

Evidence Implications:

Clinical & Policy:

Evidence provided in this review highlights key information and communication needs of patients with advanced incurable cancer and their caregivers that can inform policy and practice. It illustrates that patients and caregivers want personalised information provided in accordance with their individual preferences for when and how it is presented. Adequate time, openness and sensitivity should be provided by HCPs to facilitate understanding of prognosis, and treatment and care options. Patients' psychosocial barriers to receiving appropriate information include avoidance of the emotional impact and low health literacy. Facilitators included early access to palliative care specialists and the provision of incremental information delivered when it is suitable for patients and caregivers. These should be considered when implementing strategies and training for communicating with patient and caregivers.

The evidence base provided by the current studies is weakened by their variability in data collection and analysis but strengthened by the overlap in convergent themes.

Glossary:

(ACP) Advanced Care Planning

(HCP) Healthcare Professional

(GoC) Goals of Care

(PC) Palliative Care

(SDM) Shared Decision Making

(EOL) End of Life

(OCED) Organisation of Economic Cooperation and Development

This review was registered on PROSPERO in June 2023. The information and communication needs of patients with advanced incurable cancer: A rapid review. https://www.crd.york.ac.uk/PROSPERO/display_record.php?RecordID=434023

Context

People with advanced incurable cancer and their caregivers are faced with challenging psychological and practical issues including treatment options, symptoms, dying, and end of life decision making. However, information which fits the needs of patients and caregivers is not always readily available or appropriately communicated during this time (Nelson et al., 2020). Cancer and end of life literacy is often inadequate, particularly among certain groups (ethnic minorities, those with lower levels of literacy and those with learning difficulties) (Bires et al., 2018, Holden 2021, Nelson et al., 2021). Thus, there is a need to improve information and communication between patients, their caregivers and health services to ensure that patients are equipped to understand their disease trajectory and come to terms with its emotional implications (Rainbird, 2009). Patients can benefit from the information provided through support tools and discussions with HCPs that are tailored to their prognosis and explain the benefits and harms of treatment options (Edwards et al. 2023). However, there can be inconsistency between healthcare professionals' perceptions of what information is needed and how is best communicated compared to patients and their caregivers (Hancock, 2007). There is a need to address gaps in understanding what information is needed, and how this is implemented in different contexts such as how and when this information is preferred according to people with advanced cancer and their caregivers (Ector, 2020, Edwards et al., 2023). Therefore, this review has sought to collate primary research evidence regarding the most important information and communication needs from the perspective of patients and their caregivers. It has also aimed to understand underlying barriers and facilitators for patients and their caregivers in understanding and accessing information which is communicated in line with their needs.

A scoping review was conducted in April 2023 to source relevant literature and define the scope of the review.

Research Question

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

Objectives

- 1) To understand what are the most significant communication and information needs of patients with advanced incurable cancer and their caregivers.
- 2) To identify what are patients' and caregivers' preferences for information and communication when they have an incurable cancer diagnosis:
 - a) What information do patients and caregivers want to receive?
 - b) How and when do patients and caregivers prefer to be communicated with?
- 3) To understand how communication and information-exchange can be improved and made more inclusive for patients with advanced cancer and their caregivers.
- 4) To identify barriers and facilitators to communicating, understanding and receiving information including inequalities.

Key findings

1444 studies were initially identified. After removal of duplicates and irrelevant papers, 1349 abstracts were screened in accordance with exclusion and inclusion criteria. In total, 74 full text papers were retrieved and screened. During data extraction and critical appraisal, a further 30 studies were excluded. These were mixed qualitative and quantitative methods, describing caregivers of children or the wrong patient population e.g. patients with cancer unknown to be incurable. Another six studies were removed after data extraction and quality assessment as they did not fully fit the inclusion criteria or were not deemed to include sufficient data relevant to the review. Therefore, 38 studies were included in this review.

Key Findings (continued)

A summary of the main findings are listed in Table 1.

The most significant communication and information needs of patients with advanced incurable cancer and their caregivers.

Across the 38 articles, patients and caregivers consistently sought personalised information about their diagnosis, prognosis, treatments, side-effects and care. They wanted this communicated to them at a time and level of detail in accordance with their personal preferences, which could enable them to more readily comprehend and emotionally manage the information. HCP's' communication approaches i.e. empathy, willingness to listen and respond, openness and honesty were those most valued by patients and caregivers. They needed information to prepare for what they should expect in the short and longer-term along the cancer pathway and towards the end of life. Patients and caregivers required information about health and care services that were available and how to contact them.

Patients' and caregivers' preferences for information and communication when they have an incurable cancer diagnosis:

1) What information do patients and caregivers want to receive?

Patients and caregivers expressed a need for clear explanations of support services and processes along their cancer pathway. The most sought after explanations were of palliative care (PC), hospices and advanced care planning (ACP). Information about how and where to access advice and support was considered highly important. This included the roles and remits of HCPs and health, care and third sector services; a direct point of contact; how to access peer support; where to find financial support and help available for caregivers. Patients required appropriately detailed yet personalised information about diagnosis, prognosis, tests, and treatments. They wanted information on how their diagnosis and prognosis would impact their daily lives including their relationships and their sexual quality of life. Self-management tools and strategies were required to support daily life, particularly regarding psychological preparedness. Patients and caregivers wanted to know how to prepare for end of life. Caregivers needed information on how to care for and support loved ones, including supporting their emotional needs and practical needs. They also needed information about how their own lives would be impacted.

2) How and when do patients and caregivers prefer to be communicated with?

The studies highlighted patients' and caregivers' preferences regarding how they wanted to be communicated with, focusing on the communication approaches of HCPs. They preferred HCPs to demonstrate skills in empathy, caring, calmness and compassion but also to be open and honest when discussing their health or care. They aspired to be treated equally, and to have the opportunity to be involved in shared decision making. They expressed the importance of being listened to and responded to regarding what is important to them. There was a preference to focus on the positive and on what could be done. They wanted adequate time to receive and discuss pertinent information. Clear and succinct information was required with no room for interpretation.

Types of communication delivery that were favoured included the diagnosis being communicated according to their personal preferences e.g. face to face. Information should be easy to understand, and written materials provided, so that they can be read in their own time. They wanted HCPs to consider individualised patient preferences regarding the timing of receiving information. Opportunities to receive regular updates were desired. The timely communication of reaching key milestones and changes along the cancer pathway e.g. prognosis, changes in goals of care, introduction of ACP or PC was important for patients. Both patients and caregivers needed an explicit acknowledgement of when death and dying were close.

3) How can communication and information-exchange be improved and made more inclusive for patients with advanced cancer and their caregivers?

Patients wanted HCPs to enquire about their preferences, not to make assumptions about their needs and to ask about the degree to which they would like their caregivers to be involved in discussions. Adequate time was needed to emotionally absorb the information particularly pertaining to prognosis. Caregivers sought more open discussions about what to expect regarding their loved one's end of life and more involvement and recognition of their own needs. Communication between different health and care services could be improved with GPs being better informed of the patient's situation.

4) What are barriers and facilitators to communicating, understanding and receiving information?

Patients' psychosocial barriers to receiving and understanding information included nervousness and shock and avoiding the emotional impact of difficult information around prognosis. This was related to their fear and an inability to cope with all the details relating to their diagnosis or prognosis. Inadequate health literacy was prevalent particularly regarding understanding elements of palliative care. Patients sometimes wanted to please doctors, which restricted their willingness to take time to ask questions or challenge their perceptions.

Facilitators to patients' effective communication included receiving information in a 'layered format' that allows patients to control how much detail they want to access and when. Access to support from palliative care specialists provided better and earlier opportunities for receiving information regarding symptoms, care, end of life and initiating ACP discussions.

A. Reliability of evidence

All studies adequately explained the study design, data collection and analysis. They were all qualitative study designs but included a range of qualitative methods and analysis. The data collection methods included semi-structured interviews (1,2,3,4,5,6,8,11,12,13,14,15,16,17,18,19,20,21,22,23,24,26,28,29,30,31,32,33,34,36,38), structured interviews (35), narrative interviews (9,25) and ethnographic (observations and conversations) (6,7,25,37). The analysis methods included thematic analysis (1,2,5,7,8,11,17,18,20,21,22,24,26,29), grounded theory (10,16,23), framework (13,28), interpretative phenomenological framework (9,25), template (12,14), Silverman's qualitative methods (34), systematic text condensation (30), qualitative content (4,15,19,24,27,31,32,36,38), thematic indicative text (37) and constant comparison analysis (3,35).

The studies were suitable in size for qualitative studies and most had a small to medium number of participants ranging from seven to 61. Two studies had over 50 participants (3,23). For several studies (16,35) that focussed on the experiences of caregivers, data collection took place a significant time after the death of the person they had cared for, leading to possible recall bias and omissions. Most studies took place in single sites (3,4,6,7,8,9,10,11,13,14,17,18,20,21,22,23,24,25,26,30,33,35,36) which may have increased bias and the potential for the data collected be less applicable to different settings and geographical variability. All studies aside from (19,25,33,36,) report on financial contribution and or sponsorship and all except (4,26,33) explicitly declared no conflicts of interest.

B. Consistency of evidence

All studies were directly relevant to the study population i.e. adult patients with advanced incurable cancer and caregivers to patients with advanced incurable cancer, living/being cared for in an OECD country. However, the studies varied in terms of their comparison of outcomes as they explore different questions relating to information and communication needs of patients and caregivers. The studies explored the needs of three groups including patients (n=19) (4,6,7,8,10,13,15,17,20,21,22,25,26,28,29,31,32,33,38), caregivers (n=12) (5,9,12,14,16,18,19,23,24,30,34,35) and patients and caregivers (n=7) (1,2,3,11,27,36,37). In six studies (seven papers) (1,2,15,17,26,27,37), different types of interventions were examined. These interventions provided moderate benefit in terms of psychological and practical support for patients and/or caregivers. These contrasted with papers that explored experiences of pre-existing services or phenomena (n=31).

The studies reported varying types of demographic information, therefore it is difficult to compare the studies on this basis.

All studies were consistent in their results and conclusions.

C. Relevance of evidence

One study (Heckel et al.) (18) compared the experiences of patients with brain tumours with those of patients with non-brain tumours, so only the relevant data relating to the brain tumour patients' perspective was extracted from this study.

A Hospice Nurse Specialist was the primary researcher in the (Borland et al.) (5) study which may have positively influenced participants' experiences and outcomes.

Only two studies were based in a UK setting (5,28), the other 36 studies were based across other European settings with varying health and social care contexts (Austria (20), Belgium (32), Denmark (21), Germany (18,27,36), Iceland (26), Netherlands (6,17,35), Norway (30,31), Sweden (4,25), Switzerland (15) and non-European countries (Australia (8,9,16,37), Canada (1,2,23,34), Korea (19), New Zealand (7), and USA (3,10,11,12,13,14,22,24,29,33,38). Although this diversity of locations may limit relevance to UK practice, consistency across the most common themes in the studies indicate that findings are likely to be relevant to UK practice. However, the majority of studies were based in the USA, where information needs relating to health insurance is highlighted in a number of papers, these needs are less relevant in other countries with taxpayer funded universal healthcare.

Review Methods

Search Strategy:

A search strategy was iteratively developed between April 2023 and June 2023. After conducting three preliminary searches and piloting the selection of references by screening abstracts for relevance, a final search strategy was agreed upon in June 2023.

Comprehensive searches were conducted across multiple databases, restricted to English language articles published after 2013: MEDLINE, EMBASE, and PsycINFO.

Inclusion:

Articles that discuss the information and/or communication needs or preferences of patients with advanced incurable cancer and their caregivers (including inequalities); discuss barriers or facilitators to effective communication or information-giving in the context of an incurable cancer diagnosis; journal articles; primary data; qualitative data with direct quotations from patients or caregivers and OECD countries.

Exclusion:

Articles that do not discuss information or communication needs/preferences or barriers/facilitators of effective communication or information-giving; only discuss the views of healthcare professionals and not of patients or caregivers; discuss the view of children (aged under 16 years old); are a trial registration, protocol, book chapter or conference document; is based only in non-OECD countries; is not available in English and includes quantitative data.

Study selection

Search results were imported into Endnote v20. After removal of duplicates and irrelevant papers, all sources were screened separately by title and abstract. The Rayyan web application (a screening tool) was used for the formal screening of all papers. 1349 studies were screened separately for relevance, initially by title and abstract. At this stage the inclusion criteria was modified to only include articles published after 2013 and reporting qualitative data, due to extensive range of papers initially eligible. A full-text article search was carried in 74 articles by fully retrieving the papers.

Study selection was carried out by three reviewers and checked for accuracy by another in accordance with inclusion and exclusion criteria. Any disagreements were resolved through discussion, or with a third reviewer. Where necessary, full papers were read to decide on inclusion.

Quality Assessment

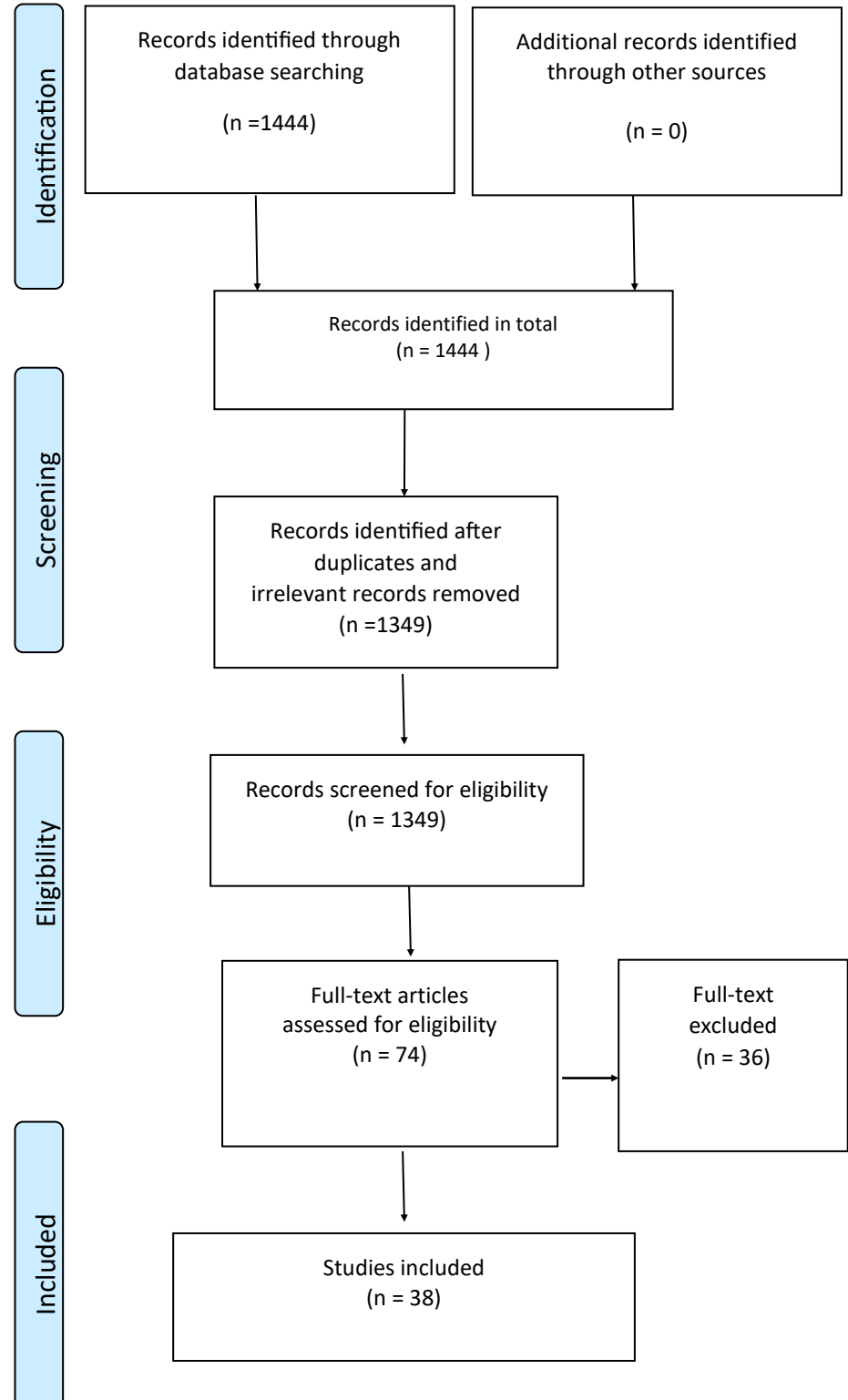
Data was extracted and recorded from 54 papers by four reviewers using data extraction forms that were developed based on the research question and objectives. Disagreements were resolved by consensus with all team members. A further 10 papers were removed at this stage.

Data Extraction

A Risk of bias (quality) assessment was carried using the Specialist Unit for Review Evidence (SURE) critical appraisal checklists. During this process, a further six papers were removed as they did not fit the inclusion criteria or were deemed to not include sufficient data relevant to the review. Thus, 38 studies were included in the review.

Data analysis was carried out using NVivo 1.7 for data management. Qualitative thematic synthesis was conducted and the key findings are presented here in a narrative format in accordance with the objectives.

Flow Diagram:



Article	Main findings related to questions
1. Ahmed et al. 2020	<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. <p>Study appraisal: A useful study with 22 participants (15 patients, 7 caregivers), which identifies information and communication gaps in advanced cancer.</p>
2. Ahmed et al. 2023	<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' situation 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 in their care. • Some carers expressed a need for a patient advocate to help navigate the healthcare system. <p>Study appraisal: This is a useful study with only 12 participants (7 patients and 5 caregivers) but some important comparisons with an earlier part of the study relating to the implementation of Early Palliative Care.</p>
3. Back et al. 2014	<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"). <p>Study appraisal: A useful and large study involving 57 participants (37 Patients and 20 family caregivers) with some novel insights into communication preferences.</p>
4. Bergqvist et al. 2019	<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. <p>Study appraisal: A useful study with 20 patients, exploring patients' communication and information preferences.</p>
5. Borland et al. 2014	<ul style="list-style-type: none"> • Hospice Nurse Specialist (HNS) acts as a "confidante" in caring for caregivers who provided reassuring information about practical, financial concerns and preparedness for death and dying, and allowed patients and caregivers to be at ease discussing their concerns. • Patients and caregivers must fully understand all aspects of the HNS' role. A clear explanation including written information is required at the point of referral into the specialist nurse service. • A public health commitment to advertising of the specialist nurse service would enhance opportunities for the public to learn about the availability of services in their area. <p>Study appraisal: A small but valuable study with 7 patient participants, and only one male, which provide some caregivers' retrospective perspectives on the role of Hospice Nurses on informal caregiving.</p>
6. Brom et al. 2017	<ul style="list-style-type: none"> • 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. <p>Study appraisal: This study has 13 patient participants and explores how decision making is used in practice and reflections from patients.</p>
7. Cameron et al. 2014	<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. <p>Study appraisal: A small study with 10 participants that provides some useful insights into the experiences of patients receiving palliative chemotherapy and their communication needs.</p>
8. Collins et al. 2018a	<ul style="list-style-type: none"> • Patient barriers to understanding PC, EOL and dying included: • 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. <p>Study Appraisal: Quite a useful study with 30 patients which provides insights into patients' perspectives into communication concerning PC and dying.</p>

9.Collins et al. 2018b	<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. <p>Study appraisal: This is a good study (25 caregivers) which provides clear preferences for communication around PC.</p>
10.Dillon et al. 2021	<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. <p>Study appraisal: A good sized study (25 patients) which describes preferences and experiences of GoC conversations.</p>
11.Dionne-Odom et al. 2019	<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 posing "what if" scenarios about current and potential future health states and treatments. 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. <p>Study appraisal: A very useful study including 18 patients and 20 caregivers. It highlights the varying communication needs and roles of family caregivers including cancer and treatment information seeker, shared understanding facilitator, decision point originator, values and illness framer discussant, collateral decisions manager, and delegated decision maker.</p>
12.Durieux et al. 2022	<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. <p>Study appraisal: A useful study of 19 participants which discusses complexity in relation to communication relating to GoC conversations.</p>
13.El-Jawahri et al. 2017	<ul style="list-style-type: none"> All patients showed variable gaps in understanding about hospice, 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 hospice 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. <p>Study appraisal: This is a useful study of 16 patients which explored the information and communication needs as they relate to hospices.</p>
14.Fenton et al. 2023	<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. <p>Study appraisal: This is a good study with 19 caregiver participants which explored how caregivers described personal and systemic communication challenges related to prognostic and EOL discussions.</p>
15.Fliedner et al. 2019	<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. The structured early PC intervention was seen as helpful in stimulating family discussions and understanding PC. <p>Study appraisal: A useful study with 20 patients who discuss the benefit of EOL discussions. Patients' experiences with the intervention affect their understanding of what PC entails and the actions that were triggered by the SENS-intervention.</p>
16.Fox et al. 2020	<ul style="list-style-type: none"> 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. <p>Study appraisal: A good study with 20 participants which explored caregivers' perspectives of communication for PC, EOL, targeted and immune therapies.</p>

17. Fraterman et al. 2022	<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. <p>Study appraisal: This is a valuable study with 13 participants that explored information needs from a patient perspective.</p>
18. Heckel et al 2018	<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. <p>Study appraisal: This is quite a large study with 28 participants which discusses the information needs of home carers.</p>
19. Jeon et al. 2020	<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. <p>Study appraisal: This is small study with 10 participants. There is no mention of whether data saturation was achieved and no information on the study's funding. Caregiver information needs are, however, well described.</p>
20. Kitta et al. 2021	<p>Patient interviews highlighted three themes regarding communicating EOL and PC:</p> <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 realization 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. <p>Study appraisal: This is a good study with 12 participants. It describes the patient communication needs regarding discussions of EOL topics.</p>
21. Lindhardt et al. 2021	<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. <p>Study appraisal: A good but small study of 11 patients, which discusses some patient preferences.</p>
22. McClelland et al. (2016)	<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. <p>Study appraisal: A large study with 32 participants about sexual health, education/ communication preferences.</p>
23. Mohammed et al. 2018	<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. <p>Study appraisal: This is a very large study with 61 participants. It outlines information needs of caregivers.</p>
24. Moss et al. 2021	<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. <p>Study appraisal: A small study with 10 participants. It outlines caregiver information needs, including information about terminology.</p>
25. Ohlén et al. 2013	<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. <p>Study appraisal: A good study with 14 participants with a focus on patient information preferences of knowledge searching and understanding.</p>
26. Ólafsdóttir et al. 2018	<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. <p>Study appraisal: A small study with 7 participants. It outlines patient experiences of an ACP discussion and booklet. Declaration of interests are not mentioned.</p>

27. Pedrosa et al. 2021	<p>Patients' and caregivers' interviews highlighted that psycho-oncological access to ACP strengthens readiness for ACP discussions by contributing to a comprehensive preparation of patients and relatives for EoL decisions. 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.</p> <p>Study appraisal: This is a good study with 25 participants. It is a useful evaluation of a complex ACP intervention approach.</p>
28. Pini et al. 2021	<p>There is a need to address misconceptions about PC, treatment and prognosis, and better prepare patients and HCPs to have accurate and meaningful conversations about PC. HCPs need to establish and communicate the relevance of PC 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.</p> <p>Study appraisal: This is a good study with 24 participants. This includes useful information on potential facilitators of PC discussions (e.g. established rapport with HCP, timing, preparedness).</p>
29. Polacek et al. 2023	<p>Patients with advanced cancer described how they understood 'prognosis' and how to improve understanding of the construct and enhance patient-physician communication. Knowledge helped patients cope with the disease and facilitated decision-making regarding future planning (e.g. ACP). The importance of explicitly asking patients about their preferences for communication about the disease status. Accurate prognostic understanding may help patients feel better prepared to navigate life-decisions.</p> <p>Study appraisal: This is quite a large study with 29 participants. It explores how patients understand 'prognosis'.</p>
30. Røen et al. 2018	<p>Caregivers described information and communication improvements to enhance their experience of supporting loved ones, including: 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.</p> <p>Study appraisal: A helpful study with 14 caregivers. It provides useful insights into carer information and communication needs in the context of supporting carer resilience.</p>
31. Rohde et al. 2019	<p>Patient interviews identified barriers to information and communication provision: 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.</p> <p>Study appraisal: A good interview study with 20 patients with incurable cancer that provides helpful insights into what made information-giving adequate or inadequate and how patients differ in their communication preferences.</p>
32. Scherrens et al. 2020	<p>Patients described positive and negative stances towards starting a conversation about PC with a professional carer: Interventions should focus on providing positive and correct information about PC to close the awareness and knowledge gap 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.</p> <p>Study appraisal: A well conducted study with sample size 25, people with 11 different types of incurable cancer.</p>
33. Sherman et al. 2018	<p>Patients described areas they regarded as essential for readiness to manage EoL: 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. 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> <p>Study appraisal: A well conducted study with 13 patients. It outlines information needs in the context of preparedness for EoL care. Funding, sponsorship, or declaration of interests are not mentioned.</p>
34. Stilos et al. 2018	<p>Main themes characterized the family caregiver experience when caring for a relative with advanced incurable cancer: 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.</p> <p>Study appraisal: This is a small study with 13 participants could be clearer on some methodological aspects but does include useful information on communication needs.</p>
35. van Oosterhout et al. 2021	<p>Patients described an appreciation for discussing death, the dying process and prognosis with the HCP but some are not ready for that discussion. 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.</p> <p>Study appraisal: A well conducted study with 16 bereaved caregivers that includes helpful information on communication preferences.</p>

36.Villalobos et al. 2018	<p>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.</p> <p>To improve patient experiences a longitudinal communication approach a focus on specific milestones was acceptable.</p> <p>Study appraisal: A good study with 18 participants. It provides details on utilised methods but are not described well. Some useful information on communication preferences and needs. However, the paper is more focussed on reporting on the focus groups with professionals than on reporting patient/carer perspectives.</p>
37.Walczak et al. 2015	<p>Many patients and caregivers did not want life expectancy estimates, citing unreliable estimates, unknown treatment outcomes, or coping by not looking ahead.</p> <p>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.</p> <p>Timing emerged as a reason not to discuss EOL issues; some patients maintain it was too early.</p> <p>Study appraisal: A large study with 42 participants. A well conducted observational study with helpful insights into information preferences (wanted vs. unwanted information), timing and need for personalised approaches.</p>
38.Walker et al. 2023	<p>Patient interviews highlighted the importance of good communication fostered by the nurse relationship. This included:</p> <p>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 were comfortable discussing various topics which supported understanding due to the personalised relationship.</p> <p>Important information was conveyed in timely fashion with clear explanations.</p> <p>Study appraisal: A small interview study with 9 patients that includes information on helpful communication-related aspects of patient-nurse relationships at the end of life (conduct of communication).</p>

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Additional materials available upon request:

- Critical appraisal / data extraction forms
- Search strategies
- List of excluded studies

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Excluded Studies: For full list of studies excluded at full text reading stage please contact PaCERSWCRC@cardiff.ac.uk

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