

The relational nature of decision-making between patients with advanced illness and their caregivers in palliative care: A systematic review and narrative synthesis

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Title

The relational nature of decision-making between patients with advanced illness and their caregivers in palliative care: A systematic review and narrative synthesis

Abstract

Background: Clinical practice in palliative care points to the involvement of caregivers in the decision-making process for patient treatment and care.

Objectives: The primary objective was to explore the relational nature of decision-making between patients with advanced illness and their caregivers in palliative care. The secondary objective was to identify decision-making styles between patients and their caregivers.

Methods: Systematic review and narrative synthesis of empirical research published between January 2004 and September 2024 relevant to the topic was conducted. Databases used included EMBASE, Medline, CINAHL, PsycINFO, Web of Science, and Google Scholar.

Results: Thirty-five studies from across 20 countries were included in the review. Multiple factors intertwined with patient and caregiver decision-making processes including patient and caregiver degree of awareness of the patient's illness, quality of communication (or lack of communication) between each other, caregiving responsibilities, the reciprocation of emotional support between the patient and caregiver, and limitations in service provision. Different approaches to and/or forms of decision-making were identified. These included patients making decisions without involving caregivers, shared decision-making between the patient and caregiver, and preference-based decision-making for both patients and caregivers. Patients and caregivers could avoid disclosure between one another which in

some cases, delayed decision-making. Caregivers assumed more control in decision-making when patients became more dependent on them.

Conclusions: Mutual disclosure between patients with advanced illness in palliative care and their caregivers could be beneficial to avoid delays in decision-making. Decision-support interventions in palliative care should be designed to both protect patient autonomy and facilitate caregiver support.

Key words: Palliative care, clinical decisions, supportive care, communication, family management

Key messages for box

What is already known on this topic

- Patients with advanced illness in palliative care face complex decisions about treatments and supportive care, and caregivers are frequently involved in discussions and decision-making about this care.

What this review adds

- This review shows that patient and caregiver awareness of the illness, the quality of communication between them, the responsibility of caregiving, and reciprocation of emotional support between the patient and caregiver shape how treatment and care decisions are made.

- Patient and caregiver shared decision-making in palliative care aids alignment of their preferences but a lack of mutual disclosure between the patient with advanced illness and caregiver can delay decision-making.

How this review might affect research, practice or policy

- The findings highlight the need to foster mutual disclosure between the patient and caregiver. They also support the need to develop palliative care decision-support interventions that accommodate both patient autonomy and caregiver involvement.

INTRODUCTION

Patients with advanced illness receiving palliative care often present with complex healthcare needs and make multiple decisions about treatment and care.¹⁻³ Caregivers (also referred to in some cases, as informal caregivers or family caregivers) provide physical, psychological, emotional, social, and practical financial support to patients receiving palliative care.^{4,5} Patients and their caregivers navigate challenges associated with advanced illness in relation to one another.^{6,7} This is because caregivers not only assist in the patient's care.⁸ They also often either by choice or by circumstance, make decisions with the patient or are simply present in discussions about the patient's care.⁹⁻¹¹ Caregivers also serve as advocates for the patient and as coordinators of the patient's care.¹²⁻¹⁴

A systematic review already conducted on concordance and discordance in decision-making between patients and caregivers in palliative care⁹ showed that multiple cultural and contextual factors (for example, patient and family caregiver relations, degree of caregiver burden) influence decision-making between patients and caregivers in palliative care.

Concordance between patients and caregivers in decision-making in palliative care refers to situations where patients and caregivers have aligned preferences and/or agree with respect to decisions made about treatment and care.⁹ Discordance arises when there are differing preferences between the patient and caregiver, in some cases leading to relational conflict and stress between the patient and caregiver.¹⁵ Good clinical practice in palliative care starts from a point of assuming that patients have capacity to make decisions and can involve anyone they want in their decision-making process. Healthcare professionals in palliative care have indicated that patients with advanced illness and their caregivers can collaborate effectively in decision-making.¹⁶ Open communication between the patient and

caregiver, coupled with an understanding of each other's preferences, aids the patient and caregiver navigate decision-making in relation to patient care.¹⁷ However, patients with advanced illness and caregivers can also feel constrained by one another in decision-making when patients feel obliged to accept support from their caregiver and when caregivers feel obliged to provide care to the patient.¹⁸ A systematic review of the patient with advanced illness and their caregiver approach to decision-making in palliative care was needed to better understand key relational dynamics in decision-making between the patient and caregiver so that healthcare professionals can work as effectively as possible with both patients and caregivers. The primary aim of this review was to explore the relational nature of decision-making between patients with advanced illness and their caregivers in palliative care. The secondary aim was to identify decision-making styles between patients and their caregivers pertaining to treatment and care.

METHODS

We conducted a systematic review with a narrative synthesis¹⁹ of original (empirical) evidence published between January 2004 and September 2024 to address the stated aims of the review. To ensure that the findings of the review are contemporary, we limited our search to evidence published in the 20-year period before the end of September 2024. We followed the Preferred Reporting Items for Systematic Reviews and Meta-Analysis guidelines²⁰ to map the full search and to record exclusion at each level of extraction. The search was run on October 9th 2024, and the review including the full synthesis, was conducted between October 2024 and February 2025.

Search strategy

The following databases were used in the search: EMBASE; Medline; CINAHL; PsycINFO; Web of Science; and Google Scholar. Authors AK and DM developed the initial strategy in EMBASE, which was subsequently reviewed by authors EG and GF. Through collaborative discussions between AK, DM, EG, and GF, search terms were refined and finalised to ensure both relevance and coverage. The strategy was then adapted to suit the requirements of each database. Appendix 1 details the finalised search strategy including the search terms used for each database. Table 1 illustrates the search strategy with one of the six databases used.

Inclusion/exclusion criteria

We included original (empirical), full-text, and peer-reviewed studies published in English that reported on decision-making among patients with advanced illness and their caregivers in palliative care. We defined palliative care as active care of people with serious health-related suffering due to life-limiting illness. Advanced illness was defined as patients having reached a severe and progressive stage of their illness. The term caregiver included family members, friends, or any other form of significant others who provided informal care. Studies which included patients (≥ 18 years) and where the sample comprised entirely or in part patient-caregiver dyads were included. Studies were not excluded purely on the level of evidence because studies to fulfil the aims of the review were likely to vary in evidence level. Quantitative descriptive, mixed-method, and qualitative studies were eligible. We excluded randomised-controlled trials, non-randomised controlled trials, feasibility studies or any other type of study focused on measurement of an intervention and/or acceptability of an intervention (including decision-making interventions) rather than explaining decision-

making between patients and caregivers. We also excluded single-case studies based on the limitations of data reporting one case.

Extraction

All records found through the search were imported to Covidence²¹ for screening. The first author (AK) and the last two authors (EG and GF) independently screened records at the title and abstract level. All records for full-text screening were retrieved by AK. AK conducted the initial review of all full texts and EG and GF acted as secondary reviewers to ensure that each full text was reviewed by at least two different reviewers. Any doubt regarding the inclusion or exclusion of full texts was removed by collective discussion between AK, EG, and GF.

Quality assessment

The Mixed Method Appraisal Tool (MMAT)²² was used to assess the quality of the included studies. The MMAT allows for the assessment of the quality of studies in a review that differ in design. Study quality was appraised independently by authors AK, EG, and GF and then agreed collectively by AK, EG, and GF. We then tabulated the studies into a table under the domains of study, location/setting, participants, aims, methods, and findings.

Supplementary Table 1 provides a tabulated summary of the studies.

Synthesis

We conducted a narrative synthesis¹⁹ of the selected studies. A narrative synthesis is used to synthesise studies where the intention is not to transform data beyond the original findings of a study.¹⁹ Rather, it uses a textual approach in the process of synthesising the

findings as they have been reported across studies.¹⁹ First, we looked for evidence in each study which reported on patient and caregiver preferences and decision-making, and on relations between the patient and caregiver pertaining to decision-making. This involved focus on what factors and processes explained or underpinned the patient and caregiver approach to decision-making and on the outcomes pertaining to decision-making. We also paid particular attention to findings which reported the impact and/or influence of the caregiver on patient decision-making. We collated and summarised the evidence at this point by undertaking descriptions of the evidence. We compared findings across studies and looked for similarities and differences between studies, and then integrated the findings across the studies to help explain key relational dynamics between the patient and caregiver in decision-making. The final steps of the synthesis involved grouping the findings of the synthesis into categories that best accounted for relationships between findings and reflected the integration of the findings in the synthesis. The first author (AK) conducted the synthesis and was guided by the last author (GF) at each stage of the synthesis. The clustering of the findings into categories and the naming of categories were cross-checked and agreed upon respectively between AK, EG, and GF.

Table 1. Example of search strategy

EMBASE [1565]
'patient decision making'/exp ('patient'/exp OR 'patient attitude'/exp) AND 'decision making'/exp ((Concordance OR discordance OR patient* OR DYAD) NEAR/3 (decision* OR decide? OR preference* OR choice* OR wishes)):ti,ab,kw #1 OR #2 OR #3 'caregiver'/exp OR 'surrogate decision maker'/exp OR 'surrogate decision making'/exp (('care-giver*' OR caregiver* OR carer* OR surrogate* OR proxy OR spouse* OR spousal OR sibling* OR wife OR husband OR guardian* OR relative*) NEAR/3 (decision* OR decide? OR preference* OR choice* OR wishes)):ti,ab,kw #5 OR #6 'terminally ill patient'/exp ((advanced OR terminal* OR life-limiting) NEAR/5 (ill* OR disease* OR condition*)):ti,ab,kw ('end stage' or 'end of life' or 'last year of life' or LYOL or 'lifes end'):ti,ab,kw 'advanced cancer'/exp (Cancer NEAR/3 (terminal OR advanced OR Metastatic)):ti,ab,kw 'congestive heart failure'/exp ('cardiac congestive failure' OR 'congestive cardiac failure' OR 'congestive heart failure' OR CHF OR 'congestive heart insufficiency'):ti,ab,kw 'organ failure'/exp OR 'lung insufficiency'/exp OR 'kidney failure'/exp OR 'liver failure'/exp (('Major organ*' OR liver OR hepatic OR kidney* OR renal OR lung* OR respiratory) NEAR/3 (failure* OR insufficiency)):ti,ab,kw 'dementia'/exp (dement* OR alzheimer OR 'vascular dement*' OR 'picks disease' OR huntington OR creutzfeldt OR cjd OR binswanger OR lewy):ti,ab,kw 'Human immunodeficiency virus'/exp OR 'Human immunodeficiency virus infection'/exp ('human immunodeficiency virus' OR HIV OR 'acquired immunodeficiency syndrome' OR 'acquired immuno-deficiency syndrome' OR 'acquired immune-deficiency syndrome' OR AIDS):ti,ab,kw #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 'palliative therapy'/exp OR 'terminal care'/exp OR 'hospice'/exp (Palliation OR 'Supportive care'):ti,ab,kw,kw ((Palliative OR end-of-life) NEAR/3 (care OR treatment* OR therapy OR therapies)):ti,ab,kw,kw ((terminal* OR hospice* OR 'end-of-life' OR 'end-stage' OR 'last year of life' OR LYOL OR 'lifes end') NEAR/5 (care OR caring)):ti,ab,kw,kw #22 OR #23 OR #24 OR #25 #4 AND #7 AND #21 AND #26

FINDINGS

The full search identified a total of 4,818 records. Of these, 1 duplicate was identified manually and an additional 1,503 duplicates were identified through Covidence, leaving 3,314 records for screening. Following title and abstract screening, 2,993 records were deemed irrelevant and excluded. This left 321 records for full-text review. The full-text review resulted in the inclusion of 38 full-text papers^{17,18,23-58} from 35 studies. Figure 1 illustrates the PRISMA flow chart of the systematic review.

Twelve of the 35 studies were quantitative^{23,26,31,42-45,47, 48,54,57,58} and the remainder were qualitative.^{17,18,24,25,27-30,32-41,46,49-53,55,56} Studies were appraised to be of moderate to high quality. The majority of studies were judged to be of high quality although some risk of nonresponse bias was evident in the quantitative studies. Table 2 and Table 3 outline the quality assessment of the studies.

The included studies spanned 20 countries, including the United States,²³⁻²⁹ United Kingdom,^{25,30-34} Ireland,^{17,18,25,35,36} Australia,³⁷⁻³⁹ Netherlands,⁴⁰ Canada,⁴¹ Germany,⁴² South Korea,^{43,44} Taiwan,⁴⁵⁻⁴⁷ Singapore,⁴⁸ China,⁴⁹ Malaysia,⁵⁰ Iran,⁵¹ Denmark,⁵² Norway,⁵³ Switzerland,⁵⁴ Italy,⁵⁵ Spain,⁵⁶ Austria,⁵⁷ and Brazil.⁵⁸ Eleven of the studies recruited patient-caregiver dyads only.^{17,23,26,31,43-47,55,58} The remaining studies^{18,24,25,27-30,32-42,48-54,56,57} included a mix of patient-caregiver dyads and patients and/or caregivers recruited without their respective other. Studies were conducted in dedicated hospice and/or palliative care units^{17,18,23,26-31,33,35,36,43, 45-47,49,50,54} and from home-based palliative care.^{27-30,32,40,41,53,55,56} Studies also recruited from palliative medicine out-patient clinics^{47,48} and out-of-hours services.³⁴ Other studies were based in hospitals,^{24,25,31,37-39,44,45,52,57} including oncology-specific

services in hospitals.^{42,51,52,58} Many of the studies covered multiple care settings.^{26,31,38,40,46,47,51,53,56}

Studies investigated preferences and/or decision-making across a wide range of domains and/or topics - symptom management,^{30,41,51,56} advance care planning^{46,47,49,54} (including end-of-life discussions^{23,42,52} and place of and preferences for death^{26,33,38,45,53,58}), quality of death,^{31,43} feeding and nutritional support,^{32,48} withdrawal of treatments,^{47,57} and euthanasia.⁴⁰ Other studies focused on hospice utilisation and enrolment,^{27-29,44} palliative care integration for non-cancer conditions,^{24,39,57} out-of-hours services,³⁴ initial perceptions of palliative care,³⁷ perceptions of need for those receiving community-based palliative care,⁵⁰ patient empowerment in advanced disease,²⁵ and emotional and relational dynamics in caregiving.^{17,18,35,36}

The majority of the studies were cancer only studies.^{26,30-35,37,41-48,50-55,58} Nine studies included a mix of patients with cancer and patients with other conditions.^{17,18,23,25,28,29,36,38,40,49,56} Other studies were specific to stroke,⁵⁷ cardiac failure²⁴ and respiratory disease.³⁹ The synthesis resulted in the grouping of findings into categories as follows. Four of the five categories emerged from integration of findings from both qualitative and quantitative studies. The category *Emotional reciprocity and strain* resulted from integration of findings from qualitative studies only.

Awareness and communication

Awareness of terminal illness among patients and caregivers facilitated alignment in their preferences for treatment and care.^{43,44} Proactive communication between patients and caregivers was associated with better patient and caregiver concordance in their end-of-life

care preferences.^{17,23,31,36} Indeed, discussions about care preferences contributed to better alignment between patients and caregivers in decisions concerning the setting for patient care.^{23,31} Conversations addressing both medical and emotional concerns of patients enabled caregivers to participate more actively in decision-making.^{24,29,38,42} Caregivers who engaged actively in these conversations felt more prepared and confident in supporting patient decisions.^{39,41,53}

However, patient and caregiver emotional avoidance and other protective behaviours (e.g. hesitation to engage in advance care planning, continuation of life-sustaining interventions when their withdrawal was clinically indicated) complicated communication between patients and caregivers.^{47,49,50} Cultural norms sometimes led caregivers to withhold information from patients as caregivers attempted to create a mutual protection dynamic in which both the patient and caregiver could avoid open discussions about the patient's illness.^{46,49,50} Both patients and caregivers avoided distressing topics, giving rise to unspoken concerns and emotional strain for both parties.^{36,42,49,55} Patient and caregiver negative perceptions of palliative care hindered timely and proactive decision-making between the patient and caregiver.^{27,34,37,52}

Caregiver roles and influence

Caregivers frequently acted as advocates for patients to ensure that patient preferences were communicated to healthcare providers and considered in treatment decisions.^{17,24,40}

Caregivers also played a key role in navigating healthcare systems, particularly with respect to facilitating access to appropriate services and coordinating transitions in the patient's care.^{24,34,38} Indeed, during out-of-hours periods, caregivers helped bridge service gaps to manage patient anxiety and maintain continuity of care.³⁴ Caregivers highlighted the need

for practical training and respite to manage their responsibilities effectively.^{41,53} Early involvement in care planning was preferred by caregivers and in some cases by patients, which facilitated collaboration between patients, caregivers, and healthcare teams.^{39,47}

Balancing patient preferences with practical considerations for care was a challenge for caregivers.^{17,38} The extent to which caregivers and patients navigated decision-making collaboratively could depend on patient illness severity^{38,57} and caregiver perceived capacity or motivation to provide care to and support the patient.^{36,53} As patients' condition deteriorated, some caregivers assumed more directive roles in decision-making and prioritised symptom management and treatment feasibility over patient autonomy.^{46,47,51} In contrast, when patients did not feel dependent on their caregivers in decision-making, caregivers adopted a collaborative role in decision-making instead of assuming primary decision-making responsibilities.^{17,38,41}

Caregivers acknowledged the importance of proactive discussions with patients because such conversations helped them to collaborate in decision-making and manage their differences in the decision-making process.^{17,24,35} Discussion about patients' preferences for care also increased caregivers' preparedness to provide care and reduced distress related to difficult care decisions.^{18,36} However, in some cases, caregiver viewpoints could override patient preferences and create discordance in decision-making between the patient and caregiver.^{18,45,51} Cultural factors (e.g., filial piety) led caregivers to prioritise certain aspects of care as a moral duty even when the care did not align with the patient's preferences or provide clinical benefit to the patient.⁴⁶⁻⁴⁹ Caregivers also experienced internal conflict when involved in discussions about sensitive aspects of care, such as treatment withdrawal and end-of-life care.^{40,47,55} In one study, discussions pertaining to euthanasia created ethical and

emotional dilemmas for caregivers and influenced the extent to which they felt able to support patient choices.⁴⁰

Decision-making styles

Patients and caregivers exhibited different decision-making styles. Patients made decisions without assistance or involvement from their caregivers,^{17,27,41,43} and in other cases, patients and caregivers made decisions together.^{17,18,24,30,38,39} Patients made care decisions independently (i.e. without involvement of their caregiver) when they had greater awareness of their prognosis and a strong preference for autonomy in treatment choices.^{27,41,43} Patients who were aware of their prognosis also took the lead in final treatment choices even if caregivers disagreed with them.⁴³

Shared decision-making between patients and caregivers occurred when patients and caregivers actively collaborated in the decision-making process.^{24,30,39} Shared decision-making between patients and caregivers required active participation from both parties so that both patient and caregiver perspectives were fully integrated into a decision made about a particular aspect of care. Shared decision-making between the patient and caregiver tended to foster agreement between patients and caregivers and necessitated active involvement from the caregiver in decision-making.^{17,18,24} Patients who were uncertain about their preferences were more likely to engage in shared decision-making with their caregiver because it allowed them to feel supported by their caregiver in the decision-making process.^{17,18,38}

Preference-based decision-making (i.e., where choices are guided by the personal values and priorities of the patient or caregiver) was evident in a number of studies^{17,26,29,31,38,47,58} including where end-of-life care discussions were framed around patient or caregiver-stated

preferences for symptom management and place of care.^{29,38,47} Caregiver-stated preferences sometimes took precedence over patient preferences, particularly when caregivers had strong opinions about what constituted quality end-of-life care.^{43,46,48} These situations often reflected the caregiver's emotional investment, concerns about caregiving burden, or beliefs about appropriate care settings.^{17,31,58}

Emotional reciprocity and strain

Emotional support between patients and caregivers influenced how they navigated decision-making and adjusted to the demands of care.^{17,18,35} Patients and caregivers often functioned as emotional anchors for one another by providing reassurance and stability to each other in challenging circumstances.^{17,36,41} In some cases, emotional-based reciprocity could restrict open communication when both patients and caregivers concealed their distress from one another.^{18,46} Caregivers shielded patients from distressing information to preserve peace of mind, whilst patients avoided sharing concerns to reduce the burden on caregivers.^{28,46,49} Behaviours intended to protect the other also created emotional distress for patients and caregivers^{36,49} and in some cases, contributed to delays in decision-making.^{27,52}

Caregivers managed emotional strain by engaging in open communication and participating in shared decision-making in the process of functioning as an advocate for the patient^{24,40} and by negotiating their own emotional and relational needs within their caregiving role.^{18,41} Early involvement in care planning and practical training in caregiving eased emotional strain for caregivers, aiding their confidence in decision-making and their ability to cope with the emotional challenges encountered in their caregiving role.^{41,53}

Place of death and end-of-life care

When patients and caregivers engaged in discussions about end-of-life preferences, alignment with respect to treatment choices and place of care was more likely.^{23,47} Open communication between patients and caregivers was associated with better agreement on end-of-life care preferences.^{17,38,47} However, some patients and caregivers avoided end-of-life discussions due to emotional strain.^{18,49} Repeated conversations during hospice enrolment reinforced patient-caregiver alignment on place-of-death preferences.^{28,29} Deference to family authority influenced whether patients were able to express or act on their own preferences regarding preferred place of death.^{45,58} Home as a place of death was preferred by a number of patients.^{26,31,45,58} However, logistical constraints in caregiving made a home death less feasible for patients.^{33,45}

Limited out-of-hours services and fragmented care systems hindered patient and caregiver decision-making for end-of-life care.^{24,30,34} Caregivers reported concerns about their preparedness for home-based care and expressed the need for support.^{38,53} However, integrated palliative care and hospice enrolment helped reduce logistical barriers in accessing appropriate care and helped facilitate structured discussions about care preferences.^{28,39} Discussions about end-of-life care between patients and caregivers were associated with improved alignment of their preferences for end-of-life care.^{23,36,47}

Table 2. Qualitative studies. Quality assessed using the Mixed Methods Appraisal Tool (MMAT)

1. Qualitative	S1. Are there clear research questions?	S2. Do the collected data allow to address the research questions?	1.1. Is the qualitative approach appropriate to answer the research question?	1.2. Are the qualitative data collection methods adequate to address the research question?	1.3. Are the findings adequately derived from the data?	1.4. Is the interpretation of results sufficiently substantiated by data?	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?
Bekelman et al. (2011) ²⁴	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Chapman et al. (2024) ³⁰	Yes	yes	yes	yes	yes	yes	yes
Cheung et al. (2020) ⁴⁹	Yes	yes	yes	yes	yes	yes	yes
Collins et al. (2017) ³⁷	Yes	yes	yes	yes	yes	yes	yes
Dees et al. (2012) ⁴⁰	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Dobrina et al. (2016) ⁵⁵	Yes	yes	yes	yes	yes	yes	yes
Fagan et al. (2024) ¹⁷	Yes	yes	yes	yes	yes	yes	yes
Foley et al. (2025)* ³⁵	Yes	yes	yes	yes	yes	yes	yes
García-Toyos et al. (2014) ⁵⁶	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Gerber et al. (2019) ³⁸	Yes	yes	yes	yes	yes	yes	no
Hopkinson and Corner (2006) ³²	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Ikander et al. (2022) ⁵²	Yes	yes	yes	yes	yes	yes	yes
Lin et al. (2019) ⁴⁶	Yes	yes	yes	yes	yes	yes	yes
McCarthy et al. (2016) ⁵⁰	Yes	Yes	Yes	Yes	Yes	Yes	Yes
McCauley et al. (2023)* ¹⁸	Yes	Yes	Yes	Yes	Yes	Yes	Yes
McCauley et al. (2023)* ³⁶	Yes	yes	yes	yes	yes	yes	yes
McDonald et al. (2023) ³⁹	Yes	yes	yes	yes	yes	yes	yes
McPherson et al. (2014) ⁴¹	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Nysaeter et al. (2024) ⁵³	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Rafii et al. (2020) ⁵¹	Yes	yes	yes	yes	yes	yes	yes
Selman et al. (2017) ²⁵	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Thomas et al. (2004) ³³	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Vig et al. (2010) ²⁷	Yes	yes	yes	yes	yes	yes	yes

Waldrop & Meeker (2012) ^{j28}	Yes	yes	yes	yes	yes	yes	Yes
Waldrop & Meeker (2014) ^{j29}	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Worth et al. (2006) ³⁴	Yes	yes	yes	yes	yes	yes	yes

*Full paper from the same study, jFull paper from the same study

Table 3. Quantitative studies. Quality assessed using the Mixed Methods Appraisal Tool (MMAT)

4. Quantitative descriptive	S1. Are there clear research questions?	S2. Do the collected data allow to address the research questions?	4.1. Is the sampling strategy relevant to address the research question?	4.2. Is the sample representative of the target population?	4.3. Are the measurements appropriate?	4.4. Is the risk of nonresponse bias low?	4.5. Is the statistical analysis appropriate to answer the research question?
Ahn et al. (2013) ⁴³	Yes	Yes	Yes	Partially	Yes	Partially	Yes
An et al. (2014) ⁴⁴	Yes	Yes	Yes	Partially	Yes	Partially	Yes
Chai et al. (2014) ⁴⁸	Yes	Yes	Yes	Partially	Yes	Partially	Yes
Davies et al. (2019) ³¹	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes
Engelberg et al. (2005) ²³	Yes	Yes	Yes	Partially	Yes	Partially	Yes
Hsieh et al. (2007) ⁴⁵	Yes	Yes	Yes	Partially	Yes	Partially	Yes
Lin et al. (2020) ⁴⁷	Yes	Yes	Yes	Partially	Yes	Partially	Yes
Pautex et al. (2018) ⁵⁴	Yes	Yes	Yes	Partially	Yes	Partially	Yes
Riesinger et al. (2021) ⁵⁷	Yes	Yes	Yes	Partially	Yes	Partially	Yes
Valentino et al. (2022) ⁵⁸	Yes	Yes	Yes	Partially	Yes	Partially	Yes
Vidal et al. (2022) ²⁶	Yes	Yes	Yes	Partially	Partially	Yes	Yes
von Blanckenburg et al. (2022) ⁴²	Yes	Yes	Yes	Yes	Yes	Partially	Yes

DISCUSSION

This review highlights important dynamics of decision-making between patients with advanced illness and their caregivers in palliative care. Patients may express strong preferences for treatment and care, but caregivers frequently mediate decisions about patient care and balance the patient's perspective with the practical and emotional efforts of caregiving. The findings show that making decisions with or without caregivers can work well for patients with advanced illness. In many cases, patients have a preference to assume full responsibility in decision-making. Shared decision-making between the patient and caregiver is also valuable because it allows patients (re)assess their preferences as required with their caregivers and help alignment of patient and caregiver expectations of treatment and care. However, even in cases of shared decision-making between patients with advanced illness and their caregivers, patients and caregivers also shield one another from distressing information to reduce emotional distress for one another. This behaviour can result in delayed discussions about end-of-life care. Difficulty accessing services can press caregivers to make decisions based on availability of services rather than patient preference. Caregivers may also assume more control in decision-making when they feel the patient is increasingly dependent on them for their caregiving needs. That said, integrated palliative care helps mitigate these challenges by facilitating smoother care transitions for both patients and caregivers and helps patients and caregivers accommodate each other's preferences in decision-making for treatment and care.

The findings of the review point to the fact that no one decision-making style for patients with advanced illness and their caregivers may guarantee disclosure. Healthcare professionals who work in palliative care have indicated that open communication between

the patient, caregiver, and healthcare professional, promotes cohesion in decision-making between the patient and caregiver.¹⁶ We found no pattern across the findings in this review to suggest that shared decision-making between patients and caregivers leads to open communication between them. The findings resonate with studies that have reported on discordance in patient and caregiver preferences regarding disclosure of terminal illness and end-of-life choices.^{59,60} The review showed that shared decision-making between patients and their caregivers was associated with greater alignment between patients and caregivers and helped both engage collaboratively in the decision-making process. However, patients and caregivers could also shield one another from distress, and which could make it more difficult for them to jointly plan care. The findings also indicate that shared decision-making between the patient with advanced illness and their caregiver is not necessarily needed for all patients with advanced illness and caregivers who make decisions about palliative care, particularly when patients feel autonomous in their decision-making and when they are less reliant on their caregivers.

Of note, we observed a strong pattern of patient obligation to accept or defer to family caregiver preferences in studies which were conducted in Asian countries (China, Malaysia, Singapore, South Korea, and Taiwan). Filial piety (the virtue of exhibiting respect for one's parents and elders) prompted caregivers to protect the patient from what they (i.e. caregivers) perceived to be distressing for the patient. Caregivers could assume a leading role in decision-making and sometimes sought to override patient preference. Although this systematic review did not set out to describe differences in decision-making in palliative care and its relational nature across cultures, the findings draw attention to the weight attached to the cultural underpinnings and role of family relations in palliative care. Understandings

of relational autonomy in end-of-life care⁶¹ are culturally sensitive and are shaped by culturally different expectations of family members in decision-making about patient treatment and care.⁶²

The findings underscore the impact of service limitations in palliative care^{63,64} on decision-making between patients with advanced illness and their caregivers who need to access palliative care. Our review identified that difficulty accessing timely palliative care can diminish patients' ability to use services in line with their preferences and render more control to caregivers in decision-making. The findings point to how limitations in service delivery can limit patient-centred decision-making in palliative care.

Strengths and limitations

This review has both strengths and limitations. We employed a systematic and transparent methodology to ensure a replicability of procedures. The robustness in the synthesis is underpinned by the quality of the studies included.¹⁹ By examining the relational nature of decision-making between patients with advanced illness and their caregivers, the review goes beyond basic constitutes of decision-making to unpack the relational dynamics of decision-making for patients with advanced illness and caregivers in palliative care.

A limitation of the review is that we did not limit the inclusion of studies to only those where all patients and caregivers were dyads. As mentioned, 11 of the included studies recruited patient-caregiver dyads only.^{17,23,26,31,43-47,55,58} The remaining studies included a mix of patient-caregiver dyads and patients and/or caregivers recruited without their respective other. We included these studies because majority of patients and caregivers in these studies are dyads. Notwithstanding, it is possible that some evidence from the review

reflects only what patients or only what caregivers perceived about their respective other. A limitation of the findings themselves is that most studies included in the synthesis are from the Global North. Including only studies published in English was likely to favour the inclusion of studies from the Global North. Although studies are from multiple healthcare systems, only three of the studies were conducted in developing countries.^{50,51,58} Hence, the findings are limited mainly to patients and caregivers in developed countries.

CONCLUSIONS

Overall, this systematic review provides a comprehensive review of evidence in the last 20 years focused on the relational nature of decision-making between patients with advanced illness and their caregivers in palliative care. Patient and caregiver decision-making is shaped by patient and caregiver awareness of the patient's illness and advancing needs, their communication (or lack of communication) with each other, how they reciprocate in emotional support of one another, and by the healthcare systems which they both operate within.

The findings of the review have important implications for research and practice in the field. First, in palliative care, researchers develop and evaluate decision-support interventions for both patients and caregivers.^{65,66} However, the tendency for caregivers to assume more control or authority in decision-making highlights the importance of developing and using decision-support interventions which serve to protect patient autonomy as well as facilitate caregiver support. Studies which capture and illustrate the complexity of different decision-making styles between patients with advanced illness and their caregivers in palliative care

in relation to control, choice and autonomy, would provide valuable insights into how decision-support interventions can best support patient-centred decision-making.

Second, it would be beneficial to investigate the relational nature of decision-making between patients with advanced illness and caregivers in palliative care from the Global South where palliative care is less developed and in places grossly insufficient.^{67,68} Such research could reveal other key relationship dynamics between patients and caregivers not identified in the Global North but which also impact on how patients and caregivers navigate decision-making and potentially affect care transitions in decision-making for both the patient and caregiver. Studies to explore how different systemic contexts influence decision-making styles between the patient with advanced illness and caregiver are needed.

Third, in terms of practice, the findings indicate that shared decision-making between patients with advanced illness and their caregivers is beneficial for patients in palliative care when they rely on caregivers for caregiving and for support in decision-making. However, some patients prefer to make decisions without directly involving caregivers. It is likely that patients and caregivers move between different decision-making styles over the course of the patient's illness. Healthcare professionals need to be sensitive to variation in patients' and caregivers' decision-making styles and decipher how best to protect and facilitate patient autonomy⁶⁹ in the patient and caregiver relationships across different decision-making styles.

Finally, emotional reciprocity between patients with palliative care needs and their caregivers is complex. Patients with advanced illness and caregivers are a source of emotional support to one another. However, emotional reciprocity constitutes in part

mutual avoidance to openly communicate their preferences and needs to one another. We already know that conversations pertaining to palliation can be particularly emotive for both patients and caregivers.⁷⁰ Training for healthcare professionals to manage the complex interplay between patient and caregiver open and closed communication in palliative care would be beneficial to avoid delays in decision-making.

Contributors

GF conceived the work. AK and DM formulated the search strategy which was approved by EG and GF. AK, EG, and GF screened all records and studies. AK extracted the evidence and lead on the synthesis. Extraction was supported by EG and GF and the synthesis was supported by GF. DM, RMcQ, KR, and CW commented on the design. AK wrote the manuscript with contributions from RMcQ, KR, EG, and GF. GF made substantial contributions to the focus and argumentation of the discussion and conclusions. The final draft was agreed by all authors (AK, DM, RMcQ, KR, CW, EG, and GF). AK is responsible for the overall content of the manuscript and acts as guarantor.

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Competing interests

None declared.

Patient consent for publication

Not applicable.

Data availability statement

All data relevant to the study are included in the article or uploaded as supplementary information.

Ethics approval

Not applicable. This work is a systematic review of published studies.

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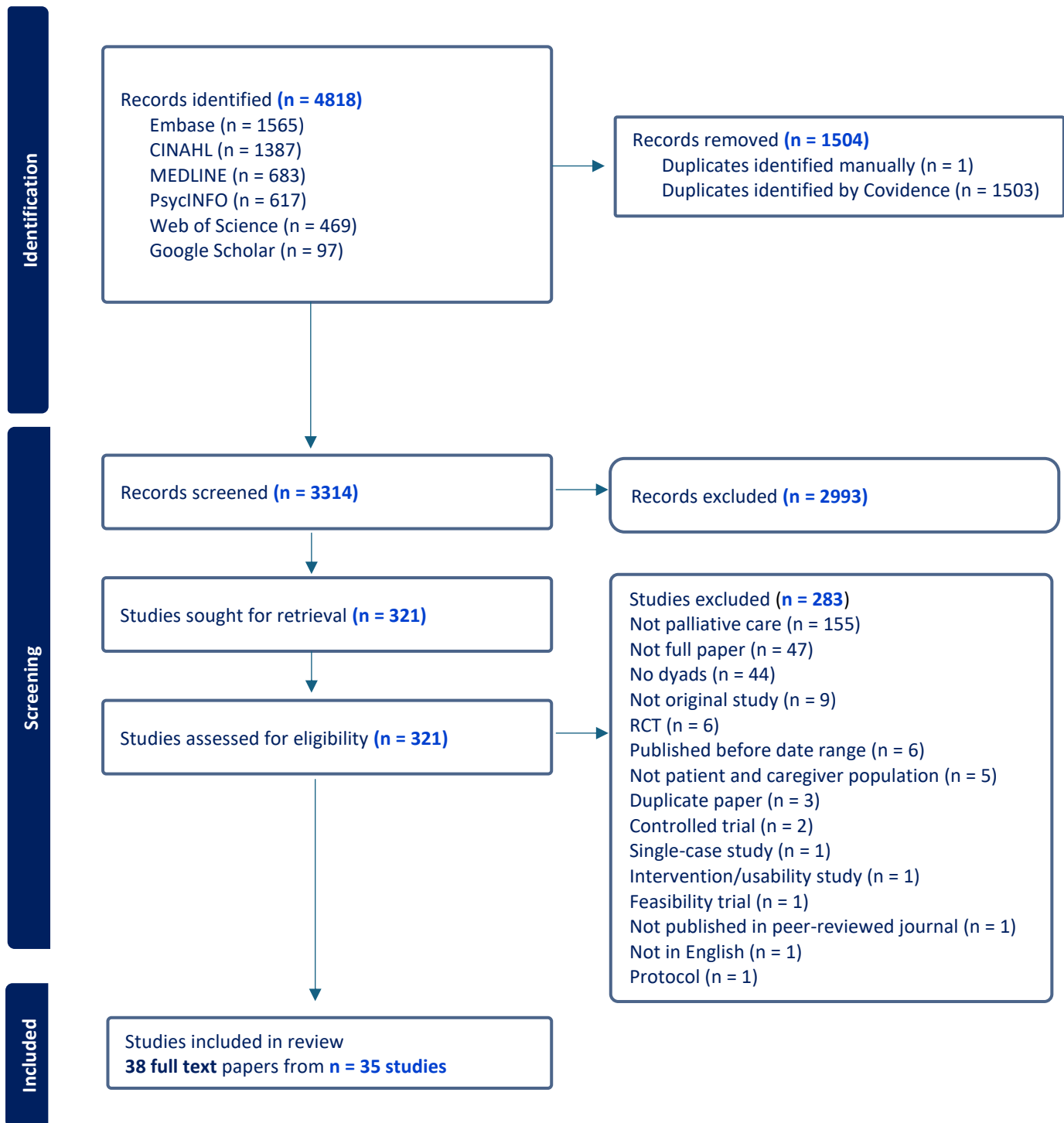
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Figure 1. PRISMA flow chart



Appendix 1. Search strategy

EMBASE [1565]

'patient decision making'/exp

('patient'/exp OR 'patient attitude'/exp) AND 'decision making'/exp

((Concordance OR discordance OR patient* OR DYAD) NEAR/3 (decision* OR decide? OR preference* OR choice* OR wishes)):ti,ab,kw

#1 OR #2 OR #3

'caregiver'/exp OR 'surrogate decision maker'/exp OR 'surrogate decision making'/exp

((('care-giver*' OR caregiver* OR carer* OR surrogate* OR proxy OR spouse* OR spousal OR sibling* OR wife OR husband OR guardian* OR relative*) NEAR/3 (decision* OR decide? OR preference* OR choice* OR wishes)):ti,ab,kw

#5 OR #6

'terminally ill patient'/exp

((advanced OR terminal* OR life-limiting) NEAR/5 (ill* OR disease* OR condition*)):ti,ab,kw

('end stage' or 'end of life' or 'last year of life' or LYOL or 'lifes end'):ti,ab,kw

'advanced cancer'/exp

(Cancer NEAR/3 (terminal OR advanced OR Metastatic)):ti,ab,kw

'congestive heart failure'/exp

('cardiac congestive failure' OR 'congestive cardiac failure' OR 'congestive heart failure' OR CHF OR 'congestive heart insufficiency'):ti,ab,kw

'organ failure'/exp OR 'lung insufficiency'/exp OR 'kidney failure'/exp OR 'liver failure'/exp

((('Major organ*' OR liver OR hepatic OR kidney* OR renal OR lung* OR respiratory) NEAR/3 (failure* OR insufficiency)):ti,ab,kw

'dementia'/exp

(dement* OR alzheimer OR 'vascular dement*' OR 'picks disease' OR huntington OR creutzfeldt OR cjd OR binswanger OR lewy):ti,ab,kw

'Human immunodeficiency virus'/exp OR 'Human immunodeficiency virus infection'/exp

('human immunodeficiency virus' OR HIV OR 'acquired immunodeficiency syndrome' OR 'acquired immuno-deficiency syndrome' OR 'acquired immune-deficiency syndrome' OR AIDS):ti,ab,kw

#8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20

'palliative therapy'/exp OR 'terminal care'/exp OR 'hospice'/exp

(Palliation OR 'Supportive care'):ti,ab,kw,kw

((Palliative OR end-of-life) NEAR/3 (care OR treatment* OR therapy OR therapies)):ti,ab,kw,kw

((terminal* OR hospice* OR 'end-of-life' OR 'end-stage' OR 'last year of life' OR LYOL OR 'lifes end')
NEAR/5 (care OR caring)):ti,ab,kw,kw

#22 OR #23 OR #24 OR #25

#4 AND #7 AND #21 AND #26

Web of Science [469]

((Concordance OR discordance OR patient* OR DYAD) NEAR/3 (decision* OR decide* OR
preference* OR choice* OR wishes OR consideration*))

((("care-giver*" OR caregiver* OR carer* OR surrogate* OR proxy OR spouse* OR spousal OR sibling*
OR wife OR husband OR guardian* OR relative*) NEAR/3 (decision* OR decide* OR preference* OR
choice* OR wishes OR consideration*))

((advanced OR terminal* OR life-limiting) NEAR/5 (ill* OR disease* OR condition*)) OR "end stage" or
"end of life" or "last year of life" or LYOL or "lifes end" OR (Cancer NEAR/3 (terminal OR advanced OR
Metastatic)) OR "cardiac congestive failure" OR "congestive cardiac failure" OR "congestive heart
failure" OR CHF OR "congestive heart insufficiency" OR (("Major organ*" OR liver OR hepatic OR
kidney* OR renal OR lung* OR respiratory) NEAR/3 (failure* OR insufficiency)) OR dement* OR
alzheimer OR "vascular dement*" OR "picks disease" OR huntington OR creutzfeldt OR cjd OR
binswanger OR lewy OR "human immunodeficiency virus" OR HIV OR "acquired immunodeficiency
syndrome" OR "acquired immuno-deficiency syndrome" OR "acquired immune-deficiency syndrome"
OR AIDS

Palliation OR "Supportive care" OR ((Palliative OR end-of-life) NEAR/3 (care OR treatment* OR
therapy OR therapies)) OR ((terminal* OR hospice* OR "end-of-life" OR "end-stage" OR "last year of
life" OR LYOL OR "lifes end") NEAR/5 (care OR caring))

#1 AND #2 AND #3 AND #4

Medline [683]

(exp Decision Making/ OR exp Decision Support Techniques/ OR Decision Making, Shared/) AND
(Patient Participation/ OR exp Patient Satisfaction/ OR Patients/)

((Concordance OR discordance OR patient* OR DYAD) adj3 (decision* OR decide*1 OR preference*
OR choice* OR wishes)).tw.

1 OR 2

(Caregivers/ OR exp Family/ OR exp Legal Guardians/) AND exp Decision Making/

((care-giver* OR caregiver* OR carer* OR surrogate* OR proxy OR spouse* OR spousal OR sibling*
OR wife OR husband OR guardian* OR relative*) adj3 (decision* OR decide*1 OR preference* OR
choice* OR wishes)).tw.

4 OR 5

((advanced or terminal* OR life-limiting) adj5 (ill* or disease* OR condition*)).tw.

(end stage or end of life or last year of life or LYOL or lifes end).tw.

(Cancer adj3 (terminal OR advanced OR Metastatic)).tw.

exp Heart Failure/

(cardiac congestive failure OR congestive cardiac failure OR congestive heart failure OR CHF OR congestive heart insufficiency).tw.

Multiple Organ Failure/ OR exp Respiratory Insufficiency/ OR exp Renal Insufficiency/ OR exp Liver Failure/

((Major organ* OR liver OR hepatic OR kidney* OR renal OR lung* OR respiratory) adj3 (failure* OR Insufficiency)).tw.

exp Dementia/ OR exp Alzheimer Disease/

(dement* OR alzheimer OR vascular dement* OR picks disease OR huntington OR creutzfeldt OR cjd OR binswanger OR lewy).tw.

exp "HIV"/ OR exp "HIV Infections"/

(human immunodeficiency virus OR HIV OR acquired immunodeficiency syndrome OR acquired immuno-deficiency syndrome OR acquired immune-deficiency syndrome OR AIDS).tw.

or/7-17

Palliative Care/ OR exp Terminal Care/ OR exp Terminally Ill/

(Palliation OR Supportive care).tw.

((Palliative OR end-of-life) adj3 (care OR treatment* OR therapy OR therapies)).tw.

((terminal* OR hospice* OR end-of-life OR end-stage OR last year of life OR lifes end) adj5 (care OR caring)).tw.

or/19-22

3 and 6 and 18 and 23

[CINAHL \[1387\]](#)

(MH "Decision Making, Patient+")

(MH "Patients+") AND (MH "Decision Making")

TI ((Concordance OR discordance OR patient* OR DYAD) N3 (decision* OR decide* OR preference* OR choice* OR wishes OR consideration*)) OR AB ((Concordance OR discordance OR patient* OR DYAD) N3 (decision* OR decide* OR preference* OR choice* OR wishes OR consideration*))

S1 OR S2 OR S3

(MH "Caregivers") AND (MH "Decision Making")

(MH "Decision Making, Family")

TI ("care-giver*" OR caregiver* OR carer* OR surrogate* OR proxy OR spouse* OR spousal OR sibling* OR wife OR husband OR guardian* OR relative*) N3 (decision* OR decide* OR preference* OR choice* OR wishes OR consideration*)) OR AB ("care-giver*" OR caregiver* OR carer* OR

surrogate* OR proxy OR spouse* OR spousal OR sibling* OR wife OR husband OR guardian* OR relative*) N3 (decision* OR decide* OR preference* OR choice* OR wishes OR consideration*)

S5 OR S6 OR S7

(MH "Terminal Care") OR (MH "Hospice Care") OR (MH "Palliative Care")

TI (((advanced OR terminal* OR life-limiting) N5 (ill* OR disease* OR condition*)) OR "end stage" or "end of life" or "last year of life" or LYOL or "lifes end" OR (Cancer N3 (terminal OR advanced OR Metastatic)) OR "cardiac congestive failure" OR "congestive cardiac failure" OR "congestive heart failure" OR CHF OR "congestive heart insufficiency" OR ("Major organ*" OR liver OR hepatic OR kidney* OR renal OR lung* OR respiratory) N3 (failure* OR insufficiency)) OR dement* OR alzheimer OR "vascular dement*" OR "picks disease" OR huntington OR creutzfeldt OR cjd OR binswanger OR lewy OR "human immunodeficiency virus" OR HIV OR "acquired immunodeficiency syndrome" OR "acquired immuno-deficiency syndrome" OR "acquired immune-deficiency syndrome" OR AIDS) OR AB (((advanced OR terminal* OR life-limiting) N5 (ill* OR disease* OR condition*)) OR "end stage" or "end of life" or "last year of life" or LYOL or "lifes end" OR (Cancer N3 (terminal OR advanced OR Metastatic)) OR "cardiac congestive failure" OR "congestive cardiac failure" OR "congestive heart failure" OR CHF OR "congestive heart insufficiency" OR ("Major organ*" OR liver OR hepatic OR kidney* OR renal OR lung* OR respiratory) N3 (failure* OR insufficiency)) OR dement* OR alzheimer OR "vascular dement*" OR "picks disease" OR huntington OR creutzfeldt OR cjd OR binswanger OR lewy OR "human immunodeficiency virus" OR HIV OR "acquired immunodeficiency syndrome" OR "acquired immuno-deficiency syndrome" OR "acquired immune-deficiency syndrome" OR AIDS)

TI (Palliation OR "Supportive care" OR ((Palliative OR end-of-life) N3 (care OR treatment* OR therapy OR therapies)) OR ((terminal* OR hospice* OR "end-of-life" OR "end-stage" OR "last year of life" OR LYOL OR "lifes end") N5 (care OR caring))) OR AB (Palliation OR "Supportive care" OR ((Palliative OR end-of-life) N3 (care OR treatment* OR therapy OR therapies)) OR ((terminal* OR hospice* OR "end-of-life" OR "end-stage" OR "last year of life" OR LYOL OR "lifes end") N5 (care OR caring)))

S9 OR 10 OR S11

S4 AND S8 AND S12

[PSYCInfo \[617\]](#)

(DE "Patients") AND (DE "Group Decision Making" OR DE "Decision Making")

TI ((Concordance OR discordance OR patient* OR DYAD) N3 (decision* OR decide* OR preference* OR choice* OR wishes OR consideration*)) OR AB ((Concordance OR discordance OR patient* OR DYAD) N3 (decision* OR decide* OR preference* OR choice* OR wishes OR consideration*))

S1 OR S2

(DE "Caregivers" OR DE "Caregiving" OR DE "Family Members" OR DE "Family" OR DE "Adult Offspring" OR DE "Daughters" OR DE "Grandchildren" OR DE "Grandparents" OR DE "Siblings" OR DE "Sons" OR DE "Spouses" OR DE "Stepchildren" OR DE "Filial Responsibility") AND (DE "Group Decision Making" OR DE "Decision Making")

TI ("care-giver*" OR caregiver* OR carer* OR surrogate* OR proxy OR spouse* OR spousal OR sibling* OR wife OR husband OR guardian* OR relative*) N3 (decision* OR decide* OR preference* OR choice* OR wishes OR consideration*)) OR AB ("care-giver*" OR caregiver* OR carer* OR

surrogate* OR proxy OR spouse* OR spousal OR sibling* OR wife OR husband OR guardian* OR relative*) N3 (decision* OR decide* OR preference* OR choice* OR wishes OR consideration*)

S4 OR S5

DE "Palliative Care" OR DE "Death and Dying" OR DE "Hospice" OR DE "Terminally Ill Patients"

TI (((advanced OR terminal* OR life-limiting) N5 (ill* OR disease* OR condition*)) OR "end stage" or "end of life" or "last year of life" or LYOL or "lifes end" OR (Cancer N3 (terminal OR advanced OR Metastatic)) OR "cardiac congestive failure" OR "congestive cardiac failure" OR "congestive heart failure" OR CHF OR "congestive heart insufficiency" OR ("Major organ*" OR liver OR hepatic OR kidney* OR renal OR lung* OR respiratory) N3 (failure* OR insufficiency)) OR dement* OR alzheimer OR "vascular dement*" OR "picks disease" OR huntington OR creutzfeldt OR cjd OR binswanger OR lewy OR "human immunodeficiency virus" OR HIV OR "acquired immunodeficiency syndrome" OR "acquired immuno-deficiency syndrome" OR "acquired immune-deficiency syndrome" OR AIDS) OR AB (((advanced OR terminal* OR life-limiting) N5 (ill* OR disease* OR condition*)) OR "end stage" or "end of life" or "last year of life" or LYOL or "lifes end" OR (Cancer N3 (terminal OR advanced OR Metastatic)) OR "cardiac congestive failure" OR "congestive cardiac failure" OR "congestive heart failure" OR CHF OR "congestive heart insufficiency" OR ("Major organ*" OR liver OR hepatic OR kidney* OR renal OR lung* OR respiratory) N3 (failure* OR insufficiency)) OR dement* OR alzheimer OR "vascular dement*" OR "picks disease" OR huntington OR creutzfeldt OR cjd OR binswanger OR lewy OR "human immunodeficiency virus" OR HIV OR "acquired immunodeficiency syndrome" OR "acquired immuno-deficiency syndrome" OR "acquired immune-deficiency syndrome" OR AIDS)

TI (Palliation OR "Supportive care" OR ((Palliative OR end-of-life) N3 (care OR treatment* OR therapy OR therapies)) OR ((terminal* OR hospice* OR "end-of-life" OR "end-stage" OR "last year of life" OR LYOL OR "lifes end") N5 (care OR caring))) OR AB (Palliation OR "Supportive care" OR ((Palliative OR end-of-life) N3 (care OR treatment* OR therapy OR therapies)) OR ((terminal* OR hospice* OR "end-of-life" OR "end-stage" OR "last year of life" OR LYOL OR "lifes end") N5 (care OR caring)))

S7 OR S8 OR S9

S6 AND S6 AND S10

[Google Scholar \[97\]](#)

"Concordance|discordance|patient|patients|DYAD AROUND(3)
decision|decisions|decide|decides|preferences|choices|wishes"
"carer|carers|caregiver|caregivers AROUND(3)
decision|decisions|decide|decides|preferences|choices|wishes"

Supplementary Table 1. Summary of studies

Study	Location/Setting	Participants	Aim(s)	Methods	Findings
Ahn et al. (2013)⁴³	34 inpatient palliative care centres, South Korea	690 participants: 345 patient-caregiver dyads (345 patients with advanced cancer and 345 caregivers).	To assess how the awareness of a terminal illness can affect care decision-making and the achievement of a good death in advanced cancer patients receiving inpatient palliative care services.	Quantitative: Prospective; survey; clinical and demographic data, awareness of illness disclosure, Korean version of Good Death Inventory, decision-making processes questionnaires; descriptive statistics, analysis of covariance, multivariate logistic regression.	- Awareness: 68.4% of patients were aware of their terminal status. - Decision-making discordance: Discordance in care decision-making tended to be less frequent in the awareness of terminal illness group than the non-awareness group (25.1% vs. 31.5%; aOR = 0.55; 95% CI: 0.29–1.07) - Patient-led decisions: In cases of discordance, aware patients made the final decision more often (48.9% vs. 24.1% for unaware patients; aOR = 3.79). - Caregiver influence: Caregivers often withheld information and assumed decision-making roles when patients were unaware. This led to more aggressive treatment options.
An et al. (2014)⁴⁴	12 public and private hospitals, South Korea	718 patients: 359 patient-caregiver dyads (359 patients with advanced cancer, 359 caregivers).	To evaluate the association between attitudes toward hospice/palliative care of both patients with advanced cancer and their caregivers and actual utilisation of inpatient hospice/palliative care facilities.	Quantitative: Prospective cohort; clinical data from medical records, questionnaires for demographic data and awareness of terminal illness and attitudes towards hospice palliative care, caregiver post-bereavement questionnaire; descriptive statistics, logistic regression, multivariate analysis.	- Caregiver-driven decision making: Caregivers' preferences significantly predicted hospice palliative care utilisation (aOR: 2.67, 95% CI: 1.53–4.67). - Awareness as a factor: Awareness of terminal status increased preferences for hospice/palliative care among both patients (aOR: 1.87) and caregivers (aOR: 2.14). - Low concordance: Only 48.2% of patient-caregiver dyads showed agreement on hospice palliative care preferences (Cohen's kappa = –0.03). - Barriers: Lack of information about hospice palliative care was a primary reason for non-utilisation, cited by 46.4% of patients and 40.8% of caregivers.
Bekelman et al. (2011)²⁴	Outpatient cardiology and geriatric clinics in a tertiary hospital, Colorado, USA	53 participants: 33 patients with heart failure, 20 caregivers (includes 20 patient-caregiver dyads).	To identify concerns, needs, and preferences of patients with heart failure and their caregivers for palliative care.	Qualitative: Semi-structured interviews; constant comparative analysis derived from grounded theory.	- Caregiver roles and influence: Caregivers played a key role in advocating for patient preferences, ensuring care coordination, and integrating palliative care into treatment planning. - Collaborative: Patients and caregivers favouring a team-based approach to align treatment goals. - Emotional support: Emotional counselling and anticipatory guidance helped caregivers navigate decision-making challenges. - Barriers to communication: Fragmented communication and lack of accessible support impeded effective discussions about palliative care needs and preferences.
Chai et al. (2014)⁴⁸	Palliative medicine outpatient clinic, National Cancer Centre, Singapore	100 participants: 38 patients with advanced cancer and 62 caregivers of patients with advanced cancer (includes 38 patient-caregiver dyads).	To explore the factors influencing caregivers' decisions to continue feeding terminally ill cancer patients.	Quantitative: Cross-sectional; demographic interviewer-administered questionnaires for demographic data, decision-making preferences, perceptions of and attitudes toward food, route of administration, complications of continued nutrition and hydration, decision to stop artificial nutrition and hydration, and family involvement; non-parametric statistical analysis using the Mann-Whitney test.	- Caregiver influence: Decisions were influenced by filial piety, emotional obligation, and dignity concerns, often overriding patient preferences. - Cultural impact: Feeding was viewed as a moral duty, driven by Confucian values and fear of "losing face". - Emotional strain: Caregivers experienced financial burden and stress but saw feeding as maintaining hope and family bonds. - Patient-caregiver alignment: Preferences were largely culturally driven rather than based on the patient's medical needs.

Chapman et al. (2024)³⁰	A hospice including home-based palliative care, UK	12 participants: 6 patients with advanced cancer, 6 caregivers (includes 5 patient-caregiver dyads).	To gain an understanding of the patient and caregiver experience of symptom management for advanced cancer in palliative care.	Qualitative: Semi-structured interviews; framework analysis.	Shared decision-making: Patients and caregivers collaborated on symptom management, sharing responsibilities. - Caregiver role: Managed medications, advocated for patients, and ensured treatment adherence. - Barriers: Communication gaps and fragmented care hindered decision-making. - Caregiver burden: Emotional and logistical challenges affected engagement in decision-making.
Cheung et al. (2020)⁴⁹	Palliative care day centre in a rehabilitation hospital, Hong Kong	30 participants: 17 patients with advanced illness, 13 caregivers (includes 13 patient-caregiver dyads). Patient diagnosis: advanced cancer and other advanced illnesses (numbers for each not reported). Other advanced illnesses were not reported.	To explore barriers to advance care planning (ACP) for seriously ill patients and their caregivers.	Qualitative: Focus groups and in-depth interviews; qualitative content analysis.	Decision-making: Patients deferred to family and doctors due to cultural norms and trust. - Barriers to ACP: Emotional avoidance and poor communication limited patient autonomy. - Caregiver role: Managed decisions but hesitated due to cultural and emotional concerns. Caregivers withheld information about diagnosis and prognosis to avoid psychological distress, maintain patient peace of mind, and protect patients from emotional burdens. - Healthcare barriers: Poor care continuity and limited professional communication impeded ACP discussions. - Avoidance of burdening family: patients withheld concerns so as "not to bother" children or spouse.
Collins et al. (2017)³⁷	Tertiary metropolitan hospital, Melbourne, Australia	55 participants: 30 patients with advanced cancer, 25 caregivers (includes 7 patient-caregiver dyads).	To explore initial perceptions of palliative care among patients with advanced cancer and their families when palliative care is first raised with them.	Qualitative: Cross-sectional, prospective, exploratory qualitative design; narrative-style interviews; interpretative phenomenological analysis.	Negative perceptions: Patients and caregivers viewed palliative care as diminished care with diminished possibility and diminished choice. - Disempowered decision-making: These perceptions led to passive or reluctant engagement. - Caregiver role: Caregivers influenced patient decisions and shared initial misconceptions that hindered patient advocacy.
Davies et al. (2019)³¹	Two hospitals and Five hospices, UK	240 participants: 120 patient-caregiver dyads (120 patients with advanced cancer and 120 caregivers).	To investigate concordance between patients and their caregivers on the factors associated with a good death and other end-of-life decisions.	Quantitative: Prospective observational; patient and caregiver demographics, cancer diagnosis status, questionnaires about end-of-life care issues, Memorial Symptom Assessment Scale, Zarit Burden Interview Scale; descriptive statistics and univariate binary logistic analysis.	Preference-based decision-making: Home was the most preferred place of death (50%) for patients, with good concordance with caregivers (90%). - Caregiver influence: Caregivers experiencing high burden were less likely to choose home as an acceptable place of death for the patient ($p = 0.037$). - Symptom management priority: Both groups ranked symptom control as the most important factor for a "good death." - Communication gaps: Despite overall good concordance, 31% of patients and caregivers had not discussed end-of-life preferences.
Dees et al. (2012)⁴⁰	Home, hospice, and nursing home settings, Netherlands	91 participants: 32 patients with advanced illness, 31 caregivers, 28 physicians (includes 31 patient-caregiver dyads). Patient diagnosis: n=14 cancer; n=6 neurodegenerative; n=4 psychiatric; n=3 chronic pain; n=1 heart failure; n=4 other (specific conditions for other not reported).	To explore the decision-making process in cases where patients explicitly request euthanasia.	Qualitative: Semi-structured interviews; thematic analysis.	Decision-making process: Phases included initiation, relationship-building, legal steps, and aftercare. - Shared decision-making: Patients, caregivers, and physicians collaborated with trust and empathy. - Caregiver role: Advocated for patient preferences and supported planning. - Ethical and emotional dilemmas: Caregivers struggled with euthanasia decisions, sometimes experiencing internal conflict. - Legal barriers: Stringent verification and communication requirements influenced decision-making.

Dobrina et al. (2016)⁵⁵	Home-based palliative care cancer service, Italy	22 participants: 11 patient-caregiver dyads (11 patients with advanced cancer, 11 caregivers).	To explore the needs and wishes of advanced cancer patients and their caregivers during the last week of life at home.	Qualitative: Descriptive phenomenological; semi-structured interviews; phenomenological analysis.	Dyad as one: Patients and caregivers shared interrelated needs, forming a unit with dynamic preferences. - Observable preferences: Patients valued maintaining normality, but unmet desires led to frustration. - Caregiver burden: Decisions often prioritised pain control and logistical needs over patient autonomy. - Communication gaps: Patients and caregivers avoided discussing future concerns to protect each other and which limited their alignment on EOL decisions. - Emotional presence: Caregivers' presence was highly valued, though caregiving demands diminished their own quality of life.
Engelberg et al. (2005)²³	Two hospice programs (outpatient and inpatient/outpatient), USA	184 participants: 92 patient-caregiver dyads. Patient (with advanced illness) diagnosis: n=69 cancer; n=7 cardiovascular/heart disease; n=7 COPD, n=3 neurological; n=6 other (specific conditions for other not reported).	To examine the agreement between hospice patients' preferences for desired experiences during the last week of life and their family members' understanding of those preferences.	Quantitative: Prospective; survey; multiple instruments (demographic items, preferences for death and dying, illness impact, symptom assessment, communication); statistical analysis including per cent agreement, Bland-Altman plots, and intraclass correlations.	Concordance: Patients and caregivers agreed on 47% of end-of-life preferences, with higher concordance for observable domains (e.g., pain control, time with loved ones) than more abstract domains (e.g., finding meaning and purpose). - Communication impact: Patients who discussed preferences with caregivers had a significantly higher agreement with their caregiver (mean 13.49 vs. 9.43 agreements, p = 0.01). - Over/underestimation: Caregivers overestimated the importance of "saying goodbye" but underestimated concerns such as avoiding burdening loved ones.
Fagan et al. (2024)¹⁷	Regional specialist palliative care service comprising three hospice sites, Ireland	22 participants: 11 patient-caregiver dyads. Patient diagnosis: n=10 advanced cancer; n=1 neurodegenerative.	To examine how patients with advanced illness and their caregivers support one another in decision-making for patient care.	Qualitative: Semi-structured interviews; thematic analysis.	Shared decision-making: Patients and caregivers collaborated iteratively and openly to align care preferences. - Independent decision-making: Patients sought autonomy to reduce caregiver burden. - Emotional support: Essential in navigating differences and maintaining alignment. - Caregiver role: Advocated for patient preferences, provided trust and logistical support. - Healthcare role: Professional guidance helped mediate discussions and align care plans.
García-Toyos et al. (2014)⁵⁶	Seven healthcare centres, a hospice, and palliative home-based care, Andalusia, Spain	42 participants: 22 patients with advanced illness, 20 caregivers (includes 12 patient-caregiver dyads). Patient diagnosis: n=26 cancer; n=16 non-cancer (specific non-cancer conditions not reported).	To explore patient and caregiver values, preferences, and beliefs regarding opioid use in terminal care.	Qualitative: Semi-structured interviews; qualitative content analysis.	Participation: Only 8% actively participated in decision-making; most followed physician guidance. - Beliefs: Erroneous beliefs about opioids (e.g., addiction, premature death) influenced treatment acceptance. - Caregiver role: Caregivers managed administration in 50% of cases and mediated adjustments in treatment. - Side effects: Constipation, nausea, and drowsiness were the most commonly reported adverse effects. - Disparities: Caregivers were often better informed about the prognosis than patients, limiting collaborative decision-making.
Gerber et al. (2019)³⁸	Acute palliative care hospital ward, sub-acute hospice unit, and a palliative homecare organisation, Melbourne, Australia	17 participants: 8 patients with advanced illness, 9 caregivers (includes 6 patient-caregiver dyads). Patient diagnosis: n=6 advanced cancer, n=2 non-cancer.	To gain an understanding of how terminally ill patients and family caregivers make decisions about their preferred place of care and place of death.	Qualitative: semi-structured interviews; thematic qualitative description and elements of grounded theory analysis.	Contextual preferences: Preferences were dynamic and conditional on circumstances such as illness progression and caregiver capacity. - Negotiated alignment: patients and caregivers negotiated openly to reach flexible, shared choices on place of care/death. - Relational decision-making: Patients adjusted preferences to reduce caregiver burden, while caregivers looked at demands, support, needs, and conflicts. - Uncertainty and flexibility: Decision-making reflected the uncertainty of end-of-life circumstances and required iterative planning. - Emotional and cognitive factors: Emotional responses and hypothetical scenarios shaped preferences, emphasising the role of relational and practical considerations.

Hopkinson and Corner (2006)³²	Two community palliative care teams, Southern England	67 participants: 30 advanced cancer patients, 23 caregivers, 14 nurse specialists (includes 23 patient-caregiver dyads).	To develop an understanding of the manifestations, management, and eating changes in patients with advanced cancer.	Qualitative: Hermeneutic phenomenological; semi-structured interviews; inductive and cross-case analysis.	Self-action vs. acceptance: Patients adopted varied strategies, from self-action (manipulating diet) to acceptance (relinquishing control over eating). - Caregiver pressure: Caregivers often pressured patients to eat, leading to tension and distress. - Professional role: Nurses focused on fostering acceptance but provided limited support for self-action strategies. - Cultural and emotional challenges: Patients and caregivers faced conflicting societal and personal expectations about eating habits.
Hsieh et al. (2007)⁴⁵	Inpatient palliative care unit of a tertiary hospital, Taipei, Taiwan	92 participants: 46 patient-caregiver dyads (46 patients with advanced cancer, 46 caregivers).	To identify the preferred place of death for dying cancer patients and their caregivers: to examine the congruence of a patient's wish and a family caregiver's wish for place of death with the actual place of death; and to investigate the impact of place of death on caregivers' grief reactions.	Quantitative: Prospective observational; demographic questionnaire, Interpersonal Support Evaluation List, Texas Revised Inventory of Grief (immediate and one-month post-bereavement); descriptive statistics, t-tests, and logistic regression.	Caregiver-driven decisions: 74% of patients preferred to die at home, but only 17% did, with caregivers' preferences aligning in 70% of cases. - Caregiver Role: The caregiver acted as gatekeepers, often overriding patient preferences based on logistical constraints and support availability. - Alignment challenges: Only 43% of patient preferences for place of death aligned with outcomes.
Ikander et al. (2022)⁵²	Outpatient oncology/palliative care clinic, Odense University Hospital, Denmark	28 participants: 9 patients with advanced lung cancer, 8 caregivers, 11 nurses (includes 8 patient-caregiver dyads).	To investigate nursing practice related to end-of-life (EOL) discussions with incurable lung cancer patients and their family caregivers during palliative chemotherapy.	Qualitative: Phenomenological-hermeneutic; participant observations, informal interviews, formal semi-structured interviews, and focus groups; structural analysis and critical interpretation.	EOL discussions: Most discussions were initiated too late, typically when treatment options were exhausted. Topics addressed in end-of-life discussions were treatment, location of care, practical and economic concerns, and existential matters. - Caregiver roles: Caregivers initiated discussions, but some also delayed them out of concern for patient distress. - Barriers: Systemic issues like time constraints, unsuitable environments, and lack of protocols hindered discussions. - Continuity in care: Patients preferred discussing EOL matters with familiar nurses to foster trust. - Treatment-centric conversations: Discussions primarily focused on treatment logistics rather than emotional or existential matters.
Lin et al. (2019)⁴⁶	One hospice and one oncology unit in a tertiary hospital, northern Taiwan	45 participants: 15 patient-caregiver dyads (15 patients with advanced cancer, 15 caregivers), 15 healthcare professionals.	To explore the decision-making processes and drivers of receiving palliative care in advance care planning discussions from perspectives of patients, families, and healthcare professionals.	Qualitative: Semi-structured interviews; thematic analysis.	Decision trajectories: Patients chose palliative care to reduce suffering and burdens, declined it to fulfil family priorities, or had no opportunity due to cultural and communication barriers. - Family influence: Caregivers dominated discussions, often prioritising family harmony over patient preferences. - Cultural barriers: Filial piety and mutual emotional protection between patients and caregivers hindered open discussions about end-of-life care. - Healthcare challenges: Inconsistent communication and limited professional skills in EOL discussions reduced informed decision-making.

Lin et al. (2020) ⁴⁷	Inpatient hospice, palliative care unit, and outpatient clinics in one tertiary centre, northern Taiwan	108 participants: 54 patient-caregiver dyads (54 patients with advanced cancer, 54 caregivers).	To compare preferences on the timing for advance care planning (ACP) and life-sustaining treatment withdrawal between terminally ill cancer patients and their family caregivers.	Quantitative: Prospective; survey; self-reported questionnaires based on clinical scenarios of frailty stages and treatment withdrawal preferences; descriptive statistics, and Chi-square and Fisher's exact test for comparative analysis.	Shared decision-making: Patients and caregivers preferred initiating ACP discussions during the non-frail stage (80% agreement). The majority reported that frailty was the indicator to withdraw certain life-sustaining treatments. - Relational autonomy: Decisions reflected family-oriented values of harmony and filial piety, rather than individualistic autonomy. - Caregiver influence: Caregivers prioritised continuation of artificial nutrition and hydration due to emotional and cultural obligations, even when frailty was recognised as a withdrawal indicator. - Early discussions: ACP discussions were considered meaningful and non-distressing by both patients and caregivers.
McCauley et al. (2023) ¹⁸ McCauley et al. (2023) ³⁶ Foley et al. (2024) ³⁵	One regional specialist care service comprising two hospice sites, Ireland	36 participants: 15 patients (n=14 advanced cancer, n=1 neurodegenerative) and 21 caregivers (includes 14 patient-caregiver dyads).	To identify processes of mutual support between patients and family caregivers in palliative care, how reciprocal support between patients and caregivers impacts decision-making in palliative care, and how patients with advanced illness and family caregivers accommodate each other in decision-making.	Qualitative: Grounded theory; semi-structured interviews, grounded theory analysis.	Mutual emotional support: Patients and caregivers reciprocated emotional support to maintain normalcy and cope with illness. - Decision-making collaboration: Patients involved caregivers in care decisions to support caregiver adjustment and which gave caregivers a sense of control. - Caregiver influence: Caregivers often guided discussions about care options, balancing their emotional needs with patient preferences. Decision-making was influenced by whether caregiving was driven by obligation or choice. - Disclosure and concealment: Protective communication behaviours shaped how both parties expressed or concealed preferences and emotions. - Communication: Open discussions improved alignment of care preferences. - Relational accommodation: Patients adjusted their preferences to reduce caregiver burden, and caregivers adjusted their preferences to support patient autonomy. Prior conflict between the patient and caregiver reduced mutual accommodation.
McCarthy et al. (2016) ⁵⁰	Hospice Malaysia, a community-based hospice care, Malaysia	34 participants: 14 patients with advanced cancer, 13 family caregivers, and 7 nurses (includes 13 patient-caregiver dyads).	To explore the experiences and needs of patients with advanced cancer receiving community palliative care and of their formal and informal caregivers.	Qualitative: Semi-structured interviews, focus groups; thematic analysis.	Family-led decision-making: Families often made treatment decisions, sometimes shielding patients from full disclosure, reflecting cultural norms. - Deference to healthcare professionals: Patients typically trusted doctors to lead decisions, though some caregivers sought greater involvement over time. - Communication barriers: Limited honest dialogue between healthcare teams and families hampered shared decision-making efforts. - Emotional and spiritual coping: Caregivers faced high emotional distress but drew strength from spiritual beliefs to navigate challenges. - Cultural acceptance of suffering: Cultural and religious values framed suffering as natural, influencing decisions to prioritise comfort over aggressive interventions.
McDonald et al. (2023) ³⁹	An integrated respiratory and palliative care service in a tertiary hospital, Victoria, Australia	23 participants: 10 patients with advanced lung disease (n=9 COPD, n=1 interstitial lung disease), 8 caregivers, 5 general practitioners (includes 4 patient-caregiver dyads).	To explore patients with advanced lung disease, caregiver, and general practitioner views on integrated respiratory and palliative care services to understand which services were considered valued and effective.	Qualitative: Semi-structured interviews; constant comparative method.	Integrated care: Patients and caregivers valued combining disease-focused and palliative approaches, supporting shared decision-making. - Divergent preferences: Patients varied in readiness to discuss future care, while caregivers advocated for early planning. - Communication gaps: Caregivers bridged discussions between patients and professionals to align care preferences. - Physician role: Holistic approaches improved patient autonomy and caregiver confidence. - Emotional advocacy: Caregivers relied on professionals to facilitate sensitive discussions about death.

McPherson et al. (2014)⁴¹	Home-based palliative care coordinator organisation, Canada	33 participants: 18 patients with advanced cancer, 15 caregivers (includes 15 patient-caregiver dyads).	To explore the roles and perspectives of older patients with advanced cancer receiving palliative care at home and their caregivers in managing pain at home.	Qualitative: Semi-structured interviews; thematic analysis.	Collaborative/independent decision-making: Patients and caregivers adjusted roles as patient functionality changed. Patients often opted for self-managed pain as not to be a burden. - Communication challenges: Barriers in pain expression impacted timely and effective care. - Caregiver role: Advocated for patients, managed medications, and observed non-verbal cues of pain. Caregivers emphasised the importance of early preparation and acquiring practical caregiving skills to manage pain effectively at home. - Complex pain management: Decisions balanced efficacy of interventions with side effects, often requiring caregiver intervention.
Nysaeter et al. (2024)⁵³	Six different municipalities with cancer care coordinator, southeast Norway	11 participants: 11 family caregivers of patients with advanced cancer (9 caregivers from patient-caregiver dyads and 2 bereaved caregivers).	To explore family caregivers' preferences for support from specialist home-based services to enable a home death when caring for a family member with cancer at the end of life who wished to die at home.	Qualitative longitudinal: Grounded theory, semi-structured interviews; constant comparative method.	Control and action: Caregivers emphasised maintaining control and being prepared for emergencies with practical training. - Collaborative care: Caregivers valued involvement in decisions and integration into care teams. - Emotional and practical needs: Balancing emotional presence with practical caregiving tasks influenced decision-making. - Duty and love: Caregivers' motivation to fulfil patient wishes framed their decision-making approach.
Pautex et al. (2018)⁵⁴	Four palliative care units (across French, German, and Italian-speaking regions), Switzerland	263 participants: 143 advanced cancer patients, 69 caregivers, 43 nurses, and 8 physicians (includes 69 patient-caregiver dyads).	To understand if certain palliative care patients' characteristics play a role in their decision whether to complete an advance directive or not; and to understand preferences for information and involvement in decision-making about advance directives among palliative care patients and their relatives.	Quantitative: Prospective; demographic questionnaire, Mini-Mental State Examination, Edmonton Symptom Assessment Scale, Hospital Anxiety and Depression Scale, Functional Assessment of Chronic Illness Therapy-Spiritual scale, and decision-making preferences questionnaires; Statistical analysis using bivariate association, Fisher's exact test, Mann-Whitney U test, and Student t test.	Shared decision-making: 38% preferred shared decision-making; 36% preferred decisions after consulting with doctors. - Barriers to advance directive completion: Only 11% completed an advance directive before hospitalisation, with lack of awareness cited by 60% of non-completers. - Caregiver role: 61% expected relatives to communicate their wishes to physicians and make joint decisions, but 33% of caregivers wanted more active involvement. - Regional differences: Italian-speaking patients were more likely to defer to physicians, while German-speaking patients were more proactive in planning.
Rafii et al. (2020)⁵¹	Oncology wards and palliative medicine clinics in hospitals affiliated with Iran University of Medical Sciences, Iran	52 participants: 20 patients with advanced cancer and 32 family caregivers (includes 20 patient-caregiver dyads).	To explore and describe advanced cancer patients' and family caregivers' perspectives of pain management at home.	Qualitative: Grounded theory; unstructured interviews; constant comparative method.	Hierarchical approach: Caregivers employed strategies, starting with non-pharmacological methods before escalating to narcotics. - Decision-making: Decisions were reassessed continuously in response to pain severity and treatment effectiveness. - Caregiver advocacy: Caregivers played a critical role in managing patient pain and advocating for appropriate interventions. - Barriers: misconceptions about pain management and a lack of healthcare support limited decision-making capacity. - Emotional interaction: Strong patient-caregiver relationships enhanced communication and decision-making effectiveness. Sometimes carers overruled patient wishes, especially when concerned about addiction, creating family conflict.

Riesinger et al. (2021)⁵⁷	Acute stroke unit in a secondary/tertiary care hospital, Austria	37 participants: 20 patients with severe ischemic stroke, 17 family members, 18 healthcare professionals [physicians and nurses] (includes 17 patient-family member dyads).	To explore decision-making processes and the involvement of specialist palliative care in the acute phase of stroke care and evaluate decision-making in the context of limiting life-sustaining therapies in severe stroke.	Quantitative: Prospective; patient demographic and medical data, standardised family questionnaire of decision-making and satisfaction with care, stroke team questionnaire on their approach to limiting life-sustaining treatments; descriptive statistics.	Surrogate decision-making: 85% of patients were incapable of making decisions, with families acting as proxies. - Collaborative decision-making: Physicians and families cooperated in life-sustaining therapy decisions, with 88% family satisfaction. - Withholding life-sustaining therapies: All patients had a do-not-resuscitate order; physicians withheld artificial nutrition in 86% of cases, while nurses reported withholding it in 30%. - Palliative care support: Specialist palliative care focused on symptom management (70%), transfer assistance (65%), and family communication (55%).
Selman et al. (2017)²⁵	Six urban hospitals (3 in England, 2 in Ireland, and 1 in USA)	91 participants: 26 patients with advanced illness, 32 caregivers, and 33 healthcare professionals, including specialist palliative care staff [11 physicians, 15 nurses, 7 from other healthcare professions] (includes 25 patient-caregiver dyads). Patient diagnosis: n=20 advanced cancer, n=6 other (other not reported).	To explore challenges and facilitators of empowerment among older adults with advanced disease in hospitals and the impact of inpatient specialist palliative care involvement on patient empowerment.	Qualitative: Ethnography; interviews and observation; thematic analysis.	Barriers to empowerment: Poor communication, fragmented care, and deprioritisation of relational care disempowered patients. - Role of specialist palliative care (SPC): SPC staff facilitated empowerment by providing tailored, patient-centred communication. - Caregiver advocacy: Caregivers advocated for patient preferences but faced systemic challenges to engagement. - Empowerment needs: Effective communication, continuity of care, and organisational focus on patient experience were identified as critical facilitators of empowerment.
Thomas et al. (2004)³³	Specialist palliative care services, northwest England	59 participants: 41 patients with advanced cancer, 18 caregivers (includes 18 patient-caregiver dyads).	To examine preferences for place of death among terminally ill cancer patients and their caregivers, and what factors influence their preferences.	Qualitative longitudinal: Semi-structured interviews; thematic analysis.	Different preferences: Place of death preferences evolved based on caregiving capacity, symptom management needs, and resource availability. - Caregiver influence: Caregivers' capacity and willingness to care shaped patient preferences. - Systemic influences: Positive hospice experiences increased preferences for hospice deaths; negative hospital encounters led to avoidance of hospital deaths. - Factors shaping preferences included dignity concerns, informal care networks, and access to professional support.
Valentino et al. (2022)⁵⁸	Oncology reference centre/hospital, Brazil	380 participants: 190 patient-caregiver dyads (190 patients with advanced cancer, 190 caregivers).	To determine the concordance between the preferred place-of-death of a sample of seriously ill cancer patients and their caregivers, and its associated factors under four different end-of-life scenarios.	Quantitative: Cross-sectional observational; demographic and clinical information, Hospital Anxiety and Depression Scale, feeling a burden to others questionnaire, patients and caregivers' preference for place of death covering four different scenarios; descriptive statistics, and inferential statistics using Shapiro-Wilk test, Chi-square test, Fisher's Exact test, Mann-Whitney Test, and T-test.	Preference-based decision making: Patients preferred home death in general deterioration scenarios (63.7%), while caregivers showed a stronger preference for institutional settings like hospitals or palliative care units. - Cultural and practical Influences: Caregivers prioritised professional support and symptom management, leading to a higher preference for hospital deaths in severe symptom scenarios (48.9%). - Patient-caregiver agreement: Agreement on preferred place of death was low to moderate ($k = 0.237-0.430$), reflecting discordant decision-making styles. - Influencing factors: Caregiver employment and patient health perception were significant factors driving disagreement.

Vidal et al. (2022)²⁶	Acute palliative care unit and outpatient supportive care centre, MD Anderson Cancer Centre, USA	432 participants: 216 patient-caregiver dyads (216 patients with advanced cancer, 216 caregivers).	To determine the place of death preference among palliative care patients with advanced cancer, and to compare subjective perceptions between patients and their family caregivers about preferred place of death.	Quantitative: Cross-sectional; demographic and clinical information; questionnaire at two points; descriptive statistics, and inferential statistics using Chi-square test, Fisher's exact test, and Cohen's kappa statistic.	Preference-based decision-making: Overall, 65% of patients preferred home death, 19% hospital death, 13% no preference, and 3% other. 58% of patients in the acute palliative care unit preferred home death in comparison to 72% of patients in an outpatient centre. - Patient-caregiver alignment: High agreement on home death preferences (86%) but lower agreement for hospital death (30%) and no preference (42%). - Preference change: After 1 month, outpatients were significantly more likely than palliative care unit patients to have the same preferred place of death as they had 1 month earlier.
Vig et al. (2010)²⁷	Three hospice organisations and hospice coordinators at two hospitals in, USA	49 participants: 10 patients with advanced illness and 20 family members (includes 6 patient-family member dyads), 9 nurses, 2 physicians and 8 national hospice experts. Patient diagnosis not reported.	To identify reasons patients who had a hospice admissions visit did not enrol in hospice; and identify how hospice admissions staff and hospice experts respond to hospice-eligible patients' reasons for not enrolling.	Qualitative: Semi-structured interviews with patients and family members who declined hospice after an admissions visit (including reasons why they declined), and with hospice staff and experts about addressing non-enrolment reasons; Content analysis.	Not ready: Delayed enrolment due to misconceptions about hospice care and reluctance to acknowledge terminal illness. - Caregiver advocacy: Caregivers often advocated for hospice enrolment but faced resistance from patients. - Communication barriers: Lack of consistent communication from healthcare professionals limited timely decisions. - Systemic issues: Misunderstandings about hospice services and eligibility criteria created additional hurdles. - Family dynamics: Conflicts between patients and caregivers further complicated decision-making processes.
Von Blanckenburg et al. (2022)⁴²	Outpatient chemotherapy centre in a University Hospital, Germany	151 participants: 85 palliative (advanced) cancer patients, 66 caregivers (includes 66 patient-caregiver dyads).	To investigate differences between palliative cancer patients and their caregivers regarding expectations of end-of-life (EOL) communication, EOL fears, and experiences with EOL communication.	Quantitative: Cross-sectional; demographic and clinical data, structured questionnaire on EOL communication, Hospital Anxiety and Depression Scale; (multivariate) analysis of variance, (multivariate) of covariance, and univariate analysis of covariance.	Shared decision-making: Patients and caregivers preferred collaborative decisions with physicians (95.3% of patients; 92.4% of caregivers). - Emotional barriers: Patients avoided EOL topics more often, while caregivers showed higher fear and anxiety levels ($p < 0.001$). - Self-other asymmetry: Both groups expected emotional relief from discussions but feared burdening the other, leading to avoidance. - Professional role: Healthcare professionals were seen as essential facilitators of EOL communication to overcome emotional barriers and foster patient and caregiver alignment.
Waldrop and Meeker (2012, 2014)^{28, 29}	Two hospice organisations in, northeastern USA	91 participants: 36 hospice patients and 55 caregivers (exact number of patient-caregiver dyads not clearly indicated). Patient diagnosis: n=21 advanced cancer, n=15 other (other advanced illness not fully reported).	To explore the process of decision-making for patients about hospice enrolment; identify factors that influence the timing of that decision; and describe decisions faced by newly enrolled hospice patients and their caregivers after hospital enrolment.	Qualitative study: Semi-structured interviews; Content analysis.	Hospice enrolment activated decisions on advance care planning, surrogate roles, meaning-making, location of death, and final acts. - Surrogate roles: Caregivers assumed increasing responsibility for practical and emotional decision-making. - Meaning-making: Patients and caregivers focused on creating significant memories and completing tasks for closure. - Barriers and facilitators: Mutual patient-caregiver protection and emotional avoidance reduced decision-making transparency, while hospice staff facilitated critical conversations. - Caregiver roles: Caregivers played a key role in initiating discussions and advocating for hospice care. - Relationship styles: Decisions were collaborative when balancing patient needs and caregiver capacity.

Worth et al. (2006)³⁴	Three general practice out-of-hours cooperative areas (urban, semi-urban, and rural), Scotland	105 participants: 36 patients with advanced cancer and 19 caregivers (includes 15 patient-caregiver dyads), and 50 healthcare professionals (general practitioners, district nurses, out-of-hours service personnel, palliative care specialists, and hospital staff).	To explore the experiences and perceptions of out-of-hours palliative care among advanced cancer patients, their informal carers, and healthcare professionals.	Qualitative: Semi-structured interviews, focus groups, and telephone interviews; Constant comparative method for analysis.	Reactive decision-making: Patients delayed seeking care until crises arose, driven by anxiety and a lack of clear information. - Caregiver role: Caregivers advocated for patients, mediated emotional and logistical barriers, and coordinated care access. - Systemic barriers: Impersonal triage and fragmented care systems hindered proactive decision-making. - Communication: Empathy and clarity in communication were key facilitators of positive experiences. - Anticipatory needs: Structured guidance and continuity of care were emphasised as critical for reducing anxiety and enabling effective decision-making.
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