured interviews. Framework analysis.	To identify current barriers, facilitators and experiences of raising and discussing palliative care with people with advanced cancer.	24 patients	<ul style="list-style-type: none"> ● There is a need to address misconceptions about palliative care, treatment and prognosis, and better prepare patients and HCPs to have accurate and meaningful conversations about palliative care. HCPs need to establish and communicate the relevance of palliative care to the patient's current and future care, and this could be more successful when the patient is emotionally prepared for the conversation and understands the factors involved. ● HCPs need to consider who has the most appropriate relationship with the patient, be clear who will have responsibility for patient care post-referral, and ensure the patient understands the referral process.
29. Polacek et al. [22]	Ambulatory clinics at the Memorial Sloan Kettering Cancer, New York, USA. Semi-structured interviews to explore the phenomenology of prognostic understanding. Thematic content analysis.	To examine how patients with advanced cancer conceptualise and define the term 'prognosis' in order to improve understanding of the construct and enhance patient-physician communication.	29. atients	<ul style="list-style-type: none"> ● Patients defined prognosis in several ways. Some participants focused on temporal survival (i.e., how much time they had left to live) while others focused on concrete medical data, e.g. results, treatment options. ● Patients held diverse perspectives on the value that they assigned to prognostic information. Responses ranged from minimisation of the information's impact on one's life to prioritising personal life goals within a potentially foreshortened lifespan.
30. Røen et al. [51]	Oncology Dept. of St. lavs Hospital, Trondheim, University Hospital, Norway. Semi-structured interviews. Systematic text condensation analysis.	To explore factors promoting carer resilience, based on carers' experiences with and preferences for health care provider support.	14 caregivers	<p>Caregivers described information and communication improvements to enhance their experience of supporting loved ones, including:</p> <ul style="list-style-type: none"> ● HCPs providing separate talks with carers as a routine to assess their needs. ● Education of HCPs should address caregivers' support needs and communication between carer and patient about prognosis and death.
31. Rohde et al. [33]	3 regional hospitals, Norway. Semi-structured interviews. Qualitative content analysis.	To explore the experiences of patients with incurable colorectal cancer and their reflections on information provided by physicians and nurses while they were in palliative care.	20 patients	<p>Patient interviews identified barriers to information and communication provision:</p> <ul style="list-style-type: none"> ● Receiving the information that they had an incurable disease was generally experienced as inadequate, while post-surgery palliative chemotherapy, physicians and nurses offered hope. ● Patients preferred customised information about treatment and likely prospects, and HCPs who used a holistic approach focusing on their lifeworld with compassion.
32. Scherrens et al. [34]	Hospitals, a regional PC Network and the Flemish Palliative Day Care Centres, Belgium. Semi-structured interview. Thematic content analysis.	To understand and explain the behaviour "starting a conversation about palliative care with a professional carer" from the perspective of people with incurable cancer.	25 patients	<p>Patients described positive and negative stances towards starting a conversation about PC with a professional carer:</p> <ul style="list-style-type: none"> ● Interventions should focus on providing positive and correct information about PC to close the awareness and knowledge gap and educate people with cancer about the relevance and benefits of PC conversations early in the disease trajectory. ● Involving family members and professional carers e.g., professional carers should know how to communicate early in the disease trajectory that they are open to PC.
33. Sherman et al. [35]	1 large academic cancer centre, USA. Semi-structured interviews. Thematic content analysis.	To examine patient perspectives regarding preparedness for EOL care.	13 patients	<p>Patients described areas they regarded as essential for readiness to manage EOL:</p> <ul style="list-style-type: none"> ● Support on whether to seek information about prognosis, and how to obtain it. ● HCPs efforts to foster clear communication and to discuss ACP including establishing GoC, location of care, symptom control and accessing appropriate services.

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Table 2 (continued)

Article	Settings and study design	Aims	Participants	Main findings
34. Stilos et al. [36]	Recruited through Ovarian Cancer website and staff supporting caregivers. Canada. Semi-structured interviews. Qualitative analysis method.	To explore the experiences of family caregivers who are caring for a loved one with advanced ovarian cancer.	13 caregivers	<ul style="list-style-type: none"> ● Opportunities to discuss aggressive treatment versus comfort care or withdrawal of life support. ● Accessible information in a lay form, that facilitated their sense of involvement in their own care. ● Advice on how best to communicate with loved ones and emotional changes e.g. existential anxiety, limited control, or loss. ● Having spiritual support and access to advice about financial matters. <p>Main themes characterised the family caregiver experience when caring for a relative with advanced incurable cancer:</p>
35. van Oosterhout et al. [37]	Tertiary university hospital. Netherlands. Structured interviews. Inductive content analysis, including constant comparison.	To explore how bereaved family caregivers experienced the shared decision-making process between their relative, themselves, and the medical oncologist.	16 caregivers	<ul style="list-style-type: none"> ● A need for better information about the diagnosis (e.g. what stages meant), prognosis, treatment, the dying process to influence more appropriate decision-making regarding treatment and care. ● Difficulties in accessing information and not understanding what support was available. ● Problems navigating the healthcare system, including contact details of HCPs, particularly when patients' needs were fluctuating. ● Patients described an appreciation for discussing death, the dying process and prognosis with the HCP but some were not ready. ● Preconditions for the decision-making process includes how carers wanted to be approached about it: respectful; close involvement; good relationship, good listening; empathic, human interaction and a personal approach.
36. Villalobos et al. [45]	Dept. of Thoracic Oncology, University Hospital Heidelberg, Germany. Semi-structured interviews. Qualitative content analysis.	To explore the patients' and family caregivers' needs and preferences regarding communication, quality of life and care within pre- defined milestones.	9 patients 9 Caregivers	<ul style="list-style-type: none"> ● Patients and caregivers described a situation of shock and coping deficits regarding their prognosis with moments of insufficient communication and lack of continuity in care. ● To improve patient experiences, a longitudinal communication approach with a focus on specific milestones was acceptable. ● Many patients and caregivers did not want life expectancy estimates, citing unreliable estimates, unknown treatment outcomes, or coping by not looking ahead. ● Most caregivers displayed an interest in ACP, often motivated by a loved one's EOL experiences, clear treatment preferences, concerns about caregivers or recognition that ACP is valuable regardless of life expectancy. ● Timing emerged as a reason not to discuss EOL issues; some patients maintained it was too early.
37. Walczak et al. [20]	Six medical oncology clinics in Sydney, Australia. Nurse-facilitated communication support program sessions were audio-recorded and transcribed verbatim. Thematic indicative text analysis.	To explore patient/caregiver response to the QPL and their openness to discussing prognosis, EOL issues and ACP.	31 patients 11 caregivers	<ul style="list-style-type: none"> ● Patient interviews highlighted the importance of good communication fostered by the nurse relationship. This included: ● Cancer nurses were valued for their knowledge and expertise, they enabled open dialogue about concerns through being caring, active listening and being the main, accessible point of contact for health concerns. ● Patients felt comfortable discussing various topics which supported understanding due to the personalised relationship. ● Important information was conveyed in timely fashion with clear explanations.
38. Walker et al. [57]	2 outpatient cancer centres (part of a large academic medical centre in the Northeastern USA. Semi-structured interviews and written field notes. Qualitative content analysis.	To describe the relationships between patients with cancer and their cancer nurses near EOL.	9 patients	<ul style="list-style-type: none"> ● Identified themes which characterised the impact of minority (LGBTQ+) stress for caregivers at EOL: ● Providers' discomfort and awkward communication, which felt challenging or
39. Cloyes et al. [58]	Across USA via social media channels/ email newsletters of community partners serving LGBTQ+ cancer patients and caregivers. Semi-structured interviews.	To describe LGBTQ + caregivers' experiences of providing EoL care to a family member or friend receiving in home hospice services.	20 caregivers	<ul style="list-style-type: none"> ● Providers' discomfort and awkward communication, which felt challenging or

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Table 2 (continued)

Article	Settings and study design	Aims	Participants	Main findings
	Interpretative descriptive approach and comparative analysis of data contents and patterns.			invalidating. This included perceptions of rudeness or disrespect. ● Providers' normative assumptions that did not align with the caregivers' reality when discussing situations. ● Lack of access to culturally competent EOL support resources.
40. Kolstrøm et al. [60]	Home service primary healthcare system in Northwest Norway; a palliative care doctor identified eligible patients' interviews conducted in patients' homes. Semi-structured interviews. Systematic text condensation analysis.	To explore the experiences of patients with advanced cancer experiencing Advance care planning (ACP) communication and drawing up a palliative plan.	5 patients	ACP conversations were experienced as a process. Three main themes included: ● The starting point was difficult for the patients since they had to talk about cancer and death, patients wished they had been prepared for these conversations. ● Wished the place for the conversation was in their own homes. ● The interactions with the doctors/nurses helped the patients feel valued and involved focusing on their wishes. ● Preparing a plan for the future and death was a meaningful process which provided a sense of security, and safety.
41. López-Salas et al. [47]	An association of cancer patients in Spain. Semi-structured interviews. Analysed using qualitative thematic analysis and a grounded theory approach.	To assess how patients living with Metastatic Breast Cancer would re-imagine cancer care delivery.	3 patients 12 caregivers	Participants put a high priority on having access to assistance in effectively expressing and communicating these needs including: ● Informed decision-making ensuring patient inclusion and autonomy in decisions that are made throughout the end-of-life period. ● Honesty of HCPs when sharing information with them, to support them with coping with doubts and make informed decisions. ● They want information on the prognosis, therapeutic options, legal and bureaucratic procedures, psychological and social resources, and shared experiences of other patients.
42. Roberson et al. [40]	Project Life members (non-profit) online wellness community for patients with MBC. USA. Semi-structured interviews. Phronetic Iterative Analysis (PIA) using two-stage deductive and inductive analysis.	To assess how patients living with MBC would re-imagine cancer care delivery.	36 patients	Participants lacked knowledge of medication side-effects, mental health needs, integrative treatment options. They desired: ● Support for navigating conversations about their diagnosis and future with their loved ones. ● Candid conversations with HCPs about topics including dietary changes, vitamin supplements, and alternative therapies. ● Accessible information available about their diagnosis, prognosis, and treatment options in addition to clinical trials and metastatic-specific resources. ● Curated, evidence-based information. ● Information tailored to the complexities of living with metastatic cancer specifically.

PC = Palliative care, QPL= Question prompt list, EOL = End of Life ACP= Advanced care plan, HCPs= Healthcare professionals

studies in 2024. A risk of bias assessment was carried out using the Specialist Unit for Review Evidence (SURE) critical appraisal checklist. [19] This 11 item checklist was designed specifically to assess the quality of qualitative papers and perceived as suitable for this rapid review. During this stage, six more papers were removed after a more in depth reading of the papers, as they did not fit the inclusion criteria or were deemed to provide insufficient data relevant to the review. The QA was used to examine the relevance and robustness of the included papers, rather than to exclude papers.

QA was carried out by three researchers, one researcher conducted an initial QA, and then it was checked by a second researcher. Disagreements were resolved by consensus, or by consulting a third researcher. QA forms for the individual studies are available as on request. Table 3 provides a summary of the QA items and results for each paper, which are rated as 'yes', 'no' or 'can't tell'. This illustrates that majority of papers comprehensively reported on most items. However, most papers did not report on the relationship between the researcher and participants.

2.7. Characteristics of included studies and participants

Of the final 44 studies, most studies were reported from the perspectives of patients (n = 21), or caregivers (n = 13), or both (n = 8). The studies reported between five and sixty-one participants. The data collection methods included semi-structured interviews, structured interviews, narrative interviews and ethnographic (observations and conversations). Analysis methods comprised thematic analysis, grounded theory framework analysis, interpretative phenomenological framework analysis, template analysis, systematic text condensation analysis, qualitative content analysis, thematic indicative text analysis, and constant comparison analysis. The studies were based in varying health, social care and community contexts across the OECD. This included thirteen in the USA, nineteen in different European countries and ten non-European countries. Characteristics of these studies are provided in Table 2.

Table 3
Quality Appraisal.

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10a	Q10b	
Ahmed, S. et al. (2020)	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	10
Ahmed, S. et al. (2023)	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	10
Back, A. et al. (2014)	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	10
Bergqvist, J. et al. (2019)	Y	Y	Y	Y	N	Y	Y	Y	CT	Y	N	8
Borland, R. et al. (2014)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	11
Brom, L. et al. (2017)	Y	Y	Y	Y	Y	Y	Y	Y	CT	Y	Y	10
Cameron, J. et al. (2014)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	11
Cloyes, K. G. (2024)	Y	Y	Y	N	N	Y	Y	Y	Y	Y	Y	9
Collins, A. et al. (2018)	Y	Y	Y	Y	N	CT	Y	Y	Y	Y	Y	9
Collins, A. et al. (2017)	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	10
Dillon, E. C. et al. (2021)	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	10
Dionne-Odom, J. N. et al. (2019)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	11
Durieux, B. N. et al. (2022)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	11
El-Jawahri, A. et al. (2017)	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	10
Fenton, A. et al. (2023)	Y	Y	Y	Y	CT	Y	Y	Y	Y	Y	Y	10
Fliedner M. et al. (2019)	Y	Y	Y	Y	Y	CT	Y	Y	Y	Y	Y	10
Fox J. A. et al. (2020)	Y	Y	Y	Y	CT	Y	Y	Y	Y	Y	Y	10
Fraterman I. et al. (2022)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	11
Heckel M. et al. (2018)	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	10
Jeon H. et al. (2023)	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	10
Kitta A. et al. (2021)	Y	Y	Y	Y	Y	CT	Y	Y	Y	Y	Y	10
Kolström, A. et al. (2023)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	11
Lindhardt C. L. et al. (2021)	Y	Y	Y	Y	CT	CT	Y	Y	Y	Y	Y	9
López-Salas, M. et al. (2024)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	11
McClelland S. et al. (2016)	Y	Y	Y	Y	CT	CT	Y	Y	Y	Y	Y	9
Mohammed S. et al. (2018)	Y	Y	Y	Y	CT	Y	CT	Y	Y	Y	Y	9
Moss K. O. et al. (2021)	Y	Y	Y	Y	CT	Y	Y	Y	Y	Y	Y	10
Ohlén J. et al. (2013)	Y	Y	Y	Y	CT	Y	Y	Y	Y	Y	Y	10
Ólafsdóttir K. L. (2018)	Y	Y	Y	Y	Y	Y	Y	Y	CT	Y	Y	10
Pedrosa Carrasco A. J. et al. (2021)	Y	Y	Y	Y	CT	Y	Y	Y	Y	Y	Y	10
Pini S. et al. (2021)	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	10
Polacek L. C. et al. (2023)	Y	Y	Y	Y	CT	Y	Y	Y	Y	Y	Y	10
Roberson, M. L. et al. (2023)	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	10
Røen I. et al. (2018)	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	10
Rohde G. et al. (2019)	Y	Y	Y	Y	CT	Y	Y	Y	Y	Y	Y	10
Scherrens A. L. et al. (2020)	Y	Y	Y	Y	CT	Y	Y	Y	Y	Y	Y	10
Sherman A. C. et al. (2018)	Y	Y	Y	Y	CT	Y	Y	Y	CT	Y	Y	9
Stilos, K. et al. (2018)	Y	Y	Y	Y	CT	Y	Y	Y	Y	N	Y	9
Van Oosterhout, S. P. C. et al. (2021)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	11
Villalobos, M. et al. (2018)	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	10
Walczak, A. et al. (2015)	Y	Y	Y	Y	CT	Y	Y	Y	Y	Y	Y	10
Walker S. et al. (2023)	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	10

Key: Y=Yes N = No CT= Can't Tell Score= total number questions answered yes out of 11 Questions

- Q1. Does the study address a clearly focused question/hypothesis?
- Q2. Is the choice of qualitative method appropriate?
- Q3. Is the sampling strategy clearly described and justified?
- Q4. Is the method of data collection well described?
- Q5. Is the relationship between the researcher(s) and participants explored?
- Q6. Are ethical issues explicitly discussed?
- Q7. Is the data analysis/interpretation process described and justified?
- Q8. Are the findings credible?
- Q9. Is any sponsorship/conflict of interest reported?
- Q10a. Did the authors identify any limitations?
- Q10b. Are the conclusions the same in the abstract and the full text?

Key: Y=Yes N = No CT= Can't Tell Score= total number questions answered yes out of 11

2.8. Data analysis

Qualitative thematic synthesis was conducted using Thomas and Harden's 2008 thematic synthesis approach to aggregated level data. [16] Thematic synthesis was applied, as it translates methods for the analysis of primary 'thematic' research for use in systematic reviews. Primary data were initially extracted using a deductive approach which identified data that related to the review's questions. A further stage of analysis was conducted using an inductive approach to the qualitative results reported in the included studies. These were analysed using the three stages of thematic synthesis: the coding of text 'line-by-line'; the development of 'descriptive themes'; and the generation of 'analytical themes'. Initial coding of the data was conducted by three researchers,

each researcher independently coded different studies and 20% were double coded by another researcher. A framework for descriptive themes was agreed to ensure consistency. The development of analytical themes involved a process of interpretation where new interpretive constructs, explanations or hypotheses were developed. NVivo v.1.7 was used to manage the data analysis. The themes presented in this paper focus on addressing the review's questions and illustrate the key themes and sub-themes derived from the papers (i.e. only themes described in at least two or more papers) rather than all themes which were coded.

3. Results

3.1. Thematic synthesis

The following results are synthesised themes from 42 papers, these are presented in accordance with the review’s objectives and descriptive themes (Table 4).

3.2. The information that patients and caregivers wanted to receive

3.2.1. Preferences for personalised information

Patients and caregivers sought personalised information tailored to their individual needs, particularly regarding information about diagnosis and prognosis, including how long they would have left to live. [20–41]. Information about individual treatments including risks and benefits, and alternative options, were required to inform shared decision making based on realistic outcomes. [25,27,30,33,36,37,40,42–45] Information was sought about how diagnosis and prognosis would impact their daily lives, including their relationships, [21,22,30,33,34,38,46,47] how their disease would change and what treatment side-effects they might experience. [21,24,30,31,33,36,40,47].

3.2.2. Explanations of services and processes along cancer and end of life pathways

Clear and explicit explanations of services and processes along the cancer and end of life pathways were desired by patients and caregivers. Explanations of palliative care (PC), [21,23,24,32,34,37,43,48–50], and hospices [21,26,28,42,49,50] were most commonly sought. Being better informed about what to expect along the patient pathway was required, particularly regarding understanding clinical terminology and processes. [26,30,32,33,36,51] This included information supporting preparation for end of life and dying [27,35,36,51,52] and what the dying process entailed. [28,31,36,37,53,54] Information about how to access relevant advice and support was highly valued, including the specific responsibilities of HCPs and health, care and third sector services. [23,37,38,49,50,54,55].

3.2.3. Accessing bespoke advice and support

Patients desired access to support from peers with relevant lived experiences of the same type of incurable cancer. [34,38,40,51,41] Patients and caregivers wanted to be provided with access to financial advice. [28,36,38,49,52] Self-management tools and strategies were needed to support daily life, principally regarding psychological preparedness [30,35,46,52]. Caregivers required information about caring for a loved one, including supporting their practical needs, [36,38,44,49,52,54,55] and their emotional needs, including changes in their

Table 4
Review questions and descriptive themes.

Review questions	Descriptive themes
The information that patients and caregivers wanted to receive	<ul style="list-style-type: none"> ● Preferences for personalised information ● Explanations of services and processes along cancer and end of life pathways ● Accessing bespoke advice and support
Communication preferences of patients and caregivers	<ul style="list-style-type: none"> ● Skills and approaches of healthcare professionals ● Delivery of information
Barriers to and facilitators of communicating, receiving and understanding information	<ul style="list-style-type: none"> ● Patients’ psychological barriers ● Inadequate health and death literacy ● Practical barriers ● Facilitators to understanding accepting information
Improvements to information and communication for patients and their caregivers	

mood and personality. [28,34–36,49,51,54].

3.3. Communication preferences of patients and caregivers

3.3.1. Skills and approaches of healthcare professionals

Communication preferences focused on the skills and attitudes of HCPs. Empathy, caring, calmness, respect and compassion were sought from HCPs, particularly when delivering bad news. [21,28,31,33,34,37,42,54,56–58] Openness and honesty were required, alongside sensitivity. [26,33,34,39,45,47,52,57,59,41] Patients wanted to be treated as equals, co-producing their care and being afforded the opportunity to be involved and supported in shared decision making. [21,23,31,40,43,55,56,59] Patients desired to be treated holistically, as an individual and not just referred to in terms of their disease. [30,33,37,42,57,60] They expressed the importance of being listened and responded to in relation to their questions and needs, [22,23,27,33,37,52,56] with a specific focus on what is important to them, [22,23,27,34,37,43,51,56,59,61] including their personal goals and preferences. [21,23,27,34,35,40,43,51,56,59–61] HCPs focussing on positive aspects of patients’ lives was considered important, including discussing what could realistically be done for the patient rather than what could not, while considering their need for hope. [33,39,42,52,57].

3.3.2. Delivery of information

Patients and caregivers required adequate time to receive and discuss pertinent information. [31–33,37,45,62] Information that is accessible and succinct was considered valuable to enable comprehension and assessment of what was relevant. [24,33,34,37,42,43,45,57,59] Explicit and evidence-based information was desired, with no room for interpretation. [26,36,37,40,43,45,51,56,60] The types of communication delivery that were favoured included diagnosis being communicated through a method in accordance with individual preferences, e.g. face to face. [23,34,37,51] Information was required to be accessible and easy to understand and provided in written formats, so that it can be taken home. [26,52,61] They wanted HCPs to consider individualised patient preferences for the timing of receiving information. [21,27,34,51,52,56].

Opportunities to receive regular clinical updates from HCPs was desired. [34,36,54,57] Communicating to patients that they have reached key milestones and changes along the cancer pathway, including prognosis, changes in goals of care or symptoms, introduction of Advance Care Planning (ACP) or PC was considered important. [21,27,34,47,51–53,55,56,60] A need for the explicit acknowledgement of when death and dying were close was sought, so patients and caregivers could feel suitably prepared for the end of life. [26,28,29,36,53,54].

3.4. Barriers to and facilitators of communicating, receiving and understanding information

3.4.1. Patients’ psychological barriers

Key barriers to understanding and discussing information included patients avoiding difficult information and not wanting to discuss topics that confronted them with the reality of the terminal nature of their illness. [20–22,26,27–30,32,33–35,37,39,45,47,51–53,59,61,62] Patients sometimes conveyed ambivalence between wanting and not wanting to know information about their prognosis. [22,27,32,35] They expressed a lack of emotional readiness to discuss or contemplate information related to the end of their life [20,21,34,35,37,61] pointing to how end of life (EoL)¹³ conversations took away hope or were too depressing. [29,34,59,60,62] When faced with difficult news during consultations, patients’ emotional responses sometimes impaired their ability to process and internalise that information. [30,32,33,52,62] There was also a tendency for patients to want to please doctors,

¹³ EoL =End of life

therefore holding back with questions, trying not to take up too much time or focusing on medical rather than emotional aspects of their care. [23,26,28,39].

3.4.2. Inadequate health and death literacy

A lack of accurate understanding of key terminology or concepts hindered effective communication about EoL care and informed decision-making. [21,22,29,32,34,36,37,43,55] Some patients avoided discussing PC or EoL, as they incorrectly perceived that such discussions were not yet relevant to them. [20,26,32,34,37,59,63].

3.4.3. Practical barriers

Further barriers to effective communication included time limited consultations with inadequate opportunities to ask questions. [30,32,33]. A lack of a specified, reliable HCP contact made it difficult to know who to contact with their queries. [36,51,54].

3.4.4. Facilitators to understanding accepting information

Facilitators included 'layered' and incremental information-giving, which was important for patients to make navigating difficult information more manageable and ensuring that patients are in control of how much information they want to access and when. [22,23,27,30,33,62] Trusting relationships with HCPs, particularly nurses, tended to enable patients and caregivers to feel supported and comfortable about engaging in open discussions. [21,23,33,34,49,50,55,57,64] Early access to PC provided opportunities to gain greater understanding of PC and increase awareness of available support and care options. [40,50,52,55].

3.5. Improvements to information and communication for patients and their caregivers

HCPs should consult patients and caregivers about their information and communication preferences, including how to frame the situation and personalising their response to the specific needs of individual by acknowledging cues and not making assumptions. [29,51,56] Patients and caregivers should be asked whether they would like their caregivers to be involved in discussions, as some preferred to discuss matters in private. [23,37,51,59,60].

Adequate time is required to emotionally absorb information and to ask follow-up questions particularly pertaining to prognosis. [27,32–34,52,59] Caregivers require more open discussions about what to expect regarding their loved one's end of life [23,26,28,54,64] and more involvement and recognition of their own needs from health services. [23,26,34,35,40,51,59].

Improvements to communication between different health and care services could involve ensuring updates regarding patients are provided to HCPs including to General Practitioners (family doctors), as they can provide a more generalist or holistic approach to patients. [23,33,42,55] Caregivers suggested that healthcare navigators and advocacy for those without personal or social support could be more consistently provided. [40,55,57,59].

4. Discussion

4.1. Main findings

This review synthesised data of key information and communication needs reported by patients with advanced incurable cancer and their caregivers from qualitative studies. It emphasises that personalised information and communication approaches were favoured, in accordance with individual preferences, to enable enhanced comprehension and emotional management of information. The need for healthcare professionals to provide adequate time, openness, and sensitivity to facilitate understanding of prognosis, treatment and care options towards end of life. Barriers to receiving, communicating and understanding

information included difficulties engaging with and processing challenging information, a lack of key HCP contact and inadequate cancer, health and death literacy. Facilitators included incremental information provision and early access to palliative care specialist expertise.

4.2. Embedding information and communication needs into practice

Previous research concurs with the need for more tailored and reliable information provision to patients and their caregivers, which specifically addresses their needs relating to cancer. [9,65–67] However, there has been an inconsistent integration of these approaches into routine clinical practice due to health service and patient level barriers. HCP and healthcare systems barriers which are highlighted in this review, focus on inadequate time in consultations and a lack of a specified HCP contact. Other research illustrates key barriers that need to be addressed, including HCPs' concerns about harming patients through the disclosure of difficult information, [68] lack of clarity among HCPs regarding the key components necessary for high-quality communication [12] and lack of training to have conversations about end-of-life matters. [69].

Recent digital initiatives [70,71] have been established to enhance access to personalised information including web-based applications. These have been developed to improve information provision between healthcare services and patients, including access to bespoke advice, electronic health records, managing care plans and sharing clinical information. They also have the capacity for embedding information interventions (e.g. question prompt lists and shared decision-making tools) which can enhance be spoke support throughout cancer and end of life pathways. However, these applications are in the early stages of implementation and the quality of the content to be included, as well as corresponding support from healthcare practitioners will determine their efficacy for patients with advanced incurable cancer. [72,73] Alike any non-digital forms of information provision, these interventions need to include the use of accessible and culturally sensitive information, user-friendly terminology and visual aids to ensure genuine inclusivity of all patients. [74–76].

Prior research has also demonstrated that providing access to a specified clinical contact,

[77] ideally a key cancer worker, [78,79] can help to ensure consistent provision of pertinent information, explanation of clinical terms and practical support along cancer pathways. However, where these resources and approaches are not mandated by policy, inequity of provision remains for patients with advanced cancer, which can negatively affect their experiences.

Equally, the communication skills of HCPs are emphasised among patients' and caregivers' key priorities, which have also been recognised in previous research. Interpersonal skills are desired in empathy, caring and compassion, [80] open and honest conversations and positively presented information delivered with sensitivity [81], particularly relating to PC and prognosis. [82,83] The importance of HCPs actively listening and responding to questions, needs and preferences was also highlighted. [84] Other studies have also emphasised the importance of non-verbal communication, which can impact on the quality of these interactions, particularly when language and capacity to concentrate are barriers. [85,86] Prior systematic reviews reporting the results of quantitative [87] and mixed methods studies [88] of end-of-life communication training for HCPs describe lack of sufficient evidence to determine whether communication skills training positively impacted patient or caregiver level outcomes, as they tend to focus on the views of HCPs rather than patients and caregivers. The Brighton et al., 2017 review also concluded that patient and family involvement in training development was rare. [88] This illustrates the need for people with advanced incurable cancer and their caregivers to play a central role in HCP skills training coproduction and evaluation.

This review also highlights how patients' emotional responses to difficult information and avoidant coping mechanisms can impact

information comprehension and retention. Quantitative research has highlighted that not all patients want to be provided with a prognosis by their clinicians and just 70% of the patients recalled being given a detailed prognosis. [89] Negative emotions observed during clinical conversations about poor prognosis or PC can impair how information is cognitively processed and recalled. [90,91] This emphasises the need to gain a better understanding of how emotions impact on information processing and decision-making in clinical communication contexts. [90,92] Clinician-expressed empathy has been found to improve information recall in advanced cancer consultations, [93,94] yet HCPs do not always recognise patients' emotions and often 'miss' opportunities to respond empathically, [95] especially when emotions are expressed in lower intensity. [96] HCPs tend to respond more empathically to patients' positive news rather than disclosure of challenges or negative emotions. [97,98] This underscores the need for medical communication training to include recognising and addressing negative emotions in these conversations.

Patients regularly adjust their communication behaviour, actively avoiding distressing information if they do not feel ready for it, [99] which helps them cope in the short-term but limits their ability to fully engage in clinical conversations. Terms which are widely misunderstood, including 'palliative care', often trigger negative emotional responses including fear and avoidance. [100] Previous research exploring the early integration of PC concurs that it supports better understanding of the purpose and benefits of palliative care, [100,101] timelier and more frequent discussions of goals and preferences based on a better understanding of their prognosis at a time when EoL care decisions are not yet crucial. [101,102] Similarly, communication approaches such as the pathway mediation model developed by Street et al. (2009)[103] have sought to address health information avoidance. This method is facilitated through HCPs supporting the development of patient trust and healthcare literacy. [104] This approach demonstrated that patient-centred communication is directly associated with reduced information avoidance, especially among cancer patients. Illustrating that further development of HCPs skills which support patients' individual psychological and information needs should be more widely integrated into end-of-life cancer pathways.

4.3. Practical implications

Health and care services and policy makers should consider co-producing and evaluating communication strategies with patients with incurable cancer and caregivers, which focuses on their needs towards end of life. This will help underpin the provision of the tailored information and communication approaches identified in this review. Building on previous calls for communication skills training for HCPs, which focus on personalised and empathic information delivery, time and resources should be committed at a policy level to ensure consistent provision. Likewise, prioritising the early integration of a specialist cancer key worker, PC expertise and improved access to psychosocial support before, after and during discussions may help patients better cope and improve their ability to process and understand information.

Further research is required to understand how to improve communication between health and care services centring on the needs of patients with advanced cancer towards end of life. Additionally, research initiatives should explore ways to incorporate health, cancer and death literacy research into communication approaches. This could include further examination of the impact of inequalities on information provision and comprehension towards end of life using such as public health research approaches and intervention development. Research into patient-level psychological factors such as the impact of emotional readiness and emotional literacy could identify ways to improve patients' capacity to understand and cope with medical and end of life information. Future studies could incorporate and compare qualitative results with quantitative data, which have been excluded in this rapid study.

4.4. Strengths and limitations

Combining the PaCERS review method and thematic synthesis provided a systematic approach to exploring these questions regarding information and communication needs. This ensured the richness of the qualitative data were captured and interpreted transparently and rigorously. Although the study decontextualises each paper, we provided context summaries of all included studies and a quality assessment. Despite the varied geographical locations and data collection methods of the papers, shared preferences and needs for information and communication were illustrated across the study's varying national boundaries. Also, due to the rapid nature of the review, studies using quantitative or mixed qualitative and quantitative methods were not included, so it is potentially limited in its coverage of relevant patients' and caregivers' perspectives.

5. Conclusions

This review consolidated qualitative data which discussed the key information and communication needs of patients with advanced incurable cancer and their caregivers. It highlighted the need to be communicated with at a time and level of detail in accordance with their personal preferences. Consistent provision of adequate time, openness and sensitivity was required by HCPs to facilitate understanding of prognosis, palliative treatment and care options. The specific barriers and facilitators identified should be considered when developing and implementing communication strategies.

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Contribution Statement

DHH led the study, designed the question, completed screening, data extraction, quality assessment, data analysis, and drafted the manuscript. SG contributed to screening, data extraction, quality assessment, data analysis and drafting the manuscript. IH contributed to data extraction, quality assessment, data analysis and drafting the manuscript. MM designed and oversaw the search, contributed to the methodology, screening and editing the manuscript. All authors contributed to revisions of the manuscript and approved the final version.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.pec.2024.108559](https://doi.org/10.1016/j.pec.2024.108559).

Data availability

The dataset(s) supporting the conclusions of this article(are) included within the article and its additional file(s) any further data can be requested from the authors.

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