

Table 1. Summary of included studies

Study	Location/setting	Participants	Aims	Methods	Findings	Summary Score
<b>An et al.</b> <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 and 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
<b>Bukki et al.</b> <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
<b>Cheung et al.</b> <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
<b>Clarke et al.</b> <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
<b>Davies et al.</b> <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
<b>de Graaff et al.</b> <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.</b> <sup>50</sup>	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.</b> <sup>51</sup>	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.</b> <sup>32</sup>	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</b> <sup>59</sup>	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</b> <sup>52</sup>	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