

Clinical and Policy implications:

This review identifies those aspects of specialist palliative care perceived to be of value by those who have already experienced care from a specialist service and also the perceptions of generalist clinicians who had experience of working alongside such teams. The areas of value were defined by their presence in care, and also occasionally by their perceived absence. The domains described have important implications for a revised definition of specialist palliative care and, by extension, a consolidated specification for what specialist services should be expected to deliver. The thematic areas identified are only from the perspectives described above, and should be combined with the perspectives of specialists, policymakers and expert opinion. For example, areas of perceived value such as education, training and research are not included here as they are beyond the experiences of study participants. However, it is reassuring that the themes described here map across onto the 10 core competencies defined by the European Association of Palliative Care and the Wales core outcome set for measuring the quality of palliative care service interventions.

Glossary:

(CES) Community Engagement Studio

(COPD) Chronic Obstructive Pulmonary Disease

(HCPs) Health Care Professionals

(IPA) interpretative phenomenological analysis

(IPC) Inpatient Palliative Care

(PD) Parkinson's Disease

(SPC) Specialist Palliative Care

(SPCS) Specialist Palliative Care Service

Context

There are over 650,000 deaths each year in the UK, and it is estimated that 70-80% of people in the last year of life will require palliative care support (Murtagh et al. 2014). Receipt of timely, coordinated and integrated palliative care is recognized by the World Health Organisation (WHO) as a basic human right (WHO 2020). The WHO defines core components of that care and there is wide acceptance that integrated care delivery is achieved through a combination of generalist and specialist approaches (World Health Assembly 2014).

In response to this, the number of specialist services has continued to grow globally, with greatest increases in Western societies (Arias-Casais et al. 2020). Given that death and dying are universal population-level events, creating specifications for specialist services to guide future models of palliative and end of life care delivery within complex health and social systems is essential.

However, a clear definition of what constitutes specialist service intervention is lacking. The WHO identifies complex case management – including symptom control – as well as education and research to promote consistent, evidenced based care as amongst the remits of specialist services (World Health Assembly 2014). Complex case management, improving workforce competencies and research are also core components considered relevant by palliative care experts (Higginson 2021).

The perception of those in receipt of, or working alongside, specialist palliative care services (SPCS) is of clear importance in informing any such definition. This review therefore aims to synthesize evidence on the perceptions of those who have experienced specialist palliative care service support, and generalist clinicians who work alongside specialist teams, on what constitutes specialist palliative care. The review has been undertaken on behalf of the Board for Palliative and End of Life Care. Results will inform an updated definition of specialist palliative care to underpin future service specification for specialist palliative care delivery in Wales.

Research Question

Is there evidence of what patients' and carers' perspectives are of a specialist palliative care service and what it should provide?

Is there evidence of what generalist (i.e. non-specialist palliative care) healthcare professional perspectives are of a specialist palliative care service and what it should provide?

Key Findings

This review focused on the perceptions of what constitutes specialist palliative care provision specifically by those who had already experienced receipt of care by a specialist service and by generalist clinicians who had experience of working alongside specialist services.

14 studies were included as detailed in the PRISMA flow diagram shown in Figure 1. The studies originated from 7 countries (Australia, Canada, France, Italy, Sweden, UK and USA) and from a range of conditions experienced by those in receipt of care (including Chronic obstructive pulmonary disease, Colorectal cancer, Parkinson's disease etc.).

Six core themes emerged from the data, which describe key domains of specialist palliative care provision and inform a definition of specialist palliative care (SPC).

A summary of the main themes and sub-themes is listed in Table 1. The themes of 'Control of Symptoms', 'Communication and Information Provision', 'Care Coordination' and 'Quality of Life Improvement' fit with the integrated care approach incorporated within the broader WHO definition but are of interest in being perceived as being most comprehensively met by specialist services. We have described two additional cross-cutting themes of 'Empowerment and Facilitation of Coping' and 'Compassionate Care', as these distinct descriptions appeared to encapsulate the sub-thematic content, whilst also recognizing that they incorporate concepts partially covered in one or several of the other thematic areas. The subthemes underpinning empowerment by SPCS included facilitation of day-to-day independence, empowering both patients and caregivers with information to support preparedness for the future, and creating partnerships with them as key stakeholders in all activities. These concepts resonate strongly with the adaptive coping responses identified in other literature associated with positive responses to critical illness (Boezeman et al. 2022). The concepts identified under the theme of 'Compassionate Care' included tenor of care, the promotion of self-esteem, and valuing the knowledge and expertise of the individual in shared decision making, with participants recognizing the skill and capability of the specialist practitioner in achieving these. These again resonate with other literature seeking to define the concept of compassionate care, including recognition of caregiver needs and roles and the importance of the capable practitioner (Burnell et al. 2013).

The key concepts identified in this review which contribute to a definition of SPC are reassuring in several respects. The themes and sub-themes recur across the disparate studies as outlined in Table 2 (characteristics of the included studies) and often across the particular perspectives of patients, caregivers and generalist clinicians. The concepts also map across onto the 10 core competencies defined by the European Association of Palliative Care (Gamondi et al. 2013) and also broadly map across to the key outcome domains to be measured as part of the core outcome set for palliative care service interventions in Wales (Goss et al. 2022). Planned educational and evaluation approaches in Wales would therefore appear to align with the professional and service user concepts described here, in support of their contribution to an updated definition.

Reliability of evidence:

The evidence was drawn from studies using a range of methodological approaches. They were mainly qualitative in nature – with diverse participant groups. Most of the studies included used semi-structured interviews (Ahmed et al. 2023, Badger et al. 2018, Bellhouse et al. 2020, Ciemins et al, 2015, Constantini et al, 2017, Economos et al. 2023, Hay et al. 2017, Hayle et al. 2013, Russo et al. 2022, Walshe et al. 2023). Additionally, there was an exploratory qualitative interview study (Enguidanos et al. 2014), and interviews which used open-ended questions (Klarare et al. 2018). Other studies included a survey with scaled questions and open text questions (Bainbridge et al. 2017), a focus group and consultative session (Shinall et al. 2022), an exploratory, qualitative study (Enguidanos et al. 2014) and interviews which used open-ended questions (Klarare et al. 2018). Each study considered for inclusion was consistently assessed for relevance and quality using the appropriate Critical Appraisal Skills Programme (CASP) appraisal tool. The studies were excluded if they did not meet inclusion criteria, or methodologically unreliable. A summary of quality is included in the individual study summaries (Table 2).

Consistency of evidence:

Evidence was drawn from studies conducted across a range of geographical settings and a mix of HCP and service user participants. There was also a range of methodological approaches as described above. However, data extracted from each study was checked by a second author and the development of themes and sub-themes was undertaken by the whole authorship group with iterative refinement based on whole group discussions to ensure consistency of interpretation and reporting.

Many themes and sub-thematic areas were repeatedly identified across multiple studies and participant groups which reassures as to the consistency of the perspectives and are mapped onto competencies agreed but consensus across the interdisciplinary research group previously developed by professional groups and expert opinion.

Relevance of evidence:

We specifically sought evidence based on the experience of service users and HCPs working alongside specialist palliative care services, excluding theoretical perspectives or opinion – so that the evidence is directly relevant to the questions posed. The studies were undertaken across a number of countries. Most of these studies were from a non-UK setting (Australia, Canada, France, Italy, Sweden, USA). The majority of these countries have health economies which are comparable to the UK. Even though the four studies based in the USA (Ciemins et al, 2015, Enguidanos et al. 2014, Hay et al. 2017, Shinall et al. 2022) are from a health economy which differs from the UK, similar themes emerged as to the perceptions of patients, caregivers and generalist healthcare professionals on the role and value of specialist palliative care services.

Review Methods

Search Strategy: A systematic search was conducted across a wide-ranging set of databases: Ovid Medline All, Ovid Embase, Ovid Emcare, Scopus via Elsevier and Clarivate Web of Science databases.

The preliminary search strategy was developed on Ovid Medline using both text words and Medical subject headings from January 2013 to January 2024 restricted to English language and humans. The search strategy was modified to capture indexing systems of the other databases. (Search strategies available upon request). To identify additional papers, we searched Google Scholar.

In addition, reference lists of systematic reviews were checked for any relevant studies. The searches generated 1012 citations after removing duplicates and irrelevant records. Figure 1 represents the flow of information through the different phases of the review.

Eligibility Criteria

Inclusion:

- Definition of specialist palliative care
- Offer of specialist palliative care to a patient/family
- HCP and patients/carers perceptions of what SPC is and what the components of care on offer might include.
- Adult palliative care

Exclusion:

- Perceptions of barriers/facilitators to access rather than interrogation of the components of care
- Paediatric palliative care
- Time limited (e.g. Covid pandemic) or geographically limited accounts which are not generalizable (e.g. paper on South Dakota or culturally specific aspect of Pacific Coast population in New Zealand).

Study selection: Study selection was based upon review of the abstract by two independent reviewers. The full text was then assessed independently using a pre-designed eligibility form according to inclusion criteria. Any discrepancies between reviewers were resolved by consensus by the team or by a third reviewer.

Data extraction/Critical appraisal: Data extraction was carried out within a pre-agreed form, initially piloted with one article. Critical appraisal of studies was carried out using the relevant study design tool. Any discrepancies between the two reviewers were resolved by consensus by the team or by a third reviewer.

Flow Diagram:

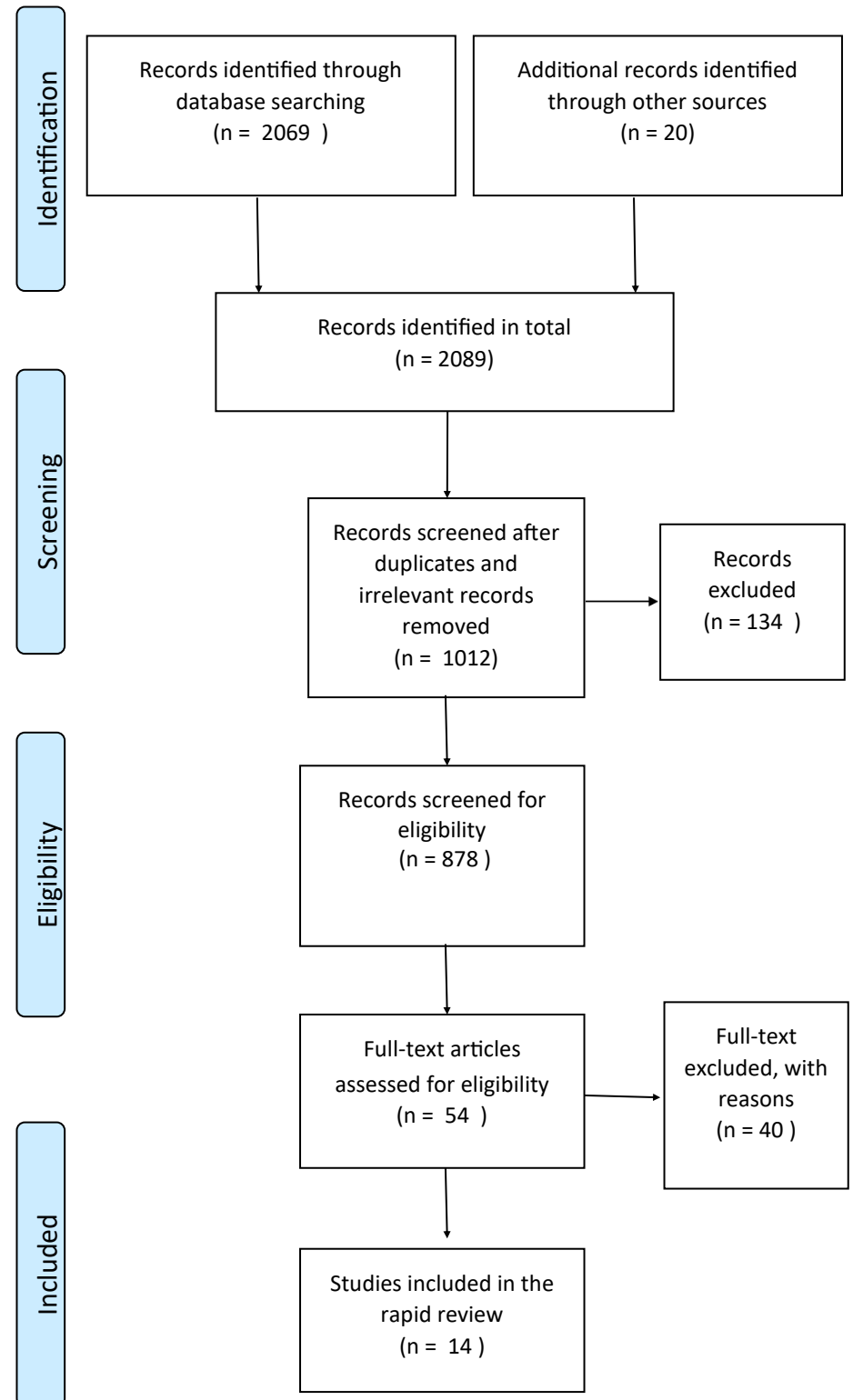


Table 1: Main themes and sub-themes/key domains summary

Main themes	Sub themes/key domains
Care coordination	<ul style="list-style-type: none"> Responsive, reliable, proactive, patient centred care. Working alongside specialists, providing continuity, consistency and improved access.
Empowerment and facilitation of coping	<ul style="list-style-type: none"> Creating partnerships with patients and families to provide support for independence and self-management. Enable shared decision making. Enhancing coping strategies.
Compassionate care	<ul style="list-style-type: none"> Treating the patient holistically. Valuing and supporting patients to enable a safe environment to explore patient understanding, expectations and discuss Advance Care Planning (ACP).
Communication / information provision	<ul style="list-style-type: none"> Enhanced communication with patients leading to improved decision making
Improved quality of life	<ul style="list-style-type: none"> Providing psychological and emotional wellbeing support Providing proactive care.
Control of symptoms	<ul style="list-style-type: none"> Providing expert symptom control and management

Table 2: Characteristics of included studies [in alphabetical order]

Negative comments in **Red**

Author, Year, Country	Ahmed S et al 2023, Canada
Study Objective	To understand the experiences of advanced colorectal cancer patients and caregivers after receiving early specialist palliative care support. The study secondarily compared these experiences with those of a separate cohort of patients who had been interviewed prior to the instigation of early specialist palliative care support.
Participants	12 participants: seven patients and five carers with two patient-carer dyads, but all participants were interviewed separately. All patients had advanced colorectal cancer and a caregiver was defined as an adult described by the patient as their primary unpaid caregiver. Patients had to have received at least one face to face visit from the specialist palliative care nurse.
Study Methods	Semi structured telephone interviews with individual patients or dyad of patient and caregiver (each interviewed separately). An interview guide was developed in collaboration with specialist palliative care clinician researchers and patient and family research partners.
Summary of Results	Four themes emerged in relation to the perception of what the specialist palliative care nurse intervention provided: <ol style="list-style-type: none"> Care coordination. This highlighted the importance of specialist palliative care in coordinating a more integrated approach to care particularly by engaging specialist oncology and primary care physicians. This improved communication and information giving. Perception of palliative care, and Advance Care Planning. This incorporated the timing of palliative care, the understanding of the role of palliative care and facilitation of advance care planning. The early introduction of specialist palliative care was also perceived as important in aiding coordination and communication as well as symptom control and quality of life. Coping with advanced cancer. Specialist palliative care was perceived as important in supporting day to day independence by involving other specialties for task-specific interventions (e.g. pharmacy and dietetics) and empowering caregivers with information and advice. Patient and family engagement in care. This describes the impact of specialist palliative care in advocating for the patient, encouraging communication within families and supporting decision-making.
Appraisal Summary	Context of the research was well described and the aims of the study were explicitly defined. The aim was to understand experience of specialist palliative care receipt, justifying a qualitative interview approach. A person centred qualitative approach was defended in the text on the basis of the context and aims of the study. Purposive sampling was used; no data was given on the number of participants approached vs the number consented and interviewed, or reasons for declining.

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Table 2: Characteristics of included studies (Continued)

Author, Year, Country	Badger, N.J., et al., 2018. UK
Study Objective	To provide an understanding the experiences of patients with Parkinson's Disease (PD) and their caregivers, and the impact of specialist palliative care on their ability to cope.
Participants	Participants were recruited from an integrated SPC movement disorder service. Eight participants – five carers and three patients. Six women and two men. Age range 61-79 years. Patients had idiopathic PD, received at least two face to face Specialist Palliative Care (SPC) contacts and had mental capacity for consent.
Study Methods	The study used qualitative semi structured interviews. These were analysed using interpretative phenomenological analysis (IPA).
Summary of Results	<p>Three themes were developed reflecting how SPC affected participants' coping with Parkinson's Disease:</p> <ol style="list-style-type: none"> I. Managing uncertainty – SPC seemed to help participants manage uncertainty. Respite and day hospice services or just knowing the service was there meant carers could reduce their vigilance for danger. SPC was able to address issues that other services had not such as end of life discussions and provision of practical adaptations. II. Impacts on the self – SPC appeared to enable participants to engage in coping efforts themselves. Carers had some respite from their carer role. Practical adaptations to help self-care activities helped them feel good about themselves. SPC service gave the message that patients and carers are worthy of attention and care. III. Supported maintaining a positive outlook – SPC support the maintenance of emotional balance. Participants had a strong positive evaluation of SPC, sometimes in contrast to expectations. SPC provided something to look forward to while recognising that it was not able to fix all concerns.
Appraisal Summary	<p>The aims of the study were explicitly defined, which sought to understand experiences of patients and carers, therefore the qualitative interview approach was appropriate. Reflexivity is addressed regarding the researchers' role, who were independent of the clinical service, however prior expectations of psychosocial benefits may have influenced questioning and data analysis.</p> <p>The themes identified were similar to ones previously found in other illness groups and therefore the findings are thought to be relatable to patients with other conditions, and users of SPC services. There is clear explanation of the analysis used and the five stages used to develop the final themes. There are clear findings outlined within the themes and subthemes which relate back to the research question.</p>

Table 2: Characteristics of included studies (Continued)

Author, Year, Country	Bainbridge, D., D. 2017. Ontario, Canada
Study Objective	To understand the patient and bereaved caregiver experience of those who received palliative home care at end of life. To identify strengths and weaknesses in the quality of end-of-life care services and to assess the usefulness of qualitative survey data for quality improvement.
Participants	330 caregivers of patients who had received palliative home care services in Ontario, Canada, 271 of which completed one of the open text questions. Participants were most often patient's spouses (57%) followed by adult children (31%).
Study Methods	A retrospective observational survey study with scaled questions and open text questions. A modified version of the UK's Voices Survey was used. Respondents were asked what was good and what was bad about the services provided in the last three months of life in separate open-text questions. A qualitative constant comparison approach was used to derive themes from the responses.
Summary of Results	<p>Two themes emerged:</p> <ol style="list-style-type: none"> I. What Was Good About the Care Experience. There were 522 individual statements about something good about the care received in the last three months of life, which were grouped into 17 main themes. II. What Was Bad About the Care Experience. There were 294 individual statements about something bad about the care received in the last three months of life, which were grouped into 19 themes. <p>Caregivers valued being taught by home care providers what to expect as the patient declined and how best to handle symptoms and situations that might arise.</p> <p>Home care providers doing palliative care require standard training and education because some were perceived as lacking expertise, initiative, or compassion.</p> <p>Although caregivers wanted providers with palliative care experience, they did not want specialized providers to replace the long-standing team in the final day or two of life.</p> <p>Caregivers wanted there to be clearer and better communication with and between home care agencies to avoid complications in transitions between settings of care, but also so that there was awareness of the patients' concerns without them having to continually repeat themselves to providers.</p>
Appraisal Summary	The aims were described clearly. The research design was appropriate, and the population was well explained including how participants were recruited from the sites. Participants used home care services rather than hospital or hospice palliative care services, so results are limited to this setting. The paper explains the analysis process, including initial steps, maintaining an audit trail, and using a grounded theory approach. Direct quotations are used within the text to underpin each section. The study was conducted in Ontario, Canada, but has applicability to other health systems including in the UK.

Table 2: Characteristics of included studies (Continued)

Author, Year, Country	Bellhouse, S., et al., 2020. UK
Study Objective	To explore the care needs and perceptions of specialist palliative care from the perspectives of patients with advanced cancer, to inform integration of SPC services into phase 1 cancer treatment.
Participants	10 participants with advanced cancer referred to the Experimental Cancer Medicine team were interviewed. Set in a UK specialist cancer centre.
Study Methods	A cross-sectional qualitative design using semi-structured interviews to explore the perceptions of SPC. Thematically analysed using a framework approach.
Summary of Results	<p>Three themes emerged:</p> <ol style="list-style-type: none"> I. The paradox of cancer burden and the perceived need for palliative care intervention. Despite reporting considerable physical and psychological impacts from cancer and cancer treatment, participants did not recognise a need for specialist palliative care support, due to misinterpretation of the term. II. Perception of palliative care limited to care provided at end of life. When asked to describe the role of palliative care, most participants discussed pain management and making people comfortable at the end of life. III. Introduction of palliative care. For some participants, there was perceived conflict between considering a phase I trial and receiving specialist palliative care; a phase I trial offers hope for the future which is at odds with receiving care associated with end of life.
Appraisal Summary	This is a single-centre study in a specialist cancer centre setting with a small sample, despite this data saturation was felt to have been reached. The study reports that findings might not be generalisable to other settings. The aims were clearly described to understand experiences of patients and carers, therefore qualitative interview approach appropriate. There was a clear description of the themes and subthemes with tables to support this.

Author, Year, Country	Ciemins, E.L., et al., 2015, USA.
Study Objective	To explore patient and family perceptions of palliative care services at the end of life or during serious illness and to identify facilitators and barriers to receipt of palliative care services.
Participants	Twelve interviews took place with 14 participants who received palliative care services, interviewed either alone or with their families. Three patients and eleven family members participated, two in patient/family pairs. One interviewee was an outpatient, and the remaining were hospitalised patients or their families.
Study Methods	In-depth, semi-structured, face-to-face interviews to understand patient and family experiences of palliative care. It was set in an integrated multispecialty health system serving three large rural western states.
Summary of Results	<p>Presence, Reassurance, and Honouring Choices emerged as central themes linked to a satisfactory palliative care experience, and all must be present to some degree for a positive patient/family experience.</p> <p>HCP competencies contribute to the positive palliative care experience both directly and indirectly through the three primary attributes reported by patients and families.</p> <p>Presence included both physical (i.e., showing up) and emotional/behavioral (i.e., how one shows up) components.</p>
Appraisal Summary	This study was limited by a small sample size. Semi structured interviews were appropriate for gathering patient and family members experiences. The process of data analysis was described thoroughly, including that five qualitative investigators independently reviewed the data. Relevant quotes were included to underpin the themes described. There is no description of how the participants were recruited, reflexivity or ethical issues.

Table 2: Characteristics of included studies (Continued)

Author, Year, Country	Costantini, M., et al. 2018. Italy
Study Objective	To assess the feasibility of early integration of palliative care, and explore concerns perceived and problems encountered by patients, relatives and oncologists.
Participants	18 participants consisting of patients (n=6), relatives (n=6) and oncologists (n=6) were interviewed.
Study Methods	An approach, using semi-structured interviews.
Summary of Results	<p>Three themes and 14 subthemes were identified.</p> <p>I. Perceived benefits/strengths</p> <ul style="list-style-type: none"> Improved symptoms control Reassurance by a physician dedicated to symptom control Honest information Time for the patient Psychological support Practical support Improved communication skills <p>II. Perceived concerns/weaknesses</p> <ul style="list-style-type: none"> Less useful in absence of symptoms Too much early palliative care (oncologists) Too much information about illness (oncologists) Problems in communication with relatives Difficult communication between professionals (oncologists) <p>III. Suggestions for improvement</p> <ul style="list-style-type: none"> Making the intervention available to other patients Introducing the intervention permanently
Appraisal Summary	Framework method (analysis) is particularly suitable for helping inter-professional and interdisciplinary research team analyse and manage qualitative data. There are clear themes and subthemes illustrated by quotations from participants.

Table 2: Characteristics of included studies (Continued)

Author, Year, Country	Economos et al. 2020, France
Study Objective	To explore what palliative care represents from the perspective of physicians working in cancer care, and to better understand factors influencing the referral of patients.
Participants	Eighteen participants, n=7 female and n=11 male. Physicians involved in providing cancer care: medical oncologists (n=5), lung specialist (n=5) and other specialties (n=8) licensed to provide cancer treatments.
Study Methods	Face to face semi structured interviews that were audio recorded, anonymised, transcribed verbatim and then analysed using thematic analysis.
Summary of Results	<p>Three themes were identified from exploring perceptions of physicians working in a cancer care. Within one theme negativity was indicated.</p> <ol style="list-style-type: none"> I. Continuity of care as an important feature. However, association between palliative care and death/terminal care. II. Psychosocial support provided by a multidisciplinary approach was recognised as a valuable. III. Symptom management was used as a trigger for palliative care referral.
Appraisal Summary	Context of the research was well described, to explore perceptions of palliative care and factors influencing reasons to refer to SPC amongst cancer care physicians. There is a clear description of themes and subthemes with quotes from participants included. Follows consolidated criteria for reporting qualitative research guidelines. The process of reviewing and refining themes and patterns is well described. Mainly young physicians agreed to take part, and it's possible they already more aware of integrated palliative care alongside cancer care. As the French health system differs from other countries, transferability into another setting may be a challenge.
Author, Year, Country	Enguidanos et al. 2013, USA
Study Objective	To determine how inpatient palliative care (IPC) consultations impacted family members' understanding of the patient's condition, knowledge of available care options, and decision-making ability.
Participants	23 family members participated. Ages ranged from 20 to 73 years. Male (n=8), female (n=15).
Study Methods	An exploratory, qualitative study interviews among family members of seriously ill patients, recruited purposively. Interviews were conducted in person, at the hospital, or via telephone, using a semi structured.
Summary of Results	<p>Five themes emerged with some reflecting negative aspects.</p> <ol style="list-style-type: none"> I. Specific qualities of the IPC identified included communications style, including tone used in conversation and improved access to physicians and other medical team members. II. Family members readiness to receive information. Family felt supported as the quality of conversation provided a comfortable environment and supported patients and family seeking information. However, one described as being "shocked" when the meeting focussed on hospice and end-of-life options. III. Change of focus for clinical care, moving from a focus on aggressive care to one on quality of life. IV. Improving pain and symptom management V. The comprehensive information given by the IPC team about the illness etc. was new to family members. The consultant educated them on services and care options. Some reported feeling overwhelmed by the information and receiving conflicting information. Receiving information earlier empowered them in the decision-making process and enabled them to make different care decisions.
Appraisal Summary	Context of the research was well described, and the aims of the study were explicitly defined. The aim was to determine how inpatient palliative care consultations impacted family members' understanding of the patient's condition, knowledge of available care options, and decision-making ability. There is a clear statement of findings. However, the findings may have limited generalizability to other populations/settings because the study was conducted with a small sample in a single hospital, and employed purposive recruitment, which may have biased perceptions of the IPC team.

Table 2: Characteristics of included studies (Continued)

Author, Year, Country	Hay et al. 2017, USA
Study Objective	To understand how gynaecologic oncologists' views influence outpatient specialty palliative care referral to help inform strategies for improvement.
Participants	Participants (n=34) gynecologic oncologists
Study Methods	Semi-structured telephone interviews focused on attitudes, experiences, and preferences related to outpatient SPC.
Summary of Results	<p>Three themes emerged in relation gynecologic oncologists views on outpatient specialty palliative care.</p> <ol style="list-style-type: none"> I. Influencing use of outpatient SPCS. This required them to obtain the best possible care for the patients, thus increasing palliative care referrals. Gynecologic oncologists prefer SPC embedded within gynecologic oncology clinics and continued involvement throughout the disease course. II. Valued managing symptoms with other professionals. III. Communication skills and third-party perspective to increase prognostic awareness and help negotiate differences between patient preferences and physician recommendation.
Appraisal Summary	Context of the research was well described, and the aims of the study were explicitly defined. The aim to understand how gynecologic oncologists' views influence outpatient SPC referral to help inform strategies for improvement. There is a clear statement of the findings. Study strengths include a diverse, multi-institutional sample and high response rate. However, results may not generalizable to countries with varying healthcare system structures.

Author, Year, Country	Hayle et al. 2013, England UK.
Study Objective	To evaluate the experiences of patients with chronic obstructive pulmonary disease who accessed specialist palliative care.
Participants	8 patients accessing SPC within one city in North West England. Male (n=5), female (n=3). The mean age was 68.6 years (range 63–77 years). At the time of analysis, four patients had died (all within 1 year of interview).
Study Methods	Semi-structured interviews were analysed using a hermeneutic phenomenological approach.
Summary of Results	<p>Four themes emerged in relation to experiences of patients with chronic obstructive pulmonary disease who accessed specialist palliative care. Under one theme a negative comment was reported.</p> <ol style="list-style-type: none"> I. Improved perception of self-worth increased confidence. II. Compassionate caring attitude of staff and the staff going 'above and beyond' the call of duty to provide individually tailored care. III. Participants recognized and appreciated the holistic approach of the IPC team extending beyond traditional medical approach. Enhanced their psychological well-being and improved physical and psychological symptoms. However, some participants recalled feeling distressed about the prospect of referral as they perceived an association between palliative care and death. IV. Reducing physical restriction caused by the symptoms of COPD.
Appraisal Summary	Context of the research was well described, and the aims of the study were explicitly defined. Data was collected via semi-structured interviews, which were audio-recorded. However, it was not clear how interviews were conducted. Author report that due to the small numbers within each category of the service, it was difficult to draw conclusions and implies that saturation of data was not met. The main findings are explicit. There is a discussion of these findings compared to prior findings and are relevant to the original question.

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Table 2: Characteristics of included studies (Continued)

Author, Year, Country	Klarare, A., et al., 2018, Sweden
Study Objective	To describe patients' and family caregivers' experiences of specialist palliative home care team actions that are identified by the participants as helping or hindering interventions.
Participants	13 participants (n=6) patients and (n=7) family caregivers were interviewed using the enhanced critical incident technique.
Study Methods	Qualitative interviews. The interviews were completed and audio recorded
Summary of Results	<p>Five themes were identified describing patients' and family caregivers' experiences of specialist palliative home care team actions. Both positive and negative comments reported throughout the themes.</p> <ol style="list-style-type: none"> I. Care Coordination ability to identify and respond to individual patient needs. Responsiveness (timely) when SPC integrated, however issues of not responding to individuals needs or preferences in a timely manner. Patient centred provision and organised care, increased access to support for bespoke equipment. Poor inter-disciplinary relationships resulted in delays in referrals to PC. II. Empowered them, this included looking after and supporting families, carers and their needs as well as the patients III. Treating the patient holistically and having an overview of what was going on with the patient. With some responses it was reported, failed to provide privacy, respect for patient or responding to needs. IV. Anticipatory care (proactive care) improved QoL. HCPs going out of their way to provide care or an intervention, even when the participants had not expressly requested it. V. Though information was provided, HCPs did not provide enough information.
Appraisal Summary	Context of the research was well described, and the aims of the study were explicitly defined. The method used was qualitative research, enhanced critical incident technique (ECIT) was appropriate to address the aims of the study. Though some negative comments were expressed, as the participants who were interviewed in this study had been admitted to a team and were therefore in a position of being dependent on care. Experiences of non-cancer patients and family caregivers were not included. Study population would have been diverse including patients with non-cancer and family caregivers.

Table 2: Characteristics of included studies (Continued)

Author, Year, Country	Russo et al., 2022, Australia
Study Objective	To explore respiratory clinicians' perspectives regarding specialist palliative care and palliative treatments for people with progressive Interstitial lung disease (ILD) to identify possible barriers and facilitators for clinical practice improvement initiatives.
Participants	17 participant (n=13) respiratory physicians, (n=2) respiratory nurses and (n=2) physiotherapists.
Study Methods	Semi-structured interviews and Thematic analysis.
Summary of Results	<p>Four themes emerged, identifying respiratory clinicians' perspectives regarding SPC and palliative treatments for people with progressive ILDs.</p> <ol style="list-style-type: none"> I. It was reported that SPC was best delivered in conjunction with active disease-directed care, ideally as part of the multi-disciplinary ILD team. Respiratory physicians on their own not able to do everything but working in partnership functioned well. II. Enable independence and affirming patients' decisions and wishes, particularly as they transitioned to end-stage disease. III. SPC teams address patients' psychological and emotional wellbeing and improved QoL. IV. Participants valued the expertise of SPC teams to monitor and titrate opioids for patients with severe breathlessness in the community and support patients at home throughout the illness journey. This gave peace of mind for caregivers.
Appraisal Summary	<p>Context of the research was well described, and the study aimed to explore clinicians' perspectives regarding specialist palliative care and opioids to understand barriers to optimal care and guide clinical practice improvement initiatives. Four themes were identified and there is a clear description of themes and subthemes with accompanying quotes from participants.</p> <p>This study is the first type of study to demonstrate HCPs attitudes towards specialist palliative care and opioids for people with ILD. However, these views may not be same as of HCPs in the UK.</p>

Author, Year, Country	Shinall et al. 2022, Canada and USA
Study Objective	To describe the potential benefits of and barriers to specialist palliative care integration in the liver transplantation process.
Participants	24 participants, palliative care specialists (n=14) and hepatologists (n=10) from 11 institutions across the US and Canada community Engagement Studio (CES), consisted of six stakeholders (patients with liver transplant (n=4) and caregivers (n=2)). 4 were female and 2 were male.
Study Methods	Focus group and consultative session.
Summary of Results	<p>Four themes were identified as potential benefits of and barriers to specialist palliative care integration in the liver transplantation process. One comment with negative reflection.</p> <ol style="list-style-type: none"> I. PC physicians were very good at identifying particular individual needs and gave time for the patient. II. Providing clarification on advance care planning choices. III. The expertise of palliative care clinicians can inform hepatologists about how their patients are doing and understand emotional adjustment and quality of life. IV. Manage symptoms with other professionals. However, it was noted that hepatologists were unable to manage symptoms well as they didn't have any management options even for symptoms such as sleep disturbances or muscle cramps.
Appraisal Summary	<p>Context of the research was well described, and the aims of the study were explicitly defined for both HCPs and patients and carers. There is a clear description of themes and subthemes with sufficient accompanying quotes from participants and hepatologists but no clear evidence from CES.</p>

Table 2: Characteristics of included studies (Continued)

Author, Year, Country	Walshe et al. 2023, England, UK
Study Objective	To evaluate the effectiveness and effect of enhancements to 7-day specialist palliative care services, and to explore a range of perspectives on these enhanced services.
Participants	<p>Patient participants (n = 19), aged 18 and over who were referred to specialist palliative care services at one of the two localities.</p> <p>Family carer participants (n = 23), aged 18 and over Carers, who may or may not be family members, were defined as lay, unpaid people in a close supportive role who share in the illness experience of the patient.</p> <p>Staff participants (n = 33). Those involved in the provision of specialist palliative care within the two localities, including senior nurse practitioners, advanced nurse practitioners, palliative medicine consultants, consultant nurse practitioners.</p>
Study Methods	An exploratory longitudinal mixed-methods design, with a post-intervention semi-structured interviews to integrate service use data with the perspectives of care users and providers. The qualitative data were analysed thematically.
Summary of Results	<p>Three themes emerged in relation to the effectiveness and effect of enhanced 7-day specialist palliative care services from both patients' and carers' and HCPs perspectives:</p> <ol style="list-style-type: none"> I. The ability to identify and respond to individual patient needs in a timely manner. Achieving preferred place of care; working with other HCPs. Continuity of care from the same team was important. All participants referred to their 'key contact' within their team. They felt understood and did not have to re-tell their history etc. II. Supporting shared decision making. III. Valuing/supporting patients. The patients had 'somebody to turn to' outside their immediate family.
Appraisal Summary	The aims were clear, to evaluate the effect of enhanced 7-day specialist palliative care services on healthcare utilisation. As a mixed methods approach the inclusion of narrative accounts collected from those providing and using the services was valuable. No mention of data saturation. The participants had a single cancer diagnosis, and this study is generalisable as the local authorities in Wales would be similar to England.

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Additional materials available upon request:

- Critical appraisal/data extraction forms
- List of excluded studies
- Search strategies
- SPC main themes and sub themes

This report should be cited as follows:

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