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A systematic review and narrative synthesis of patient and family caregiver concordance and discordance in decision-making in palliative care

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Figure 1. PRISMA flow diagram

## **Abstract**

**Background** Decision-making in palliative care usually involves both patients and family caregivers. However, how concordance and discordance in decision-making manifest and function between patients and family caregivers in palliative care is not well understood.

**Objectives** To identify key factors and/or processes which underpin concordance and/or discordance between patients and family caregivers with respect to their preferences for and decisions about palliative care; and ascertain how patients and family caregivers manage discordance in decision-making in palliative care.

**Methods** A systematic review and narrative synthesis of original studies published in full between January 2000 and June 2021, was conducted using the following databases: Embase; Medline; CINAHL; AMED; Web of Science; PsycINFO; PsycARTICLES; and Social Sciences Full Text.

**Results** After full-text review, 39 studies were included in the synthesis. Studies focused primarily on end-of-life care, and on patient and family caregiver preferences for patient care. We found that discordance between patients and family caregivers in palliative care can manifest in relational conflict and can result from a lack of awareness of and communication about each other's preferences for care. Patients' advancing illness and impending death together with open dialogue about future care including advance care planning can foster consensus between patients and family caregivers.

## **Conclusions**

Patients and family caregivers in palliative care can accommodate each other's preferences for care. Further research is needed to fully understand how patients and family caregivers move towards consensus in the context of advancing illness.

**Key words:** Systematic review, decision-making, care preferences, family caregiver, patient, palliative care, concordance, discordance

## Key messages for box

What was already known?

- Family caregivers provide high levels of informal care
- Patients and family caregivers can differ in their preferences for care

What are the new findings?

- Discordance can be underpinned by relational conflict
- Advancing patient illness and impending death foster consensus

What is their significance?

Clinical

- Open communication can reduce discordance between patients and family caregivers

Research

- Consensus through advance care planning warrants further investigation

## INTRODUCTION

Family caregivers have significant caregiving roles in palliative care, providing important support to the person they care for.[1] Family caregivers provide a combination of physical, psychological, emotional, social, and financial support to the person with a life-limiting illness. Care is an inherently relational activity which widens the focus of palliative care to family.[2] Assuming caregiving responsibilities for a significant other with palliative care needs often means that family caregivers are, by choice or circumstance, involved in decision-making in palliative care.[3, 4]

Decision-making among patients and family caregivers in palliative care is complex. Patient and family caregiver preferences for care are shaped by one another because how patients and family caregivers navigate the illness journey is rarely independent of each other. Patients face difficult decisions about multiple domains of care (e.g., symptom management, advance care planning, and end-of-life care),[5] and engage with a range of healthcare professionals who deliver formal care.[6] In some cases, healthcare professionals situate the patient's perspective central to care plans, but patients also become dependent on their family caregivers.[7] Family caregivers in palliative care provide the majority of caregiving which their relative or friend receives[8, 9] and often function as key advocates and care coordinators.[10] Family caregivers in palliative care make decisions with patients or sometimes for patients in situations where decision-making has been delegated.[3] Indeed, family caregiver perceived burden can be a function of increasing family caregiver responsibility for decision-making.[4] Family caregivers in palliative care themselves also have care needs that are addressed by formal services including for example, psychosocial support and respite services,[11] but there has been less focus on how patients impact on the decision-making process pertaining to formal care and support accessed by family caregivers. Lastly, whilst the palliative care approach recognises the needs of both patients and family caregivers,[12] not all patients seek to involve significant others when making decisions about care, even when a significant other is available.

We know that patients and family caregivers in palliative care can have similar and different preferences for care, and that patient and family caregiver preferences and needs can diverge with illness progression.[13] Moreover, patients and family caregivers can have different perceptions of treatment decision-making processes.[14] However, prior to this review, it was unclear how concordance or discordance manifest and function between patients and family caregivers in palliative care, with respect to their preferences for care and the decisions they make about care. Moreover, little was known about how patients and family caregivers manage their discordance when making decisions about care. Hence, the aims of this systematic review were to first, identify key factors and/or processes which underpin concordance and/or discordance between patients and family caregivers in decision-making in palliative care, and second, determine how patients and family caregivers manage their discordance in decision-making in palliative care.

## **METHODS**

We conducted a systematic review with narrative synthesis[15] of original evidence on concordance and discordance between patients and family caregivers in palliative care, pertaining to their preferences for care and decision-making in care. The review was conducted between June and September 2021 and the full search was run in June 2021. We carried out the search in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)[16] to detail the numbers of records found, included and excluded, and the reasons for exclusion.

### **Search strategy**

The search was conducted using the following databases: Embase; Medline; CINAHL; AMED; Web of Science; PsycINFO; PsycARTICLES; and Social Sciences Full Text. A Boolean search strategy was first devised by authors SMS and DM in Embase and reviewed and approved by GF. The search terms were agreed through multiple rounds of discussion between SMS, DM, and GF, to ensure that all terms were relevant and comprehensive. The search strategy was then tailored to the other

databases searched. All search terms and the full search strategy are detailed in the online supplementary Appendix 1.

### **Inclusion/exclusion criteria**

We included original peer-reviewed research, published in full and in English between January 2000 and June 2021. We limited our search to this period because more historical data may not be as relevant to current practice in the context of social change over time. We took the definition of palliative care as active holistic care of individuals with serious health-related suffering due to severe illness.[17] Only studies in which data had been captured from the patient *and* family caregiver were included. This was because the focus of the review lay in the context of the relationship between patients and family caregivers. Studies were included if they reported on dimensions of (or any factors associated with) concordance and discordance between patients and their family caregivers, which pertained to their preferences for care and/or decision-making in care. The term 'family' in palliative care includes not only formalised or familial-based relationships, but also those that are patient-defined or self-defined as significant. Our definition of family caregiver extended beyond familial-based relationships, and we included studies where family caregivers were family members, friends, or any other form of significant other once they had been recruited as participants who had provided and/or were providing informal care and/or support to the patient. The review was limited to studies where patient participants were  $\geq 18$  years.

We did not limit the review to specialist palliative care or to end-of-life care, but we did exclude studies where patient participants did not have clearly advancing and non-curable conditions. In addition, although our inclusion was aimed at original peer-reviewed studies, we excluded intervention-based studies including randomised-controlled trials as their focus was on acceptability or effectiveness of a given intervention rather than on explaining concordance or discordance in decision-making. We also excluded single-case studies. Studies which reported only on the patient or only on the family caregiver were excluded.



## **Extraction**

The full search found 4,782 records in total. The full set of records were uploaded to Covidence[18] and 2,011 duplicates removed. SMS and GF screened all remaining records by title and abstract following the inclusion/exclusion criteria. 2,601 records were deemed not relevant. The remaining 170 records were then sought for full retrieval by SMS and assessed for eligibility. Any uncertainty regarding inclusion or exclusion of studies from this point was resolved by a collective review of the full text by SMS and GF. Figure 1 outlines the PRISMA flow diagram of the conducted review and the number of studies that met the criteria for inclusion.

## **Quality assessment**

We used the Standard Quality Assessment Criteria for Evaluating Primary Research Papers[19] and the Mixed Methods Appraisal Tool (MMAT)[20] to assess the quality of the included studies[21-59]. Twenty-one quantitative,[21-41] 15 qualitative,[42-56] and three mixed-methods[57-59] studies were included in the review. The Standard Quality Assessment Criteria for Evaluating Primary Research Papers was used to appraise the quantitative and qualitative studies because it allows for a replicable method of assessing the quality of a quantitative or qualitative study. Quality rating or summary scores range between 0 and 1.0 for each study. SMS appraised these studies, and GF independently scored a subset for internal consistency. The summary scores across the studies ranged between good to strong scores, with no study scoring below 0.7. The quality of the mixed-methods studies was assessed using the MMAT, chosen because it includes the option for assessing the quality of a mixed-methods study and accounts for the characteristics specific to each component (i.e., qualitative, quantitative, and mixed methods) of a mixed-methods study. The mixed-methods studies were appraised to be of moderate to high quality. We tabulated all of the 39 included studies into a table (see online Supplementary Table) under the standard domains of authors, location/setting, participants, aims, methods, and key findings. Tables 1,2, and 3 outline the quality assessment of the included studies.

## **Synthesis**

We conducted a narrative synthesis[15] of the selected studies. A narrative synthesis is commonly used to synthesise studies in a review when studies are heterogenous in design. First, we looked at all evidence in each study which reported on concordance and/or discordance between patients and family caregivers with respect to the focus of the review. We then undertook a preliminary synthesis of the studies. This comprised an exhaustive search in each study for factors and/or processes which related to or helped explain, concordance and/or discordance between patients and family caregivers in terms of their preferences for care and/or decision-making in care. Here, we undertook a short textual description for each study and tabulated the findings from each study.[15]

We then explored relationships in the data by comparing the above findings between and across studies.[15] We looked for both similarities and differences in the findings and documented these frequently by engaging in qualitative descriptions of the data.[15] We proceeded with expansion of the synthesis via clustering or grouping the findings into categories that best accounted for relationships between the findings and helped answer the aims of the review. The grouping of findings into categories was done collectively by SMS and GF, and the naming of categories was agreed between SMS and GF. The robustness in the synthesis was underpinned by the quality of the studies included in the review and by each study having clearly met the criteria for inclusion.[15]

Table 1. **Quantitative studies.** Quality assessed using the Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields.

Authors	Question/objective sufficiently described?	Study design evident and appropriate?	Method of subject/comparison group selection or source of information/input variables described and appropriate?	Subject (and comparison group, if applicable) characteristics sufficiently described?	If interventional and random allocation was possible, was it described?	If interventional and blinding of investigators was possible, was it reported?	If interventional and blinding of subjects was possible, was it reported?	Outcome and (if applicable) exposure measure(s) well defined and robust to measurement/misclassification bias? Means of assessment reported?	Sample size appropriate?	Analytic methods described/justified and appropriate?	Some estimate of variance is reported for the main results?	Controlled for confounding?	Results reported in sufficient detail?	Conclusions supported by the results?	Summary Score		
An <i>et al.</i> 21	2	2	2	1	N/A	N/A	N/A	2	2	1	1	2	2	2	0.86	Yes	2
Bukki <i>et al.</i> 22	2	2	2	2	N/A	N/A	N/A	2	1	2	2	0	2	2	0.86	Partial	1
Davies <i>et al.</i> 23	2	2	2	1	N/A	N/A	N/A	2	1	2	2	1	1	2	0.82	No	0
Engelberg <i>et al.</i> 24	2	2	2	2	N/A	N/A	N/A	2	1	2	1	1	2	2	0.86	NA	
Gao <i>et al.</i> 25	2	2	2	2	N/A	N/A	N/A	2	1	2	1	2	2	2	0.91		
Hauke <i>et al.</i> 26	2	2	2	2	N/A	N/A	N/A	2	1	1	0	1	2	2	0.77		
Heyland <i>et al.</i> 27	2	2	2	2	N/A	N/A	N/A	2	2	2	1	1	2	2	0.91		
Heyland <i>et al.</i> 28	2	2	2	1	N/A	N/A	N/A	2	1	2	2	0	2	0	0.73		
Hwang <i>et al.</i> 29	1	2	2	2	N/A	N/A	N/A	2	1	2	1	1	2	2	0.82		
Kim <i>et al.</i> 30	2	2	2	2	N/A	N/A	N/A	2	1	2	2	2	2	0	0.86		
Ozdemir <i>et al.</i> 31	2	2	2	2	N/A	N/A	N/A	2	1	2	1	2	2	2	0.91		
Pruchno <i>et al.</i> 32	2	2	1	2	N/A	N/A	N/A	2	1	1	2	2	2	2	0.86		
Sharma <i>et al.</i> 33	2	2	2	2	N/A	N/A	N/A	2	1	2	1	2	2	2	0.91		
Shin <i>et al.</i> 34	2	2	2	2	N/A	N/A	N/A	1	2	1	2	2	1	2	0.86		
Stajduhar <i>et al.</i> 35	2	2	2	2	N/A	N/A	N/A	1	1	2	0	2	2	2	0.82		
Tang <i>et al.</i> 36	2	2	2	2	N/A	N/A	N/A	2	2	1	2	2	2	2	0.95		
Tobin <i>et al.</i> 37	2	2	2	2	N/A	N/A	N/A	1	2	2	1	2	2	2	0.91		
Wen <i>et al.</i> 38	2	2	1	2	N/A	N/A	N/A	2	2	2	1	2	2	2	0.91		
Yoo <i>et al.</i> 39	2	2	2	2	N/A	N/A	N/A	1	1	1	2	2	2	2	0.86		
Yun <i>et al.</i> 40	1	2	1	2	N/A	N/A	N/A	2	2	2	2	2	2	2	0.91		
Zhang <i>et al.</i> 41	2	2	1	2	N/A	N/A	N/A	1	2	2	2	2	2	2	0.91		

The summary score for each study is derived by calculating the total score of relevant items (i.e., all items except those 'not applicable') and dividing it by the total possible score when excluding 'not applicable' items.

Table 2. **Qualitative studies.** Quality assessed using the Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields.

Authors	Question/ objective sufficiently described?	Study design evident and appropriate?	Context for the study clear?	Connection to a theoretical framework/ wider body of knowledge?	Sampling strategy described, relevant and justified?	Data collection methods clearly described and systematic?	Data analysis clearly described and systematic?	Use of verification procedure(s) to establish credibility? (Yes or No only)	Conclusions supported by the results?	Reflexivity of the account?	Summary Score		
Cheung <i>et al.</i> 42	2	2	2	2	2	2	2	2	1	0	0.85	Yes	2
Clarke <i>et al.</i> 43	2	2	1	2	1	1	2	2	2	1	0.8	Partial	1
de Graaff <i>et al.</i> 44	2	2	2	2	2	2	2	2	1	1	0.9	No	0
Dees <i>et al.</i> 45	2	2	2	2	1	1	2	2	2	1	0.85		
Gerber <i>et al.</i> 46	2	2	2	2	2	2	2	2	2	0	0.9		
Gerber <i>et al.</i> 47	2	2	2	2	1	2	1	2	1	1	0.8		
Holdsworth & King48	2	2	2	2	1	2	1	0	1	1	0.7		
Luijkx & Schols49	2	2	2	2	1	2	1	0	2	0	0.7		
Piil <i>et al.</i> 50	2	2	2	2	2	2	1	2	1	0	0.8		
Preisler <i>et al.</i> 51	2	2	2	2	2	2	2	0	2	1	0.85		
Sellars <i>et al.</i> 52	2	2	2	2	2	2	2	2	2	1	0.95		
Simon <i>et al.</i> 53	2	2	2	2	2	2	2	2	2	0	0.9		
Thomas <i>et al.</i> 54	1	2	2	2	1	2	2	2	2	1	0.85		
Yurk <i>et al.</i> 55	1	2	2	2	2	1	2	2	2	1	0.85		
Zhang & Siminoff.56	2	2	2	2	2	2	1	2	1	1	0.85		

The summary score for each study is derived by calculating the total score obtained across the ten items and dividing by 20 (the total possible score).

Table 3. **Mixed-methods studies.** Quality assessed using the Mixed Methods Appraisal Tool (MMAT).

Criteria for mixed-method characteristics of mixed-methods studies

Authors	S1. Are there clear research questions?	S2. Do the collected data allow to address the research questions?	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?	5.2. Are the different components of the study effectively integrated to answer the research question?	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?
Kim <i>et al.</i> 57	Yes	Yes	No	Yes	Yes	Yes	Partial
Nolan <i>et al.</i> 58	Yes	Yes	Partial	Yes	Yes	Yes	Partial
Puts <i>et al.</i> 59	Yes	Yes	Yes	Partial	Partial	Yes	Partial

Criteria for qualitative component of mixed-methods studies

	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?
Kim <i>et al.</i> 57	Partial	Yes	Yes	Yes	No
Nolan <i>et al.</i> 58	Partial	Yes	Yes	Yes	Yes
Puts <i>et al.</i> 59	Yes	Yes	Yes	Yes	Yes

Criteria for quantitative component of mixed-methods studies

	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?
Kim <i>et al.</i> 57	Yes	Partial	Yes	No	Yes
Nolan <i>et al.</i> 58	Yes	Partial	Yes	Partial	Yes
Puts <i>et al.</i> 59	Yes	Partial	Can't tell	No	Partial

Rating mixed-methods studies using MMAT involves scoring criteria 1.1.-1.5. [Qualitative dimension] plus (criteria 2.1.-2.5.[Quantitative - RCTs] or criteria 3.1.-3.5.[Quantitative - nonrandomised trials] or criteria 4.1.-4.5.[Quantitative descriptive]) plus criteria 5.1.-5.5.(Mixed methods).

Criteria 2.1.-2.5. or criteria 3.1-3.5. of the MMAT are not listed here because none of these studies are intervention studies.

## RESULTS

### Summary of studies

Studies were conducted in Australia,[46, 47, 52] the United States,[24, 25, 32, 33, 41, 55, 56, 58] Canada,[27, 28, 35, 53, 59] Denmark,[50] UK,[23, 43, 48, 54] Ireland,[37] South Korea,[21, 29, 30, 34, 39, 40, 57] Taiwan,[36, 38] Singapore,[31] Germany,[22, 26, 51] Hong Kong,[42] and the Netherlands.[44, 45, 49] Quantitative studies reported more on factors associated with concordance and/or discordance whilst qualitative studies reported on reasons for and/or processes underpinning concordance and discordance. None of the studies aimed from the outset to investigate how patients and family caregivers manage discordance in decision-making.

The studies investigated a range of palliative and end-of-life care domains and contexts, including place of death,[23, 24, 35, 36, 46, 48, 54] advance care planning and advance directives,[30, 39, 42, 52, 53, 57] euthanasia,[45] artificial nutrition and hydration,[22, 43] cardiopulmonary resuscitation,[27, 29] hospice care,[21, 49] end-of-life care in general (including life-sustaining treatment, life-extending treatment, and treatment approaching death)[23, 25, 38, 47] and more broadly, care over the disease trajectory.[50, 51] Other studies focused more specifically on patients' and family caregivers' preferences, values and judgements with respect to care,[28, 32-34, 37, 40, 55], and on the family caregiver and the broader family role in the decision-making process.[26, 31, 41, 44, 56, 58, 59] Although many studies examined concordance in care preferences and decision-making between patients and family caregivers, only nine studies explicitly focused on discordance, disagreement, and/or conflict between patients and family caregivers.[26, 28, 29, 31, 37, 40, 41, 44, 56].

Just over half of the studies included had a cancer-only patient population,[21-23, 25, 26, 29, 30, 34, 36, 38-41, 44, 50, 51, 54, 56, 57, 59] whilst other studies included patient populations for specific diseases including end-stage kidney disease [31, 32, 52] and amyotrophic lateral sclerosis,[33, 37, 58] or a patient population comprising different progressive neurological diseases.[43] The

remaining studies recruited patient populations across a spectrum of advanced illness and disease. Care settings included specialist cancer centres, inpatient and outpatient hospital care, specialist palliative care (including hospice care), a nursing home, and home care. In a minority of studies, patient participants were recruited through hospice or other dedicated and/or specialist palliative care settings.[23, 24, 42, 44-49, 54] Family caregivers were primarily spouses or partners, but also included parents, adult children, siblings, and friends. Overall, family caregiver participants comprised a combination of significant others and varied both within and across studies. The sample in some studies was limited to patient-caregiver dyads only.[21, 23-25, 29-36, 38, 40, 57, 58] The narrative synthesis resulted in the following categorisation of the findings.

### **Aligned and misaligned preferences and priorities**

Several studies investigated patient and family caregiver preferences for care which were focused primarily on patient care, and for the most part, patient end-of-life care.[21-25, 28, 29, 34-36, 38-41, 46-48, 53-55, 57] Both patients and family caregivers prioritised pain and symptom management.[23, 24, 55, 57] However, patients and family caregivers differed with respect to other preferences for care. For example, patients had a strong preference for information to be provided,[37] whilst family caregivers wanted more information about end-of-life care than patients.[27] Family caregivers also wished for more healthcare professional engagement and support (including bereavement support) than did patients.[37, 55] However, patients' preferences to avoid family caregiver burden and have their personal affairs in order before death could be underestimated by family caregivers.[23, 24, 57]

Life-prolonging care versus conservative care was an area of potential conflict between patients and family caregivers. Family caregivers tended to favour more active and life-sustaining treatment options than did patients.[29, 31, 51, 52, 56, 57, 59] Some patients preferred a lesser role in decision-making[23], and trusted their family caregivers to make decisions about their care.[42, 47] However, family caregiver judgements about patient preferences were in some cases incorrect[32,

33] and related more to family caregiver preferences for care than to the patient's preferences for care.[32] Agreement between patients and family caregivers manifested when patients and family caregivers had knowledge of the disease[39] and of treatment and end-of-life care options available to the patient,[30, 57] and when family caregivers were aware of patients' preferences for end-of-life care.[23, 24, 43, 48] Conversely, discordance was associated with poor communication between patients and family caregivers[34] and manifested when patients and family caregivers had insufficient knowledge of the disease and treatment options.[28]

### **The familial context to concordance and discordance**

Conflict between patients and family caregivers and within the wider family could limit reaching agreement in decision-making about care.[40, 44, 45, 47, 51, 56] Family conflict was in some cases, more stressful for patients than the experience of receiving formal care and treatment.[51] Nonetheless, patients who preferred a more independent decision-making style were more likely to have their families report that decisions were made in the style that the patient preferred.[58] Family caregivers' family roles shaped concordance and/or discordance between patients and family caregivers.[34, 36, 59] Concordance was higher if family caregivers were spouses,[36] and spouse caregivers tended to leave final decisions up to the patient.[59] Adult-children caregivers, however, preferred a more shared decision-making style and sought more information than spouse caregivers.[59] Of note, being an adult-child caregiver was associated with concordance with patients for end-of-life care and being a parent caregiver was associated with concordance with patients for disclosure of terminal illness.[34]

### **Caregiver commitment versus caregiver burden**

Tension between family caregiver commitment to the patient and perceived burden of family caregiving featured in a number of studies.[42, 46, 49, 50, 54] Dependency on their family caregivers troubled some patients because patients wished not to be a burden on their family caregivers[42, 46, 49, 50, 54, 57, 58]. However, family caregivers were committed to providing care to alleviate



distress for patients despite the burden of care[46, 49, 50, 54] and even desired to limit information to patients to reduce psychological burden for patients.[42] Some patients and family caregivers distanced themselves from each other in decision-making to maintain a sense of normality and avoid conflict,[46] but such action could limit patient and family caregivers in sharing their concerns with each other.[46, 50] Indeed, a lack of family caregiver involvement in care could lead to negative experiences for the family caregiver surrounding patient death.[55] In many cases, family caregivers wanted to be actively involved in decision-making[26, 27, 47, 49, 50, 54] and supported patients by advocating on their behalf[47] and respecting patient autonomy.[45, 49]

### **Planning end-of-life care and place of death**

Discussion surrounding end-of-life-care was challenging for both patients and family caregivers.[43, 45, 47, 48, 56] However, planning ahead for end-of-life care was a useful coping strategy for patients and family caregivers.[46, 50] Denial of or not engaging in conversation about the impending death acted as a barrier to making decisions about care including end-of-life care.[47, 51, 52] Preference with respect to place of death featured across studies.[23, 24, 35, 36, 40, 46, 48, 54] Patients and family caregivers were generally consistent on place of death, apart from one study which reported that half of patient-family caregiver dyads disagreed on place of death.[35] Higher agreement on place of death was associated with the family caregiver being a spouse[36], the patient having high levels of functional dependency[36], patients and family caregivers having had discussed preferences[24], and patients' own assessment of family caregivers' knowledge of patient preferences.[24] Patient and family caregiver concordance was also more likely if patients and family caregivers agreed on other aspects of end-of-life care.[36] Discordance on place of death was more common in situations where family caregiver burden was high[23, 36, 46] and where patients were aware of their prognosis.[36] Family caregivers' lack of knowledge of patient preference for place for death could lead to uncertainty surrounding final decisions[48] and some family caregivers regretted when death at home was not possible.[54]

## **Managing discordance**

No study aimed from the outset to investigate how patients and family caregivers manage discordance in decision-making in care, but some studies did report ways in which patients attempted to manage discordance.[42, 54, 59] In one study, patients chose to forego their own preferences for care in favour of their family caregivers' preferences for care.[59] In another study,[42] patients did not consider advance care planning to avoid potential decisional conflict with family caregivers. However, progression of the patient's illness meant that patients and family caregivers became attuned to the benefit of reaching consensus with respect to end-of-life care decisions.[49, 50, 54] Indeed, negotiation featured when patients and family caregivers jointly decided to move to conservative care or hospice care.[49, 50]

Family caregiver lack of knowledge of patient preferences could foster uncertainty surrounding decisions.[48] However, advance care planning and advance directives opened dialogue between patients and family caregivers and in turn facilitated consensus among patients and family caregivers.[30, 39, 52, 55] Although prior communication did not necessarily improve family caregivers' substituted judgement on patients' own preferences for care,[32] advance care planning enabled family caregivers to follow patient wishes even if family caregivers differed in their preferences for care.[52] Discussing death and end-of-life care was difficult and could instigate conflict in the family, particularly when there were pre-existing tensions. However, having healthcare professionals to initiate end-of-life care conversations assisted patients and family caregivers in the decision-making process.[52, 55]

## **DISCUSSION**

The focus of this review was to identify key factors and/or processes which underpin or help explain concordance and/or discordance between patients and family caregivers in palliative care with respect to their preferences for care and the decisions they make about care, and to ascertain how they manage their discordance in decision-making pertaining to care. In this review, we found that

concordance and/or discordance between patients and family caregivers is shaped by multiple factors, including patient and family caregiver perceptions of caregiver burden,[42, 46, 49, 50, 54, 57, 58] patient resistance to burdening family caregivers,[42, 46, 49, 50, 54, 57, 58] family roles and relations,[34, 36, 40, 44, 45, 47, 51, 56, 59] family caregiver awareness of patient preference,[23, 24, 32, 33, 43, 48, 57] quality of communication between the patient and family caregiver,[34, 42, 46, 50, 51] patient and family caregiver knowledge of disease and treatment options,[28, 39] patient and family caregiver coping strategies in the context of advanced illness,[46, 50] patient and family caregiver judgements about life-prolonging treatment versus end-of-life care,[29, 31, 51, 52, 56, 57, 59] and by how accepting or not the patient and family caregiver feel towards end-of-life care and the impending death.[47-49, 52] Whilst discordance between patients and family caregivers is often associated with relational conflict,[40, 44, 45, 47, 51, 56], open discussion and dialogue about patient future care can help move patients and family caregivers towards consensus.[30, 39, 49, 50, 52, 55] All studies were conducted in economically developed countries and so the findings of the review are rooted in this context.

Some key findings in our review resonate with non-palliative care literature on how concordance and discordance manifest between patients and family caregivers in decision-making about care. For example, patients with generic healthcare needs and their family caregivers also feel conflicted about caregiver burden.[60] People with non-life-limiting illness and their family caregivers also make decisions in the context of knowledge about disease and treatment options[61], and the strain and demands of living with debilitating illness.[62] Open communication between patients with non-life-limiting illness and family caregivers can also promote consensus in decision-making.[63] In the context of palliative care, the findings of our review resonate with literature on patient and family caregiver decisional conflict.[64, 65] Patients and family caregivers in palliative care have capacity to move from periods of decisional conflict to a mutual understanding, in the context of advancing illness and the impending death.[64, 65] Moreover, patients and family caregivers can accommodate changes in one another's decision-making roles in end-of-life care.[66]

## **Clinical implications**

The findings of our review have implications for clinical care and practice. First, the evidence confirms that patients and family caregivers in palliative care have both similar and different preferences for care. However, of key importance is the fact that patients and family caregivers may not necessarily be attuned to one another's preferences. Attention to patient and family caregiver knowledge of one another's preferences and to strategies to increase patient and family caregiver mutual understanding, could help optimise the decision-making process for both patients and family caregivers. Family caregivers in some cases may favour life-prolonging interventions more than patients, but increased knowledge about patient disease and treatment options can aid discussion about end-of-life care.

Second, the evidence signals that patients and family caregivers in palliative care do have capacity to approximate to one another's preferences for care, particularly when patients approach end-of-life care, and even when both patients and family caregivers are conflicted about the burden of care. In addition to the provision of formal support to the family caregiver, open discussion between patients, family caregivers and healthcare professionals about concerns in relation to caregiver burden could prove highly beneficial for both patients and family caregivers.

Third, the review highlights the wider impact of family on patients' and family caregivers' approach to decision-making in palliative care and how the familial relationship between the patient and family caregiver shapes preferences for both patients and family caregivers. Healthcare professionals should consider the impact of the wider family on concordance and/or discordance between patients and family caregivers and the expectations of both patients and family caregivers in the context of their family roles.

## **Recommendations for research**

We identified that patient illness progression and patient and family caregiver recognition of end-of-life care and impending death, were key contexts that fostered consensus between patients and

family caregivers. Moreover, engaging in dialogue about future care was a key factor that facilitated patients and family caregivers to accommodate to differences in their preferences for care.

Systematic reviews have already focused on the effects of advance care planning for people with life-limiting illness.[67, 68] Research focused on how best to facilitate consensus between patients and family caregivers through advance care planning could prove effective for both patients and family caregivers.

As stated, we did not include intervention-based studies in our review because the focus was on factors related to and/or processes underpinning concordance and/or discordance between patients and family caregivers as opposed to how effective or acceptable interventions were to patients and family caregivers or whether patients and family caregivers differed or not on acceptability of interventions. However, from the evidence reviewed, developing interventions which focus on helping patients and family caregivers understand and accommodate each other's preferences for care could prove beneficial in alleviating concerns for both patients and family caregivers.

Only in a minority of the studies synthesised, were patient participants recruited directly from designated or specialist palliative care facilities, even though this review was limited in its focus to care preferences and decision-making among patients with clearly advancing illness and their family caregivers. Patient recruitment for research can be challenging in palliative care.[69, 70] Health status of patients can alter suddenly, and the severity of patient illness can in some cases, limit patient participation. Nevertheless, more studies that recruit patients and family caregivers from designated or specialist palliative services including hospice care, could help pinpoint more clearly how and why patients and family caregivers approximate to each other's preferences in the context of advancing illness.

Lastly, we found few studies which reported on patient and family caregiver concordance and/or discordance pertaining to formal support and care for family caregivers themselves. Although caregiver burden influenced how both family caregivers and patients approached decision-making,

studies focused from the outset on patient care as opposed to formal supports for family caregivers aimed at alleviating burden of care. Family caregivers in palliative care can and do identify their own supportive and care needs,[71, 72] but few studies have focused on agreement or disagreement between patients and family caregivers on formal support and care available to or used by the family caregiver. Studies focused on patient and family caregiver concordance and/or discordance pertaining to formal support for family caregivers (e.g., respite care and counselling) would further our understanding of what underpins concordance and/or discordance in decision-making between patients and family caregivers in palliative care.

### **STRENGTHS AND LIMITATIONS**

This review was limited to original peer-reviewed and full-text published studies between 2000 and 2021. However, including only original full-text studies allowed us to critically appraise the methodological quality of each piece of evidence included. We undertook an exhaustive search of multiple databases using a comprehensive and rigorous search strategy. We did limit the review to patients with clearly advancing illness and disease and our findings might not be transferrable to concordance and/or discordance between patients and family caregivers along the full illness trajectory. Systematic reviews on concordance and discordance between patients and family caregivers in palliative care along the full illness trajectory, or more specifically at key points prior to the advanced stages of patient illness, would further our understanding of relational decision-making between patients and family caregivers in palliative care. More longitudinal qualitative studies on concordance and discordance in decision-making between patients and family caregivers would also illuminate further how patients and family caregivers in palliative care accommodate each other's preferences for and decisions about care.

### **CONCLUSIONS**

Multiple studies in the last two decades have reported on factors associated with concordance and/or discordance in decision-making between patients and family caregivers in palliative care.

Concordance and discordance between patients and family caregivers are shaped by multiple factors including family caregiver burden, pre-existing familial roles and relations, quality of communication between patients and family caregivers, patient and family caregiver knowledge of and judgements about care, patient and family caregiver awareness of each other's preferences for care, and how accepting (or not) patients and family caregivers are of end-of-life care. Few studies have focused on how patients and family caregivers manage discordance, but there is evidence that planning future care or simply discussion about patient future care can foster consensus between patients and family caregivers. Further investigation of how patients and family caregivers manage discordance in decision-making and how healthcare professionals can best support or facilitate this is needed. We have identified key factors and/or processes which help explain how concordance and discordance manifest and function between patients and family caregivers in decision-making in palliative care. The findings of the review serve to focus future research on patient and family caregiver interdependence in decision-making in palliative care.

### **Contributors**

G.F. conceived the work and design. S.M.S. and D.M. formulated the search strategy which was approved by G.F.. S.M.S. conducted the search and screened studies. G.F. assisted with screening. S.M.S. extracted the data and both S.M.S. and G.F. appraised the studies. S.M.S. conducted the synthesis and G.F. contributed to the synthesis. G.F. wrote the manuscript with substantial contribution from S.M.S. for methods and findings sections. K.R., S.A., L.S., A.D., N.C., J.L., R.McQ., and S.G. commented on the design and/or interpretation of the data and made critical contributions to the manuscript. N.O'L., M.C., and M.R. reviewed drafts for intellectual content. All authors approved the final draft.

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**Identification of studies via databases and registers**

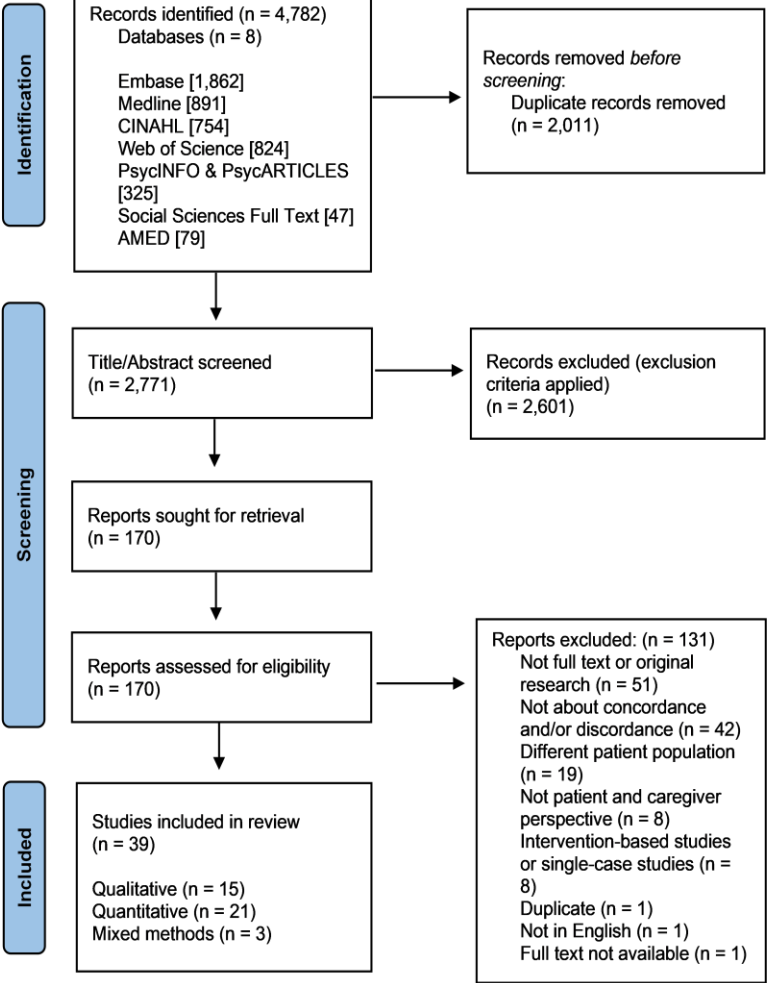




Table 1. Summary of included studies

Study	Location/setting	Participants	Aims	Methods	Findings	Summary Score
An et al. <sup>21</sup>	12 public and private hospitals, South Korea	N = 718: 359 dyads of patients with terminal cancer and their family caregivers.	To determine the association between patients' and caregivers' attitudes towards hospice palliative care and actual utilisation of care.	Quantitative: Prospective observational cohort study; Survey and medical records; Hospice palliative care preferences and utilisation; Logistic regression, Cohen's Kappa coefficient.	Patients' preferences for hospice palliative care were associated with being <60 years, religious orientation, awareness of terminal illness, presence of metastatic lesion, terminal diagnosis other than general worsening condition, and poor performance status. Caregiver preferences were associated with higher education and patient awareness of terminal illness. Caregiver preferences for hospice palliative care and religious orientation related to actual utilisation.	0.86
Bukki et al. <sup>22</sup>	A university hospital, Munich, Germany	N = 69: 39 patients with advanced cancer, 30 relatives.	To evaluate needs, concerns, and preferences with respect to decision-making on artificial nutrition and hydration (ANH) in patients and caregivers.	Quantitative: Prospective cross-sectional; Survey; ANH preferences, decision concerns and confidence of decision; Spearman correlation, Chi-square, Kruskal-Wallis.	Older patients were more likely to agree with relatives to forego ANH. Relatives were more likely to choose artificial hydration for patients than patients themselves. Relatives being informed of ANH positively correlated with caregiver confidence in decision-making. Patients' confidence with advance care documents' decisions positively correlated with patient confidence in artificial hydration and artificial nutrition decision-making.	0.86
Cheung et al. <sup>42</sup>	Palliative day centre in rehabilitation hospital, Hong Kong	N = 30: 17 seriously ill patients, 13 family caregivers.	To explore barriers to advance care planning (ACP) for patients and caregivers.	Qualitative: Semi-structured focus groups and interviews; Content analysis.	Patients did not consider ACP due to trust in healthcare professionals and family caregivers to make decisions, avoidance of decisional conflict, acceptance of death, reluctance to express feelings, not being ready to discuss death, and desire to avoid burden on family. Family caregivers had a desire to limit medical information for patients to reduce psychological burden for patients.	0.85
Clarke et al. <sup>43</sup>	Clinical collaborators, specific location(s) not reported, South-East London, UK	N = 29 13 patients with progressive neurological diseases, 16 relatives.	To explore how patients and caregivers make decisions about future care in relation to eating and drinking.	Qualitative: Longitudinal; Interviews; Thematic analysis.	For patients who planned ahead, caregivers stated they discussed and agreed with patients' wishes. Caregiver and patient views were not always consistent with healthcare professionals' advice but rather with personal values. Other patients and caregivers coped by actively pushing aside thoughts of disease progression and this strategy was more common for older patients. Some patients and caregivers thought making decisions ahead of time would be too difficult without experience of the situation. However, other patients and caregivers regretted not planning ahead because they felt they chose assisted nutrition (percutaneous endoscopic gastrostomy) too late.	0.8
Davies et al. <sup>23</sup>	Two hospitals and five hospices, Surrey, UK	N = 240: 120 dyads of patients with advanced cancer (45 hospital, 75 hospice) and their co-habiting relatives.	To investigate the concordance between patients and caregivers on the factors related to a good death and end-of-life (EOL) decisions.	Quantitative: Prospective observational; Survey; Place of death, EOL discussions with caregiver, Memorial Symptom Assessment Scale, Zarit Caregiver Burden Scale, summed ranking of factors of a good death; Logistic regression.	When aware of patient preferences for place of death and EOL care, most caregivers agreed with patients. Caregivers with higher burden were less likely to choose home as patient preferred place of death. Overall, there was similar rankings of important factors of good death between the patient and caregiver, particularly for pain and symptom management. However, sorting personal affairs was more important to patients than caregivers, and being involved in decisions was less important to patients than caregivers.	0.82
de Graaff et al. <sup>44</sup>	Palliative care providers, specific location(s) not	N = 83: 6 Moroccan/Turkish patients with advanced	To explore the influence of different care management styles on communication and decision-making in	Qualitative: Semi-structured interviews; Thematic analysis.	Decision-making was disrupted by communication problems with the family (within the family and with healthcare professionals). Distrust built if family could not reach consensus. Joint decision-	0.9

	reported, Netherlands	cancer, 30 relatives, 47 healthcare professionals.	palliative care between families and healthcare professionals; to explore what factors impede decision-making.		making only worked if all members communicated effectively and when decision-making was acceptable to all.	
<b>Dees et al.</b> <sup>45</sup>	A hospice, hospital and a nursing home, Netherlands	N = 91: 32 patients with various advanced conditions, 31 relatives, 28 HCPs.	To explore the decision-making process surrounding request for euthanasia.	Qualitative: Interviews; Thematic analysis and constant comparison.	Mutual respect for autonomy, open communication and collaboration fostered positive and effective relationships between patients and caregivers when making decisions. Patients had negative experiences if they had difficulties expressing wishes and inability to make their own choices. Sharing information, being informed, involving relatives and shared decision-making all contributed to patients' satisfaction with the decision-making process. Patient perceived positive outcomes when they felt relatives were supportive and respectful. A lack of support from relatives disrupted the decision-making process. Planning date of euthanasia was difficult for relatives when they preferred not to be involved in decision-making as they were not ready for the patient's death.	0.85
<b>Engelberg et al.</b> <sup>24</sup>	Two hospice programmes, Washington, USA.	N = 184: 92 dyads of hospice patients and their family caregivers.	To determine how closely patients and families agree on preferences about dying and place of death; and what factors are associated with higher levels of agreement.	Quantitative: Survey; Preferences about Dying and Death, Modified Memorial Symptom Assessment Scale, Short Profile of Illness Impact, communication; Percent agreement, Bland-Altman plots, intraclass correlation.	Patients and caregivers had high agreement on pain and symptom management. Caregivers overestimated patients' preferences for saying goodbye and discussing end-of-life care with healthcare professionals. Caregivers underestimated patients' preferences for spending time alone and avoiding worry/strain on family. Higher agreement between patients and caregivers was associated with high income, patient assessment of family's knowledge of preferences and the patient's recollection of discussing preferences with a family member.	0.86
<b>Gao et al.</b> <sup>25</sup>	Six cancer centres, USA	N = 442: 221 dyads of patients with advanced cancer and mild cognitive impairment and their family caregivers.	To determine if minor cognitive impairment in patients with advanced cancer is associated with end-of-life (EOL) care preferences.	Quantitative: Cohort study; Survey; Life-extending care preferences, Intensive EOL care preferences, Short Portable Mental Status Questionnaire, Karnofsky Performance Status Scale, Charlson Comorbidity Index; Logistic regression.	Increased cognitive impairment was associated with less intense EOL care and with caregivers' preference against life-extending care. Patient preference for life-extending care predicted intensive EOL care regardless of level of cognitive impairment. Caregiver preference for life-extending care and intense EOL care increased with patient cognitive impairment.	0.91
<b>Gerber et al.</b> <sup>46</sup>	Palliative care wards in an acute hospital, a sub-acute hospital (hospice) and a palliative homecare organisation, Melbourne, Australia	N = 17: 8 terminally ill patients, 9 family caregivers.	To understand how terminally ill patients and caregivers make decisions about preferred place of care and death.	Qualitative: Semi-structured interviews; Thematic analysis and grounded theory.	Preference for home care/death was moderated by caregiver burden and caregiver commitment to honour patient wishes despite burden of caregiving. Some patients preferred not to die at home to reduce caregiver burden and stress. Flexibility between the patient and caregiver was needed to negotiate care decisions. Hope, trust, and humour helped both patients and caregivers to cope with challenges and avoid fear and regret in decision-making. Active planning and information benefited some patients and caregivers, while avoidance was preferred by others to maintain a sense of normality and to manage and/or avoid conflict.	0.9

<b>Gerber et al.</b> <sup>47</sup>	Three specialist palliative care wards, and voluntary and community networks, Melbourne, Australia	N = 11: 4 older palliative care patients, 7 bereaved caregivers.	To understand perspectives of patients and caregivers on family communication and decision-making regarding end-of-life (EOL) care.	Qualitative: Semi-structured interviews; Thematic analysis	Caregivers often made decisions speedily and in the moment about EOL care as patients placed trust in them. Decisions-making was complicated by previous family conflict (financial disagreements, marital issues, religious beliefs, violence, and abuse) or denial of prognosis. This could result in care misaligned to patient preferences. Nonetheless, caregivers supported patients and advocated for patients regarding EOL care.	0.8
<b>Hauke et al.</b> <sup>26</sup>	Department of haematology and oncology, University Medical Centre, Munich, Germany	N = 133: 70 patients with advanced cancer, 63 relatives.	To determine the caregiver role in patients' decisions to limit treatments; factors affecting family involvement; and the incidence and reasons for disagreement between family, patients, and healthcare professionals.	Quantitative: Prospective cohort; Structured document form completed by researchers; Caregiver role in decisions, incidence, and reason of disagreement, Karnofsky Performance Status Scale; Mann-Whitney, Fisher's exact test, logistic regression.	Level of patient involvement was the main predictor of caregiver involvement. Patients with denial coping strategies had caregivers who were less involved in decisions than patients with realistic coping strategies. Disagreements were more common when caregivers did not support patient wishes. Caregivers were influential in treatment outcomes. Disagreements were often resolved in favour of the caregiver, particularly when patients had limited ability to communicate.	0.77
<b>Heyland et al.</b> <sup>27</sup>	Five tertiary acute care teaching hospitals, Canada	N = 600: 440 older in-patients with advanced medical conditions, 160 family caregivers.	To describe patients' and caregivers' views on communication and decision-making related to cardiopulmonary resuscitation (CPR); to explore if perspectives on CPR differed in cancer vs non-cancer patients.	Quantitative: Cross-sectional; Survey; CPR preferences, role in decision-making, important information on CPR, medical condition; Kappa score, ordinal regression.	Caregivers placed higher importance on information about CPR compared to patients. Female patients were more likely to prefer shared or healthcare professional only decision-making. Caregivers were more likely to prefer joint decision-making with healthcare professionals and less likely to prefer healthcare professional only decision-making. Caregivers were more likely to prefer shared decision-making if patient faced end-of-life issues. Agreement on role in decision-making was worse between patients and caregivers when the patient was too unwell to participate.	0.91
<b>Heyland et al.</b> <sup>28</sup>	12 teaching hospitals, Canada	N = 503: 278 older hospitalised patients with advanced conditions, 225 relatives.	To explore the internal consistency of patient and caregiver stated values, and the relationship between values and preferences; to explore if decisional conflict related to specific preferences.	Quantitative: Prospective audit; Survey; Engagement in end-of-life (EOL) decisions, End-of-life Values Scale, life-sustaining treatment preferences, Decisional Conflict Scale; Pearson correlation, Kendall's $\tau$ -b statistic, Mann-Whitney U test.	Decisional conflict was common. Reasons for decisional conflict were lack of knowledge of disease and treatment options. Patients who preferred aggressive interventions had greater decisional conflict than patients who preferred comfort care.	0.73
<b>Holdsworth &amp; King</b> <sup>48</sup>	Three hospices, Southeast England, UK	N = 21: 5 hospice patients, 5 family caregivers, 5 bereaved family caregivers, 6 community nurse specialists.	To identify issues related to discussing and recording preferences on place of death.	Qualitative: Semi-structured interviews and focus groups; Thematic analysis.	Conversations about death between patients and caregivers were difficult because it involved accepting death was imminent. No consensus about when or how to have place of death conversation, but patients thought preferences should be discussed when death is imminent. Caregivers' lack of knowledge of the patient's preferences led to uncertainty surrounding final decisions. Caregivers felt more at ease when patient preferences were known and were followed through at death.	0.7

<b>Hwang et al.<sup>29</sup></b>	11 university hospitals and a national cancer centre, South Korea	N = 722: 361 dyads of patients with terminal cancer and their family caregivers.	To identify factors associated with differential cardiopulmonary resuscitation (CPR) preferences of patients and their caregivers.	Quantitative: Cross-sectional; Survey; Willingness for CPR, awareness of terminal illness, Family Adaptability, Partnership, Growth, Affection and Resolve (Family APGAR) index, quality of life (QLQ-C30); Chi-squared, Kappa coefficient, logistic regression.	CPR pre-counselling of patients and caregivers and caregivers' knowledge of terminal illness were associated with caregiver willingness for CPR. Female or emotionally stable patients were more likely to prefer CPR than their caregivers. Caregivers preferred CPR more than patients if the patient had controlled pain, stable general health or the caregiver had no prior CPR counselling.	0.82
<b>Kim et al.<sup>30</sup></b>	A university hospital, Incheon, South Korea	N = 88: 44 dyads of patients with hematologic malignancy and their family caregivers.	To examine the association between patient attitudes and knowledge of advance directives with dyadic completion of advance directives.	Quantitative: Non-experimental correlational design; Survey; Korean-Advance Directive, advance directive attitude survey, advance directive knowledge; Kappa correlation, logistic regression.	Knowledge of advance directives and having a history of hematopoietic stem cell transplants was associated with increased likelihood for the dyad to fill out end-of-life treatment directives.	0.86
<b>Kim et al.<sup>57</sup></b>	Two tertiary hospitals, Ulsan and Yangsan, South Korea	N = 88: 44 dyads of patients with cancer their family caregivers.	To examine the extent of use of the Korean-Advance Directive (K-AD) and agreement on end-of-life (EOL) decisions in patient-caregiver dyads.	Mixed methods: Interviews; K-AD, reasons for rejection to complete K-AD; Content analysis, Kappa coefficient.	Some dyads refused use of the K-AD due to difficulties making EOL decisions, frustration or hopeless after documenting advance directives, and fear of withdrawing from treatment. Less common reasons included concern for family reaction and lack of knowledge of advance directives. Comfort of dying, specifically with no pain or pain control was important for both patients and caregivers. Dying without family burden was a highly ranked value for patients. Caregivers had higher preferences for cardiopulmonary resuscitation and artificial ventilation than patients.	Mid - range quality
<b>Luijckx &amp; Schols<sup>49</sup></b>	Three low-care hospices, two high-care hospices, and a home care organisation, Netherlands	N = 25: 13 hospice patients, 12 family caregivers.	To understand the perceptions of home and hospice care in terminal cancer patients and their caregivers.	Qualitative: Interviews; Descriptive analysis.	Caregivers facilitated patient wishes for care at home (more important for spouse caregivers) but were conflicted by the burden of caregiving. Patients wanted to enjoy time together rather than burden or depend on caregivers. Negotiation surrounding a move to hospice care occurred when remaining at home was not possible. Patient preferences were of paramount importance. Hospice care triggered acceptance of impending death for both patients and caregivers.	0.7
<b>Nolan et al. 2008<sup>58</sup></b>	Specialist teaching hospital, Baltimore, USA	N = 32: 16 dyads of patients with ALS and their family caregivers.	To compare patients' preferences for family involvement in decision-making with actual family involvement before death.	Mixed methods: Descriptive correlational design; Longitudinal; Survey and interview; Family Member Decision Making Survey, Decision Control Preferences Scale, decision process and confidence in decision; Kappa coefficient, thematic and content analysis.	Patients were conflicted by wanting to involve family vs not wanting to burden family. Patients who preferred more independent decision-making were more likely to have their families report that decisions were made in the style that the patient preferred. Patients who preferred shared decision-making with family or decision making that relied upon the family were more likely to have their families report that decisions were made in a style that was more independent than preferred. Patients' decision-making styles could conflict with caregivers' preferences. Both patients and caregivers recognised that flexibility was needed to manage discordance and make decisions.	Mid-range quality
<b>Ozdemir et al.<sup>31</sup></b>	Outpatient renal clinic in general hospital, Singapore	N = 302: 151 dyads of older patients with end-stage kidney disease	To understand patients' experiences and preferences of family involvement in treatment decisions and areas of	Quantitative: Survey with series of choice Vignettes; choices in hypothetical end-stage kidney disease treatment vignettes; Logistic regression.	Discordance increased if caregivers preferred dialysis over conservative care or chose higher cost conservative treatment. Discordance resolved in the patient's favour half of the time. The patient being employed and the desire to be in control of their final decisions predicted reconciliation in the patient's favour.	0.91

		and their family caregivers.	discordance and reconciliation.			
<b>Piil et al.<sup>50</sup></b>	Department of neurosurgery, University hospital, Copenhagen, Denmark	N = 63: 30 patients with malignant high-grade glioma; 33 family caregivers.	To explore experiences and needs for rehabilitation and support along a 1-year glioma disease and treatment trajectory.	Qualitative: Longitudinal prospective; Semi-structured interviews; Thematic analysis.	Level of information was either helpful or confronting for patients and caregivers. Controlling the level of information helped both patients and family caregivers to manage the disease trajectory. Patient and caregiver emotional distress was alleviated by supportive relationships, hope, solidarity and being pro-active in managing disease. When patient deterioration was apparent, patients and family caregivers negotiated together the transition from active treatments. However, role changes caused strains in relationships. Patients were concerned about burdening caregivers and caregivers were determined to support the patient despite strain. Some patients were upset if their caregiver disagreed with them. Overtime, patients and caregivers coped by not sharing concerns with each other.	0.8
<b>Preisler et al.<sup>51</sup></b>	Medical department of haematology and oncology, Berlin, Germany	N = 20: 11 patients with advanced cancer, 9 family caregivers.	To understand cancer patient and caregiver needs during the cancer treatment trajectory.	Qualitative: Semi-structured interviews; Grounded theory.	Different personal contact needs and coping strategies caused conflicts in families. Family conflict was more stressful for patients than undergoing treatment. Increased stress, family dynamics (i.e., distribution of roles, personalities) and level of responsibility taken by caregiver led to challenges during cancer treatment. Challenges faced during the cancer illness included not talking about death and differing in preferences for active treatment and involvement in decisions.	0.85
<b>Pruchno et al.<sup>32</sup></b>	Dialysis centres and Medicare end-stage renal disease program, USA	N = 582: 291 dyads of patients with end-stage kidney disease and their spouses.	To explore if substituted judgements of spouses affect surrogate decision-making; to explore if communication and understanding of patient preferences reflect surrogate substituted judgements.	Quantitative: Survey of preferences in series of hypothetical scenarios; patient preference, spouse preference, and spouse substituted judgement; Kappa coefficient, regression analysis.	Spouses' preferences explained more of their substituted judgements than the patients' preferences. Prior communication did not improve substituted judgement, nor did patients' belief that their spouse had a good understanding of the patient's wishes and would make decisions according to their wishes.	0.86
<b>Puts et al. 2017<sup>59</sup></b>	Two cancer centres, Toronto, Canada	N = 81: 29 patients with cancer, 24 relatives, 15 family physicians, 13 oncologists.	To understand the treatment decision-making process of patients, caregivers, and healthcare professionals; to examine if frailty, functional status, and comorbidity influence decisions about care.	Mixed methods: Longitudinal; Semi-structured interviews and surveys; Frailty, 1-item (decisional) Control Preferences Scale and Satisfaction with Decision Scale; Constant comparison approach, thematic analysis, and descriptive statistics.	Patients accepted palliative chemotherapy based on family wishes. Spouse caregivers thought final decisions were up to the patient or made in the moment. Adult-child caregivers discussed decision-making and planned decisions more than spouse caregivers and sought more information than did spouse caregivers.	Mid-high range quality
<b>Sellars et al. 2018<sup>52</sup></b>	Three renal services, Melbourne, Australia	N = 29: 24 patients with end-stage kidney disease, 15 family caregivers.	To understand the perspectives and attitudes of patients and caregivers towards advance care planning (ACP).	Qualitative: Semi-structured interviews; Grounded theory and thematic analysis.	ACP relieved burden on caregivers. The perceived support ACP gave caregivers was more important to some patients than the actual decisions via ACP. Patients who felt in denial of death left families/healthcare professionals to make decisions when the time came. ACP enabled caregivers to follow patient wishes, despite differing views or not being ready for patient's death. Some caregivers pressured patients to stay on dialysis. Caregiver grief	0.95

					interfered with caregiver capacity to make end-of-life decisions and patient preferences being followed.	
<b>Sharma et al.<sup>33</sup></b>	ALS and gastrointestinal (surgery) clinics at specialist hospital, Baltimore, USA	N = 104: 52 dyads (27 ALS, 25 advanced pancreatic cancer) of patients and their relatives.	To assess caregivers' ability to correctly identify patient preferences for family involvement and what factors are associated with agreement on preference of family involvement.	Quantitative: Cross-sectional; Survey; Decision Control Preferences Scale in patient conscious and unconscious scenario; Kappa coefficient, chi-squared, logistic regression.	Agreement was moderate for both scenarios. Caregivers frequently incorrectly identified patient preference for decisions-making style. In the conscious scenario, patient preference for independent decision-making style was associated with higher odds of agreement compared to shared decision-making. No characteristics or decision styles were associated with odds of agreement in the unconscious scenario.	0.91
<b>Shin et al.<sup>34</sup></b>	National cancer centre and nine regional cancer centres, South Korea	N = 1880: 990 dyads of patients with cancer and their family caregivers.	To assess patient preferences, caregiver preferences, and caregivers' predictions of patient preference regarding disclosure of terminal illness, family involvement and end-of-life (EOL) care; to evaluate preference concordance between patient preferences, caregiver preferences, and caregiver perceived patient preference.	Quantitative: Cross-sectional; Survey; Preferences for family involvement, disclosure of terminal illness and EOL care, Cancer Communication Assessment Tool for Patients and Families; Kappa coefficient, logistic regression.	Being a parent caregiver was associated with concordance for terminal disclosure preference. Being an adult-child caregiver was associated with concordance for EOL care. Poor family communication was associated with poor concordance for terminal disclosure preference. Predictors of concordance were similar for patient and caregiver perceived patient preference. Predictors of concordance were also similar on a subgroup analysis of advanced cancer patients.	0.86
<b>Simon et al.<sup>53</sup></b>	12 acute care hospitals, Canada.	N = 503: 278 older seriously ill, hospitalised patients, 225 relatives.	To explore patients' and relatives' perspectives on the barriers and facilitators of advance care planning (ACP).	Qualitative: Open-ended survey by interview; ACP activities; Qualitative description and naturalistic inquiry.	Patients and caregivers did not engage with ACP if they were afraid of death or desired to remain optimistic. Barriers to ACP for caregivers were not attending patient appointments and lack of access to healthcare professionals. Not knowing the appropriate healthcare professionals to engage with was a barrier for patients. ACP that occurred during a health emergency was stressful for the caregiver.	0.9
<b>Stajduhar et al.<sup>35</sup></b>	Five tertiary teaching hospitals, Canada	N = 276: 138 dyads of seriously ill, hospitalised patients and their family caregivers.	To examine patient and caregiver preferences and congruence on place of death; to examine if preferences for place of death differ by diagnosis.	Quantitative: Prospective cross-sectional; Survey; Preference for place of death, diagnosis; Kappa coefficient, chi-square tests.	Half of dyads differed on preferred place of death. No statistically significant differences were found between preferences for place of death between cancer and non-cancer patients.	0.82
<b>Tang et al.<sup>36</sup></b>	24 hospitals, Taiwan	N = 2216: 1108 dyads of patients with terminal cancer and their family caregivers.	To examine the factors of patient and caregiver concordance on preferred place of death.	Quantitative: Cross-sectional; Survey; Preferred place of death, end-of-life care preferences, caregiver burden (Caregiver Reaction Assessment), Symptom Distress Scale, Enforced Social Dependency Scale; Kappa coefficient, logistic regression.	Patients had higher concordance with caregivers if they were older, had higher functional dependency or rated importance of dying in preferred place of death highly. Concordance of place of death was higher if caregivers were spouses but lower if patients were aware of their prognosis. Agreement on preferred place of death was more likely when patients and caregivers agreed on preference for emergency cardiac massage or receiving hospice care near death. Agreement on place of death was less likely if caregiving had a greater negative impact on the caregiver.	0.95

<b>Thomas et al.<sup>54</sup></b>	Specialist palliative care service, North-West England, UK	N = 69: 41 patients with advanced cancer patients, 18 family caregivers.	To explore preferences for place of death among patients with terminal cancer and their caregivers.	Qualitative: Longitudinal; Interviews; Grounded theory and thematic analysis.	Patient and caregiver preferences were shaped by their perceptions of services, patient illness, caregiving responsibilities, patients' experiences of health services, and their beliefs. Patients did not want to burden caregivers despite caregiver willingness to support the patient. Some caregivers regretted when death at home was not possible. Both patients and caregivers recognised that preferences were contextual and negotiable.	0.85
<b>Tobin et al.<sup>37</sup></b>	National ALS multidisciplinary clinic, Dublin, Ireland	N = 149: 93 patients with ALS, 56 family caregivers.	To measure patient and caregiver preferences for health services and relative importance of aspects of care; to assess if preferences differ by patient characteristics.	Quantitative: Discrete choice experiment; nine choice sets with 13 attributes and levels of care; Random effects probit model, subgroup analysis.	Patient and caregiver priorities differed. Patients had a strong preference for information being provided and use of hospice services earlier in the diagnosis. Caregivers had a strong preference for engagement with healthcare professionals (not prioritised by patients). Female patients were more opposed to getting group emotional support and had preference for dependable healthcare professionals. Caregivers of parents had preference for personal care being provided by a relative/friend, emotional support provided by a counsellor and having dependable healthcare professionals.	0.91
<b>Wen et al.<sup>38</sup></b>	Medical centre, Northern Taiwan	N = 430: 215 dyads of patients with terminal cancer and their family caregivers.	To examine the factors and evolution of patient-caregiver concordance on life-sustaining treatment preferences in the last 6 months of life.	Quantitative: Longitudinal; Survey every 2-4 weeks; Life-sustaining treatment preferences, Patient Symptom Distress Scale, Enforced Social Dependency Scale, Patient Hospital Anxiety and Depression (HADS-A and D), Caregiver Centre of Epidemiological Studies Depression (CES-D), McGill Quality of Life, Caregiver Reaction Assessment; Hidden Markov Modelling, Kappa coefficients, logistic regression.	Patient-caregiver concordance increased slightly over time. Concordance was only statistically significant in the last 3 months of life. Concordance was more likely for patients with higher symptom distress or when caregivers preferred to reject all life-sustaining treatments or accepted nutritional support only.	0.91
<b>Yoo et al.<sup>39</sup></b>	Inpatient and outpatient care at nine university hospitals, South Korea	N = 251: 150 patients with advanced cancer patients, 101 family caregivers.	To examine the association between patients' and caregivers' understanding of illness with preferences for advance care planning (ACP) and end-of-life (EOL) care.	Quantitative: Prospective cohort; Cross-sectional; Survey; Illness understanding, ACP and EOL preferences; Chi-squared, multiple logistic regression.	Patients with an understanding of their illness were more likely to have document physician orders for life sustaining treatments, discussed ACP with family, and not prefer active treatment (assuming life expectancy was within several months) than patients who did not. Caregivers who understood the patient's illness were more likely to have a preference to write advance directives, have discussed ACP, and not prefer active or life-sustaining treatment when the patient was in the final weeks of life.	0.86
<b>Yun et al.<sup>40</sup></b>	Inpatient and outpatient care at three university hospitals, South Korea	N = 488: 244 dyads of patients with terminal cancer and their relatives as surrogates.	To examine personal and situational factors influencing differences between patient and family preferences for aggressive care.	Quantitative: Survey; Aggressive care preferences [intensive care unit or cardiopulmonary resuscitation (CPR)], participation in end-of-life (EOL) decisions, place of death and care, Family Adaptability, Partnership, Growth, Affection and Resolve (Family APGAR) index; Chi-squared, Kappa coefficient, logistic regression.	Disagreement on intensive care unit admission preference was more likely for younger, unmarried patients and patients who preferred to die in an institution. Regarding CPR, younger patients and patients with dysfunctional families were more likely to have a different preference to their relatives.	0.91

<b>Yurk et al.</b> <sup>55</sup>	A private research organisation, a community organisation, and healthcare professional referrals, San Francisco, Denver, Washington, USA	N = 32: 15 seriously ill patients, 9 bereaved caregivers, 8 medical caregivers.	To explore how patients and their caregivers rank their care preferences during advanced illness.	Qualitative: focus groups; Ranking of preferences (14 quality of life indicators) via card sorting; Open coding and thematic analysis of highest ranked indicators, weighted ranking.	There was good alignment for patients' and caregivers' quality of life preferences. Pain management was ranked first for patients and caregivers. Caregivers ranked more bereavement support and assessment of family involvement higher than patients. Patients ranked symptom management higher than caregivers. Caregivers wanted guidance on pain management for patients. Caregivers thought advance directives helped families follow patient wishes and reduce burden of decision-making on their family. Some bereaved caregivers felt patient preferences might be overlooked for family needs. Patients and caregivers thought difficult topics should be discussed with empathy and initiated by healthcare professionals to facilitate emotional needs of patients and caregivers to be met. Caregivers had poor experience of patient death if they were less involved in care, felt isolated, and not prepared for change.	0.85
<b>Zhang &amp; Siminoff</b> <sup>56</sup>	Large cancer centre, Cleveland, USA	N = 77: 37 patients with advanced-stage cancer, 40 family caregivers.	To explore where family disagreements occur regarding treatment decisions; and why these differences occur.	Qualitative: Focus groups and interviews; Content analysis.	Family disagreement and avoidance of care discussions were common. Discordance arose when families did not want patients to stop treatment, when family disagreed with healthcare professional recommendations, and when they differed in their views on level of caregiving and health improvement strategies. The decision-making process was impeded by family conflict or avoidance of end-of-life conversations due to concerns over family conflict and response. Some caregivers wanted healthcare professionals to initiate discussion for hospice care as they felt it was a difficult conversation to have with patients.	0.85
<b>Zhang et al.</b> <sup>41</sup>	Large cancer centre and a medical centre, Cleveland, USA	N = 355: 184 patients with advanced lung cancer, 171 family caregivers.	To explore differences in opinion on treatment and care decisions between patients and caregivers; to explore how differences affect psychological wellbeing of patients and caregivers.	Quantitative: Semi-structured survey; Routine care decisions, decisions on trade-off treatment, side effects and hospice care, areas of family disagreement, level of disagreement, Caregiver Centre of Epidemiological Studies Depression (CES-D) Chi-square, Fisher's exact, Mann-Whitney test, logistic regression.	Caregivers reported more disagreement than patients particularly around care and treatment decisions. Patients often did not report side effects of treatment to alleviate caregiver distress. Higher depression scores for patients and caregivers were associated with fewer family members being informed about decisions, exclusion of a family member in decisions, disagreement with physician recommendations, less willingness to discuss hospice care at home, and caregiver preference for patient to stop treatment and household income.	0.91



## Appendix 1. Search strategy and search terms

### EMBASE [1862]

'palliative therapy'/exp OR 'terminal disease'/exp OR 'death'/de OR 'dying'/exp OR 'terminal care'/exp OR 'terminally ill patient'/exp

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

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

((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)):ab,ti

('terminal\* ill\*' OR death\* OR dying OR 'terminal stage of illness'):ti,ab

#1 OR #2 OR #3 OR #4 OR #5

('caregiver'/exp OR 'family'/exp OR 'legal guardian'/exp) AND 'decision making'/exp

'surrogate decision making'/exp

((Caregiv\* OR care-giv\* OR carer\* OR famil\* OR surrogate\* OR proxy OR spouse? OR spousal OR sibling\* OR wife OR husband OR 'legal guardian' OR relative\*) NEAR/4 (Decide? OR decision? OR decision-mak\* OR opinion\* OR preference\*)):ti,ab

#7 OR #8 OR #9

'patient decision making'/exp OR ('patient preference'/exp AND 'decision support system'/exp)

('patient'/exp OR 'patient preference'/exp) AND ('decision making'/exp OR 'decision support system'/exp)

((Patient\* OR dyad\*) NEAR/4 (Decide? OR decision? OR decision-mak\* OR preference\* OR opinion\* OR choice\*)):ti,ab

#11 OR #12 OR #13

(Concord\* OR consensus OR concur\* OR consent\* OR dissent\* OR discord\* OR conflict\* OR distress OR agree\* OR disagree\* OR congruence OR negotiat\* OR prefer\* OR mismatch\* OR discrepant\* OR disparit\* OR accept\* OR reject\*):ti,ab

#6 AND #10 AND #14 AND #15

### Medline [891]

exp palliative care/ OR exp Terminal Care/ OR exp Terminally Ill/

(Palliation OR Supportive care).ti,ab.

((Palliative OR end-of-life OR terminal\*) adj3 (care OR treatment\* OR therapy OR therapies OR nursing OR approach\*)):ti,ab.

((terminal\* OR hospice\* OR end-of-life OR end-stage OR last year of life OR LYOL OR lifes end) adj5 (care OR caring)).ti,ab.

(terminal\* III\* OR death\* OR dying OR terminal stage of illness).ti,ab.

or/1-5

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

((Caregiv\* OR care-giv\* OR carer\* OR famil\* OR surrogate\* OR proxy OR spouse\* OR spousal OR sibling\* OR wife OR husband OR legal guardian OR relative\*) adj4 (Decide? OR decision? OR decision-mak\* OR opinion\* OR preference\*)).ti,ab.

or/7-8

(exp Patients/ OR "Patient Preference"/) AND (exp Decision Making/ OR exp Decision Support Techniques/ OR Decision Making, Shared/)

((Patient\* OR dyad\*) adj4 (Decide? OR decision? OR decision-mak\* OR preference\* OR opinion\* OR choice\* OR negotiat\* OR prefer\* OR mismatch\* OR discrepant\* OR disparit\* OR accept\* OR reject\*)).ti,ab.

or/10-11

(Concord\* OR consensus OR concur\* OR consent\* OR dissent\* OR discord\* OR conflict\* OR distress OR agree\* OR disagree\* OR congruence OR negotiat\* OR prefer\* OR mismatch\* OR discrepant\* OR disparit\* OR accept\* OR reject\*).ti,ab.

6 AND 9 AND 12 AND 13

#### [CINAHL \[754\]](#)

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

TI (Palliation OR "Supportive care") OR AB (Palliation OR "Supportive care")

TI ((Palliative OR end-of-life OR terminal\*) N2 (care OR treatment\* OR therapy OR therapies OR nursing OR approach\*)) OR AB ((Palliative OR end-of-life OR terminal\*) N2 (care OR treatment\* OR therapy OR therapies OR nursing OR approach\*))

TI ((terminal\* OR hospice\* OR "end-of-life" OR "end-stage" OR "last year of life" OR LYOL OR "lifes end") N4 (care OR caring)) OR AB ((terminal\* OR hospice\* OR "end-of-life" OR "end-stage" OR "last year of life" OR LYOL OR "lifes end") N4 (care OR caring))

TI ("terminal\* III\*" OR death\* OR dying OR "terminal stage of illness") OR AB ("terminal\* III\*" OR death\* OR dying OR "terminal stage of illness")

S1 OR S2 OR S3 OR S4 OR S5

((MH "Caregivers") OR (MH "Family+") OR (MH "Guardianship, Legal+")) AND (MH "Decision Making")

(MH "Decision Making, Family")

TI ((Caregiv\* OR care-giv\* OR carer\* OR famil\* OR surrogate\* OR proxy OR spouse\* OR spousal OR sibling\* OR wife OR husband OR "legal guardian" OR relative\*) N3 (Decide\* OR decision\* OR decision-mak\* OR opinion\* OR preference\*)) OR AB ((Caregiv\* OR care-giv\* OR carer\* OR famil\* OR

surrogate\* OR proxy OR spouse\* OR spousal OR sibling\* OR wife OR husband OR "legal guardian"  
OR relative\*) N3 (Decide\* OR decision\* OR decision-mak\* OR opinion\* OR preference\*)

S7 OR S8 OR S9

(MH "Decision Making, Patient+")

(MH "Patients+") AND ((MH "Decision Making") OR (MH "Decision Support Techniques") OR (MH  
"Decision Making, Shared"))

TI ((Patient\* OR dyad\*) N3 (Decide\* OR decision\* OR "decision mak\*" OR preference\* OR opinion\*  
OR choice\*)) OR AB ((Patient\* OR dyad\*) N3 (Decide\* OR decision\* OR "decision mak\*" OR  
preference\* OR opinion\* OR choice\*))

S11 OR S12 OR S13

TI (Concord\* OR consensus OR concur\* OR consent\* OR dissent\* OR discord\* OR conflict\* OR  
distress OR agree\* OR disagree\* OR congruence OR negotiat\* OR prefer\* OR mismatch\* OR  
discrepanc\* OR disparit\* OR accept\* OR reject\*) OR AB (Concord\* OR consensus OR concur\* OR  
consent\* OR dissent\* OR discord\* OR conflict\* OR distress OR agree\* OR disagree\* OR congruence  
OR negotiat\* OR prefer\* OR mismatch\* OR discrepanc\* OR disparit\* OR accept\* OR reject\*)

S6 AND S10 AND S14 AND S15

### [Web of Science \[824\]](#)

TS =(((Palliation OR "Supportive care") OR ((Palliative OR end-of-life OR terminal\*) NEAR/3 (care OR  
treatment\* OR therapy OR therapies OR nursing OR approach\*)) OR ((terminal\* OR hospice\* OR  
"end-of-life" OR "end-stage" OR "last year of life" OR LYOL OR "lifes end" OR "terminal stage of  
illness") NEAR/5 (care OR caring)) OR ("terminal\* ill\*" OR death\* OR dying)) AND ((Caregiv\* OR care-  
giv\* OR carer\* OR famil\* OR surrogate\* OR proxy OR spouse\* OR spousal OR sibling\* OR wife OR  
husband OR "legal guardian" OR relative\*) NEAR/4 (Decide\* OR decision\* OR decision-mak\* OR  
opinion\* OR preference\*)) AND ((Patient\* OR dyad\*) NEAR/4 (Decide\* OR decision\* OR decision-  
mak\* OR preference\* OR opinion\* OR choice\*)) AND (Concord\* OR consensus OR concur\* OR  
consent\* OR dissent\* OR discord\* OR conflict\* OR distress OR agree\* OR disagree\* OR congruence  
OR negotiat\* OR prefer\* OR mismatch\* OR discrepanc\* OR disparit\* OR accept\* OR reject\*))

### [PsycINFO & PsycARTICLES \[325\]](#)

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

TI (Palliation OR "Supportive care") OR AB (Palliation OR "Supportive care")

TI ((Palliative OR end-of-life OR terminal\*) N2 (care OR treatment\* OR therapy OR therapies OR  
nursing OR approach\*)) OR AB ((Palliative OR end-of-life OR terminal\*) N2 (care OR treatment\* OR  
therapy OR therapies OR nursing OR approach\*))

TI ((terminal\* OR hospice\* OR "end-of-life" OR "end-stage" OR "last year of life" OR LYOL OR "lifes  
end") N4 (care OR caring)) OR AB ((terminal\* OR hospice\* OR "end-of-life" OR "end-stage" OR "last  
year of life" OR LYOL OR "lifes end") N4 (care OR caring))

TI ("terminal\* Ill\*" OR death\* OR dying OR "terminal stage of illness") OR AB ("terminal\* Ill\*" OR death\* OR dying OR "terminal stage of illness")

S1 OR S2 OR S3 OR S4 OR S5

(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 ((Caregiv\* OR care-giv\* OR carer\* OR famil\* OR surrogate\* OR proxy OR spouse\* OR spousal OR sibling\* OR wife OR husband OR "legal guardian" OR relative\*) N3 (Decide\* OR decision\* OR decision-mak\* OR opinion\* OR preference\*)) OR AB ((Caregiv\* OR care-giv\* OR carer\* OR famil\* OR surrogate\* OR proxy OR spouse\* OR spousal OR sibling\* OR wife OR husband OR "legal guardian" OR relative\*) N3 (Decide\* OR decision\* OR decision-mak\* OR opinion\* OR preference\*))

S7 OR S8

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

TI ((Patient\* OR dyad\*) N3 (Decide\* OR decision\* OR "decision mak\*" OR preference\* OR opinion\* OR choice\*)) OR AB ((Patient\* OR dyad\*) N3 (Decide\* OR decision\* OR "decision mak\*" OR preference\* OR opinion\* OR choice\*))

S10 OR S11

TI (Concord\* OR consensus OR concur\* OR consent\* OR dissent\* OR discord\* OR conflict\* OR distress OR agree\* OR disagree\* OR congruence OR negotiat\* OR prefer\* OR mismatch\* OR discrepant\* OR disparit\* OR accept\* OR reject\*) OR AB (Concord\* OR consensus OR concur\* OR consent\* OR dissent\* OR discord\* OR conflict\* OR distress OR agree\* OR disagree\* OR congruence OR negotiat\* OR prefer\* OR mismatch\* OR discrepant\* OR disparit\* OR accept\* OR reject\*)

S6 AND S9 AND S12 AND S13

### [Social Sciences Full Text \[47\]](#)

DE "Palliative treatment" OR DE "Hospice care" OR DE "Terminally ill" OR DE "Terminal care"

TI (Palliation OR "Supportive care") OR AB (Palliation OR "Supportive care")

TI ((Palliative OR end-of-life OR terminal\*) N2 (care OR treatment\* OR therapy OR therapies OR nursing OR approach\*)) OR AB ((Palliative OR end-of-life OR terminal\*) N2 (care OR treatment\* OR therapy OR therapies OR nursing OR approach\*))

TI ((terminal\* OR hospice\* OR "end-of-life" OR "end-stage" OR "last year of life" OR LYOL OR "lifes end") N4 (care OR caring)) OR AB ((terminal\* OR hospice\* OR "end-of-life" OR "end-stage" OR "last year of life" OR LYOL OR "lifes end") N4 (care OR caring))

TI ("terminal\* Ill\*" OR death\* OR dying OR "terminal stage of illness") OR AB ("terminal\* Ill\*" OR death\* OR dying OR "terminal stage of illness")

S1 OR S2 OR S3 OR S4 OR S5

(DE "Families of the terminally ill" OR DE "Families" OR DE "Caregivers" OR DE "Male caregivers" OR DE "Older caregivers" OR DE "Women caregivers" OR DE "Family relationships of caregivers") AND (DE "Decision making" OR DE "Group decision making")

TI ((Caregiv\* OR care-giv\* OR carer\* OR famil\* OR surrogate\* OR proxy OR spouse\* OR spousal OR sibling\* OR wife OR husband OR "legal guardian" OR relative\*) N3 (Decide\* OR decision\* OR decision-mak\* OR opinion\* OR preference\*)) OR AB ((Caregiv\* OR care-giv\* OR carer\* OR famil\* OR surrogate\* OR proxy OR spouse\* OR spousal OR sibling\* OR wife OR husband OR "legal guardian" OR relative\*) N3 (Decide\* OR decision\* OR decision-mak\* OR opinion\* OR preference\*))

S7 OR S8

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

TI ((Patient\* OR dyad\*) N3 (Decide\* OR decision\* OR "decision mak\*" OR preference\* OR opinion\* OR choice\*)) OR AB ((Patient\* OR dyad\*) N3 (Decide\* OR decision\* OR "decision mak\*" OR preference\* OR opinion\* OR choice\*))

S10 OR S11

TI (Concord\* OR consensus OR concur\* OR consent\* OR dissent\* OR discord\* OR conflict\* OR distress OR agree\* OR disagree\* OR congruence OR negotiat\* OR prefer\* OR mismatch\* OR discrepant\* OR disparit\* OR accept\* OR reject\*) OR AB (Concord\* OR consensus OR concur\* OR consent\* OR dissent\* OR discord\* OR conflict\* OR distress OR agree\* OR disagree\* OR congruence OR negotiat\* OR prefer\* OR mismatch\* OR discrepant\* OR disparit\* OR accept\* OR reject\*)

S6 AND S9 AND S12 AND S13

## AMED [79]

(ZU "terminal care" or ZU "terminal illness" or ZU "palliative care" or ZU "palliative medicine" or ZU "palliative treatment" or ZU "hospice care")

TI (Palliation OR "Supportive care") OR AB (Palliation OR "Supportive care")

TI ((Palliative OR end-of-life OR terminal\*) N2 (care OR treatment\* OR therapy OR therapies OR nursing OR approach\*)) OR AB ((Palliative OR end-of-life OR terminal\*) N2 (care OR treatment\* OR therapy OR therapies OR nursing OR approach\*))

TI ((terminal\* OR hospice\* OR "end-of-life" OR "end-stage" OR "last year of life" OR LYOL OR "lifes end") N4 (care OR caring)) OR AB ((terminal\* OR hospice\* OR "end-of-life" OR "end-stage" OR "last year of life" OR LYOL OR "lifes end") N4 (care OR caring))

TI ("terminal\* ill\*" OR death\* OR dying OR "terminal stage of illness") OR AB ("terminal\* ill\*" OR death\* OR dying OR "terminal stage of illness")

S1 OR S2 OR S3 OR S4 OR S5

(ZU "caregivers" or ZU "family" or ZU "legal guardians" or ZU "proxy" or ZU "spouses") AND (ZU "decision making")

TI ((Caregiv\* OR care-giv\* OR carer\* OR famil\* OR surrogate\* OR proxy OR spouse\* OR spousal OR sibling\* OR wife OR husband OR "legal guardian" OR relative\*) N3 (Decide\* OR decision\* OR decision-mak\* OR opinion\* OR preference\*)) OR AB ((Caregiv\* OR care-giv\* OR carer\* OR famil\* OR surrogate\* OR proxy OR spouse\* OR spousal OR sibling\* OR wife OR husband OR "legal guardian" OR relative\*) N3 (Decide\* OR decision\* OR decision-mak\* OR opinion\* OR preference\*))

S7 OR S8

(ZU "decision making") AND (ZU "patients")

TI ((Patient\* OR dyad\*) N3 (Decide\* OR decision\* OR "decision mak\*" OR preference\* OR opinion\* OR choice\*)) OR AB ((Patient\* OR dyad\*) N3 (Decide\* OR decision\* OR "decision mak\*" OR preference\* OR opinion\* OR choice\*))

S10 OR S11

TI (Concord\* OR consensus OR concur\* OR consent\* OR dissent\* OR discord\* OR conflict\* OR distress OR agree\* OR disagree\* OR congruence OR negotiat\* OR prefer\* OR mismatch\* OR discrepant\* OR disparit\* OR accept\* OR reject\*) OR AB (Concord\* OR consensus OR concur\* OR consent\* OR dissent\* OR discord\* OR conflict\* OR distress OR agree\* OR disagree\* OR congruence OR negotiat\* OR prefer\* OR mismatch\* OR discrepant\* OR disparit\* OR accept\* OR reject\*)

S6 AND S9 AND S12 AND S13