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Association between advanced cancer patient-caregiver agreement on prognosis and hospice enrollment

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Abstract

Background.—Patients with advanced, incurable cancer who understand their illness is incurable are more likely to prefer hospice care at the end-of-life (EOL) than patients who believe their illness is curable. It is unclear whether patient-caregiver agreement on perceived prognosis is associated with hospice enrollment.

Methods.—This study examined the prospective relationship between patient-caregiver agreement on perceived prognosis and hospice enrollment in the last 30 days of life. Data were collected during a cluster randomized controlled trial examining a communication intervention for oncologists and patients with advanced cancer and their caregivers. At study entry, patients and caregivers (n=141 dyads) were categorized as endorsing a “good” prognosis if they (a) reported a greater than 50% chance of living 2 years or if they (b) predicted that the patient’s quality of life three months into the future would be 7 on an 11-point scale.

Results.—Approximately one-fifth of dyads agreed on a poor prognosis while one-half disagreed on prognosis. In one-third of dyads, patients and caregivers both believed the patient’s future

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quality of life would be good (34%) and that the patient would live for two years or more (30%). Patients in these dyads were less likely to enroll in hospice than patients in dyads who disagreed and those who agreed on a shorter life-expectancy and poor future quality of life.

Conclusions.—Dyadic understanding of patients' projected life-expectancy and future quality of life predicts care received at the EOL. Improving rates of hospice enrollment may be best achieved with dyadic interventions.

Precis:

Approximately one-fifth of advanced cancer patient-caregiver dyads agreed on a poor prognosis, one-third agreed on a good prognosis, and one-half disagreed on prognosis. Patients in dyads who agreed on a good prognosis were less likely to enroll in hospice than patients in dyads who disagreed and those who agreed on a poor prognosis.

Keywords

Cancer; oncology; caregiving; prognosis; hospice

INTRODUCTION

Hospice is considered the quality standard of care for patients with advanced terminal illness who have an expected prognosis of six months or less.¹ Patients with cancer who receive hospice report reductions in pain intensity,² symptom burden,³ and distress³ and receive less burdensome aggressive care than patients not enrolled in hospice.^{4,5} Personal (i.e., informal, unpaid) caregivers of patients who receive hospice are more likely to report that the patient received high quality care⁶ and that the patient had a good death than caregivers of patients who do not receive hospice care.^{7,8} Further, caregivers of patients who receive hospice care have a lower risk of death in the 18 months following the patient's death than caregivers of patients who do not receive hospice.⁹ Caregivers of patients with cancer who die in hospice also report less severe depressive symptoms and grief following the patient's death.⁸

Understanding the factors that predict hospice enrollment is vital to ensuring patients who would benefit from hospice receive this care; cancer patients' understanding of the course of their illness is one such factor. Patients with advanced cancer who understand their illness is terminal are more likely to prefer comfort care over aggressive care^{10,11} and die in their preferred place of death (home).¹² These patients are also less likely to receive aggressive care at the EOL.^{13,14} Regarding hospice in particular, advanced cancer patients who describe their illness as incurable are more likely to prefer hospice care.¹⁵ Further, advanced cancer patients enrolled in hospice are more likely to describe their disease as incurable than patients not enrolled.¹⁶ However, these findings are limited by a primary focus on a hypothetical preference for hospice care rather than actual hospice enrollment and retrospective analysis of prognostic understanding in patients already enrolled in hospice.

The curability and life-expectancy of a patient with advanced cancer is not the only prognostic consideration in decisions regarding end-of-life care. As cancer treatments improve and patients are able to live longer with advanced cancer, the quality of patients' lives becomes increasingly important to consider.^{1,17} Indeed, about 50% of patients with

advanced cancer report that quality and length of life are equally important.¹⁸ In one study, up to three-quarters of patients with advanced cancer reported a preference for care focused more on comfort than life extension.^{19,20} These patients were more likely to receive hospice care than patients who expressed a preference for life-extending care.²¹ However, prior studies have not directly assessed patients' or caregivers' beliefs about future quality of life and hospice enrollment.

Caregivers play an integral role in cancer patients' care and decision-making^{22,23} due in part to patients' desire for less control in decision-making as their disease progresses.²⁴ In fact, 51% of cancer patients report wanting family caregivers and physicians to share responsibility for decision making if they were too ill to participate.²⁵ As a result, the burden of EOL care decision-making often falls on the caregiver.²⁶ It is nonetheless true that patients and caregivers experience cancer as a dyad and impact each other in important ways.^{27–29} Research indirectly suggests that prognostic understanding in both dyad members is relevant to care received at the end-of-life.^{12,30} However, these studies are limited by reliance on retrospective caregiver report in the absence of patient data and examination of engagement in advance care planning rather than care received at the EOL, respectively.

The purpose of this study is to examine the relationship between patient-caregiver agreement on the patient's future quality of life and life-expectancy (i.e., prognosis) and hospice enrollment in the last 30 days of life. We hypothesized that patients in dyads in which the patient and caregiver agreed on a good prognosis (i.e., good future quality of life and longer life-expectancy) would be less likely to enroll in hospice than dyads in which the patient and caregiver agreed on a poor prognosis or disagreed on prognosis.

METHODS

Sample and procedures

The present analysis is a longitudinal examination of baseline data collected prior to initiation of the Values and Options In Cancer Care (VOICE) intervention and hospice enrollment in the last 30 days of life.³¹ The intervention had no discernible effect on hospice use;³² as such, data across intervention conditions were collapsed in analyses for this study. Participants were recruited from oncology practices and cancer clinics in Rochester/Buffalo, NY and Sacramento, CA. Eligible oncologists were treating patients with solid tumors and were not planning to leave the practice in the following six months. Eligibility criteria for patients included: 1) age 21 years or older, 2) able to understand spoken English, 3) not hospitalized or enrolled in hospice at recruitment or baseline survey administration, and 4) diagnosis of stage IV non-hematological cancer. Patients with stage III cancer were also eligible if their oncologist reported they "would not be surprised" if the patient were to die within 12 months. Eligible caregivers were: 1) non-professional or unpaid (i.e., personal) caregivers, 2) 21 years or older, and 3) able to understand spoken English.

Oncologists were recruited through study presentations at grand rounds and faculty meetings and personal contacts of cancer center directors and study team members. Patients were identified through review of participating oncologists' clinic rosters. Patients were

approached about the study by physicians or nurses and then by research staff or were sent a letter, study brochure, and opt-out card in the mail followed by a phone call from study staff. Caregivers were identified by patients as a “family member, partner, friend or someone else who is involved with your health care issues, for example, someone who you talk to about personal issues including medical decisions or who comes to doctor appointments with you. This person may also help with routine day-to-day activities, like transportation or paperwork.”

After obtaining informed consent, baseline measures were administered by study staff in-person; patients and caregivers completed study measures separately and received \$15 for each set of completed surveys. All baseline measures were administered before patients and caregivers were exposed to the intervention. All study methods were approved by the IRBs of participating sites (IRB# RSRB00035388; clinicaltrials.gov identifier:) and all participants provided written informed consent. Enrollment occurred from August 2012 to June 2014.

Measures

Sample characteristics: Patients self-reported age, gender, race, education, and marital status. Caregivers self-reported age, gender, race, education, marital status, and relationship to the patient.

Prognostic understanding: Prognostic understanding was assessed with two indicators:

(1) Agreement on patient’s life-expectancy: Caregiver and patient expectations about patients’ life-expectancy was assessed with the question “What do you believe are the chances that you [the patient] will live for 2 years or more?”³³ This item was designed to assess a life-expectancy unlikely to be reached by most of the sample. A two-year timeline was selected to account for the potentially beneficial impact of novel cancer therapies on life-expectancy and the inclusion of cancers that can be managed for extended periods despite being stage III or IV disease.

Responses were coded as follows: 0=“100%”, 1=“about 90%”, 2=“about 75%”, 3=“50–50”, 4=“about 25%”, 5=“about 10%”, and 6=“0%”. Dyads were coded as agreeing on a “longer” life-expectancy if the patient and caregiver believed that the odds of surviving for two or more years was greater than 50% (responded 0–2). Dyads in which both the patient and caregiver responded 3–6 were coded as agreeing on a “shorter” life-expectancy. Dyads in which one member responded 0–2 and the other responded 3–6 were coded as disagreeing. Dyads in which the patient or caregiver refused to answer this item or responded “don’t know” were excluded from analyses.

(2) Agreement on future quality of life: Patients’ and caregivers’ perceptions of the patient’s future quality of life were assessed with an item adapted from the McGill Quality of Life Questionnaire.^{34,35} Patients and caregivers were asked to rate the quality of the patient’s life three months hence; “Three months from now, how do you believe you will rate the quality of your life?” Response options ranged from Very Bad (0) to Excellent (10).³⁶ Caregivers responded to a similar question (e.g., Three months from now, what is your

best guess about how [patient] will be doing in terms of quality of life?) using identical response options. Dyads in which both the patient and caregiver responded 0–6 were coded as agreeing on a poor quality of life. Dyads in which both the patient and caregiver responded 7–10 were coded as agreeing on a good future quality of life. Dyads in which one member responded 0–6 and the other member responded 7–10 were coded as disagreeing.³⁷

Hospice enrollment: Hospice enrollment was defined as use of hospice in the 30 days before death (yes/no). Trained nurses and physicians abstracted this information from medical records of deceased patients obtained from relevant hospitals, offices, and hospice organizations.

Statistical Analysis

Logistic regression analyses were used to examine the relationships between patient and caregiver agreement on the patient's future quality of life and life-expectancy, respectively, and hospice enrollment in the last 30 days of life (dichotomous outcome). For patient-caregiver agreement on future quality of life and life-expectancy, we created three categories: 1) dyads that agreed on a good prognosis (reference group), 2) dyads that agreed on a poor prognosis, and 3) dyads who disagreed. All models included physician-level random effects to correct standard errors for within-physician clustering. Multivariable models controlled for other design variables (study site, oncologist subspecialty [breast vs. other]) as well as patient demographics known to be associated with hospice use (age, gender, education [high school or less, some college or more]).^{38–41} We report models that do not include intervention arm because baseline study measures were administered prior to intervention exposure. Sensitivity analyses additionally adjusted for intervention arm. All statistical inferences were based on two-sided tests with $p < 0.05$ considered statistically significant. Statistical analyses were conducted in version 9.4 of the SAS System.

RESULTS

Sample characteristics

Data were available on 141 dyads. Baseline surveys were administered 16 months (median) prior to the patient's death. Demographic characteristics are provided in Table 1. Most dyads were married couples ($n=87$; 62%). Most patients were white ($n=126$, 89%) and had more than a high school education ($n=98$, 70%). The same was true of caregivers.

Agreement on future quality of life and hospice enrollment

In 34.0% of dyads ($n=48$), both parties believed the patient would have a good future quality of life and in 23.4% ($n=33$) both agreed the patient would have a poor quality of life. The remaining dyads disagreed on the patient's future quality of life ($n=60$, 43%). Of dyads who agreed on a good future quality of life, 50.0% ($n=24$) subsequently enrolled in hospice; 78.8% ($n=26$) of dyads who agreed on a poor future quality of life enrolled in hospice (Table 2). Most patients in dyads who disagreed on future quality of life enrolled in hospice ($n=45$, 75%).

Table 3 reports the results of multivariable analyses of the relationship between patient-caregiver agreement on future quality of life and hospice enrollment. In contrast to patients in dyads who both predicted a good quality of life in the future, patients in dyads who disagreed about future quality of life (OR, 3.9 [95% CI 1.45, 10.49], $p < .01$) and patients in dyads who agreed that quality of life would be poor (OR, 4.28 [95% CI 1.61, 11.39], $p < .001$) were significantly more likely to enroll in hospice.

Agreement on life-expectancy and hospice enrollment

In approximately one-third of dyads ($n=42$, 29.8%), patients and caregivers agreed on a longer life-expectancy; patients and caregivers in 20.6% ($n=29$) of dyads agreed on a shorter life-expectancy. The remaining dyads disagreed on the patient's life-expectancy ($n=70$, 49.6%). Of dyads in which both members projected longer life-expectancy, 52.4% ($n=22$) of patients enrolled in hospice; in contrast, 86.2% ($n=25$) of dyads who projected shorter life-expectancy enrolled in hospice (Table 2). Patients in two-thirds of dyads who disagreed on life-expectancy enrolled in hospice ($n=48$, 68.6%); rates of hospice enrollment in this group were lower than those who agreed on shorter life-expectancy and higher than those who agreed on longer life-expectancy.

Table 4 reports multivariable analyses of the relationship between patient-caregiver agreement on life-expectancy and hospice enrollment. In contrast to patients in dyads who agreed on a longer life-expectancy, patients in dyads who disagreed on the patient's life-expectancy (OR, 3.15 [95% CI, 1.35, 7.33], $p < .01$) and patients in dyads who projected shorter life-expectancy (OR, 7.99 [2.4, 26.6], $p < .001$) were significantly more likely to enroll in hospice in controlled analyses.

Results in Tables 3 and 4 were essentially unchanged in sensitivity analyses that adjusted for intervention arm.

DISCUSSION

This study examined the contributions of patient-caregiver agreement on the future quality of life and life-expectancy to hospice enrollment in the last 30 days of life. The majority of dyads agreed on the patient's future quality of life and life-expectancy.²⁷⁻²⁹ Despite the advanced nature of the patient's illness, approximately one-third of dyads agreed on a positive view of future quality of life and life-expectancy, and these dyads were less likely to enroll in hospice.

Unrealistic optimism about the future or the tendency to believe one is at lower risk for health problems than others⁴² may explain patients' and caregivers' positive views of patients' life-expectancy and future quality of life and lower rates of hospice enrollment. Past experience is one predictor of unrealistic optimism.⁴³ For many dyads, advanced cancer is a first-time experience which may drive optimism about the future that is not tempered by awareness of the likely decline associated with advanced cancer.⁴² Providing prognostic information, particularly to dyads in which both members have an optimistic view of the patients' prognosis, and assessing understanding^{44,45} may decrease unrealistic optimism.

The relationship between prognostic understanding and hospice enrollment in this study may also be attributable to a desire to maintain hope and a positive perspective.⁴⁶ Messages regarding the benefits of hope and a positive attitude are often embedded within cancer care. Moreover, the scientific literature on the health benefits of a positive perspective generates considerable media attention.³⁷ These messages may interfere with patients' and caregivers' willingness to discuss poor prognosis and enroll in hospice.^{46,47} Further, hospice enrollment may be considered synonymous with "giving up," reducing patient and caregiver willingness to pursue hospice.⁴⁸ Of course, patients can hope for multiple outcomes simultaneously such as hoping for good quality of life, a long life, and a good death.¹⁷ Future studies should examine whether hope for outcomes such as a cure and perceived social pressure to "be positive"^{49,50} influence un-tempered optimism about life expectancy and low hospice enrollment.

Patients with advanced cancer who recognize their illness is terminal are more likely to prefer¹⁰ and receive¹² symptom-directed care and less likely to receive futile aggressive care¹³ that undermines quality of life.^{10,51} This study adds to these findings in three notable ways. First, this study used a dyadic approach to understand the relationship between understanding of life expectancy and future quality of life and hospice enrollment. Identification of patients in dyads in which the patient and caregiver both believe the patient's life-expectancy and future quality of life will be good may allow providers to intervene on patients at greatest risk for not accessing hospice care. Further, if a patient reports believing their life-expectancy and future quality of life are good, assessing illness understanding in the caregiver may improve estimates of the likelihood of hospice enrollment. Finally, in the current study, patient and caregiver agreement on prognostic understanding over a year before the patient's death predicted hospice enrollment, suggesting that early evaluation of shared prognostic understanding may help providers identify patients who may not utilize hospice services at the end-of-life. Patient-caregiver disagreement about prognosis may indicate poor communication within the dyad that could impair decision-making. Early intervention to improve patient-caregiver communication may improve patient-caregiver agreement on prognosis and promote patients' ability to make treatment decisions consistent with their prognosis and personal preferences for care.

Second, this study assessed beliefs about quality of life in the future as well as beliefs about life-expectancy, consistent with the importance of quality of life to patients with cancer.¹⁸ Discussions of projected life-expectancy can be difficult for patients, caregivers, and providers which can lead to avoidance.⁵² In contexts in which assessing patients' and caregivers' shared understanding of the patients' life-expectancy is clinically inappropriate, unlikely to occur, or impaired by distress, assessing their view of the patient's future quality of life may be an informative alternative. In addition, future studies should examine whether a compounding effect of agreement on future quality of life and life-expectancy exists such that patients in dyads who agree on both aspects of prognosis are more likely to enroll in hospice than patients in dyads who only agree on one component of prognosis.

Third, most research on quality of life focuses on current quality of life but more research is needed on patients' and caregivers' outlook on their future quality of life. Patients whose current quality of life is good may inaccurately believe this will continue indefinitely,

prompting them to make decisions about future care based on unrealistic expectations about the future. Assessment of patients' and caregivers' views of quality of life in the future may help providers identify and correct these unrealistic expectations before they impact treatment decisions.

Study Limitations and Future Directions

This study provides a longitudinal dyadic perspective on the relationship between illness understanding and hospice enrollment in the last 30 days of life. Some limitations should be noted when interpreting findings. First, the sample was primarily white and married with education beyond high school. Due to these demographic characteristics of the sample, the results cannot be generalized to other populations. Second, dyads in which one or both members responded “don't know” (n=22; 13.8%) to the items assessing estimations of the patient's life-expectancy and future quality of life were excluded from analyses given our interest in examining respondents who are willing to harbor a guess about the future. Third, we did not distinguish between the two types of dyadic disagreement: 1) patients predicted better prognosis (i.e., prediction of longer life-expectancy and better future quality of life) than caregivers, and 2) caregivers predicted better prognosis (i.e., prediction of longer life-expectancy and better future quality of life) than patients. Future dyadic research could examine differences in EOL care as a function of whether a caregiver or patient has more favorable views of prognosis. Finally, the study was not powered to explore the moderating impact of patient-caregiver relationship variables on hospice enrollment. This association may differ based on caregiver type (e.g., spouse, adult child) or relationship variables such as perceived closeness and communication quality. Evaluation of the moderating impact of these variables on the relationship between patient-caregiver agreement and hospice enrollment could identify dyads at high risk for underutilization of hospice services.

In conclusion, the focus of this study on the relationship between patient and caregiver agreement on the patient's prognosis and future quality of life and hospice enrollment adds to our knowledge of factors impacting end-of-life care. Our findings highlight the importance of assessing illness understanding in patients and caregivers and including both dyad members in conversations about the patient's prognosis and quality of life.

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REFERENCES

1. IOM (Institute of Medicine). 2014 Dying in America: Improving quality and honoring individual preferences near the end of life Washington, DC: The National Academies Press.
2. Petracci E, Nanni L, Maltoni M, Derni S, Campana G, Scarpi E. Impact of admission to hospice on pain intensity and type of pain therapies administered. *Support Care Cancer* 2016;24:225–232. [PubMed: 26003422]
3. Currow DC, Allingham S, Yates P, Johnson C, Clark K, Eagar K. Improving national hospice/palliative care service symptom outcomes systematically through point-of-care data collection,

- structured feedback and benchmarking. *Support Care Cancer* 2015;23:307–315. [PubMed: 25063272]
4. Obermeyer Z, Makar M, Abujaber S, Dominici F, Block S, Cutler DM. Association between the Medicare hospice benefit and health care utilization and costs for patients with poor-prognosis cancer. *JAMA* 2014;312:1888–1896. [PubMed: 25387186]
 5. Breitkopf CR, Stephens EK, Jatoi A. Hospice in end-of-life patients with cancer: Does it lead to changes in nonhospice health care utilization after stopping cancer treatment? *The American Journal of Hospice & Palliative Care* 2014;31:392–395. [PubMed: 23666617]
 6. Bainbridge D, Seow H. Palliative care experience in the last 3 months of life: A quantitative comparison of care provided in residential hospices, hospitals, and the home from the perspectives of bereaved caregivers. *The American Journal of Hospice & Palliative Care* 2018;35(3):456–463. [PubMed: 28610431]
 7. Miyashita M, Morita T, Sato K, Tsuneto S, Shima Y. A Nationwide survey of quality of end-of-life cancer care in designated cancer centers, inpatient palliative care units, and home hospices in Japan: The J-HOPE Study. *J Pain Symptom Manage* 2015;50:38–47.e33. [PubMed: 25656327]
 8. Hatano Y, Aoyama M, Morita T, et al. The relationship between cancer patients' place of death and bereaved caregivers' mental health status. *Psychooncology* 2017;26:1959–1964. [PubMed: 28345777]
 9. Christakis NA, Iwashyna TJ. The health impact of health care on families: A matched cohort study of hospice use by decedents and mortality outcomes in surviving, widowed spouses. *Social Science & Medicine* (1982) 2003;57:465–475. [PubMed: 12791489]
 10. Mack JW, Weeks JC, Wright AA, Block SD, Prigerson HG. End-of-life discussions, goal attainment, and distress at the end of life: Predictors and outcomes of receipt of care consistent with preferences. *J Clin Oncol* 2010;28:1203–1208. [PubMed: 20124172]
 11. Enzinger AC, Zhang B, Schrag D, Prigerson HG. Outcomes of prognostic disclosure: Associations with prognostic understanding, distress, and relationship with physician among patients with advanced cancer. *J Clin Oncol* 2015;33:3809–3816. [PubMed: 26438121]
 12. Seale C, Addington-Hall J, McCarthy M. Awareness of dying: Prevalence, causes and consequences. *Social Science & Medicine* 1997;45:477–484. [PubMed: 9232741]
 13. Temel JS, Greer JA, Admane S, et al. Longitudinal perceptions of prognosis and goals of therapy in patients with metastatic non-small-cell lung cancer: Results of a randomized study of early palliative care. *J Clin Oncol* 2011;29:2319–2326. [PubMed: 21555700]
 14. Norton SA, Wittink MN, Duberstein PR, Prigerson HG, Stanek S, Epstein RM. Family caregiver descriptions of stopping chemotherapy and end-of-life transitions. *Support Care Cancer* 2018 [epub ahead of print]. 10.1007/s00520-018-4365-0
 15. Tzuh TS, Tsang-Wu L, Jyh-Ming C, et al. Associations between accurate prognostic understanding and end-of-life care preferences and its correlates among Taiwanese terminally ill cancer patients surveyed in 2011–2012. *Psycho-Oncol* 2014;23:780–787.
 16. Hongbin C, HW E, RB, SR. Decisions for hospice care in patients with advanced cancer. *Journal of the American Geriatrics Society* 2003;51:789–797. [PubMed: 12757565]
 17. DeMartini J, Fenton JJ, Epstein R, et al. Patients' hopes for advanced cancer treatment. *J Pain Symptom Manage* 2018. doi: 10.1016/j.jpainsymman.2018.09.014
 18. Meropol NJ, Egleston BL, Buzaglo JS, et al. Cancer patient preferences for quality and length of life. *Cancer* 2008;113:3459–3466. [PubMed: 18988231]
 19. Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 2008;300:1665–1673. [PubMed: 18840840]
 20. Rose JH, O'Toole EE, Einstadter D, Love TE, Shenko CA, Dawson NV. Patient age, well-being, perspectives, and care practices in the early treatment phase for late-stage cancer. *J Gerontol A Biol Sci Med Sci* 2008;63:960–968. [PubMed: 18840801]
 21. Loggers ET, Maciejewski PK, Jimenez R, et al. Predictors of intensive end-of-life and hospice care in Latino and white advanced cancer patients. *J Palliat Med* 2013;16:1249–1254. [PubMed: 24053593]

22. Sudore RL, Fried TR. Redefining the “planning” in advance care planning: Preparing for end-of-life decision making. *Ann Intern Med* 2010;153:256–261. [PubMed: 20713793]
23. Winzelberg GS, Hanson LC, Tulskey JA. Beyond autonomy: Diversifying end-of-life decision-making approaches to serve patients and families. *J Am Geriatr Soc* 2005;53:1046–1050. [PubMed: 15935032]
24. Butow P, Maclean M, Dunn S, Tattersall M, Boyer M. The dynamics of change: Cancer patients’ preferences for information, involvement and support. *Annals of Oncology* 1997;8:857–863. [PubMed: 9358935]
25. Degner LF, Sloan JA. Decision making during serious illness: What role do patients really want to play? *Journal of Clinical Epidemiology* 1992;45:941–950. [PubMed: 1432023]
26. Wendler D, Rid A. Systematic Review: The Effect on Surrogates of Making Treatment Decisions for Others. *Annals Of Internal Medicine* 2011;154(5):336–346. [PubMed: 21357911]
27. Epstein RM. Whole mind and shared mind in clinical decision-making. *Patient Educ Couns* 2013;90:200–206. [PubMed: 22884938]
28. Segrin C, Badger T, Dorros SM, Meek P, Lopez AM. Interdependent anxiety and psychological distress in women with breast cancer and their partners. *Psychooncology* 2007;16:634–643. [PubMed: 17094160]
29. Williams AL, McCorkle R. Cancer family caregivers during the palliative, hospice, and bereavement phases: A review of the descriptive psychosocial literature. *Palliative & Supportive Care* 2011;9:315–325. [PubMed: 21838952]
30. Shen MJ, Trevino KM, Prigerson HG. The interactive effect of advanced cancer patient and caregiver prognostic understanding on patients’ completion of do not resuscitate orders. *Psychooncology* 2018;27:1765–1771. [PubMed: 29611241]
31. Hoerger M, Epstein RM, Winters PC, et al. Values and options in cancer care (VOICE): Study design and rationale for a patient-centered communication and decision-making intervention for physicians, patients with advanced cancer, and their caregivers. *BMC Cancer* 2013;13:188. [PubMed: 23570278]
32. Epstein RM, Duberstein PR, Fenton JJ, et al. Effect of a patient-centered communication intervention on oncologist-patient communication, quality of life, and health care utilization in advanced cancer: The VOICE randomized clinical trial. *JAMA Oncology* 2017;3:92–100. [PubMed: 27612178]
33. Gramling R, Fiscella K, Xing G, et al. Determinants of patient-oncologist prognostic discordance in advanced cancer. *JAMA Oncology* 2016;2:1421–1426. [PubMed: 27415765]
34. Cohen SR, Mount BM, Strobel MG, Bui F. The McGill Quality of Life Questionnaire: A measure of quality of life appropriate for people with advanced disease. A preliminary study of validity and acceptability. *Palliat Med* 1995;9:207–219. [PubMed: 7582177]
35. Cohen SR, Mount BM, Bruera E, Provost M, Rowe J, Tong K. Validity of the McGill Quality of Life Questionnaire in the palliative care setting: A multi-centre Canadian study demonstrating the importance of the existential domain. *Palliat Med* 1997;11:3–20. [PubMed: 9068681]
36. Halpern J, Arnold RM. Affective forecasting: An unrecognized challenge in making serious health decisions. *Journal of General Internal Medicine* 2008;23:1708–1712. [PubMed: 18665428]
37. Steptoe A, Deaton A, Stone AA. Subjective wellbeing, health, and ageing. *Lancet* 2015;385:640–648. [PubMed: 25468152]
38. Diamond EL, Russell D, Kryza-Lacombe M, et al. Rates and risks for late referral to hospice in patients with primary malignant brain tumors. *Neuro-oncology* 2016;18:78–86. [PubMed: 26261221]
39. Lackan NA, Ostir GV, Kuo YF, Freeman JL. The association of marital status and hospice use in the USA. *Palliat Med* 2005;19:160–162. [PubMed: 15810757]
40. Nuha AL, Ostir GV, Freeman JL, Jonathan DM, Goodwin JS. Decreasing variation in the use of hospice among older adults with breast, colorectal, lung, and prostate cancer. *Medical Care* 2004;42:116–122. [PubMed: 14734948]
41. Chen H, Haley WE, Robinson BE, Schonwetter RS. Decisions for hospice care in patients with advanced cancer. *Journal of the American Geriatrics Society* 2003;51:789–797. [PubMed: 12757565]

42. Weinstein ND. Reducing unrealistic optimism about illness susceptibility. *Health Psychology* 1983;2:11–20.
43. Weinstein ND. Unrealistic optimism about susceptibility to health problems: Conclusions from a community-wide sample. *J Behav Med* 1987;10:481–500. [PubMed: 3430590]
44. Brown R, Bylund CL, Eddington J, Gueguen JA, Kissane DW. Discussing prognosis in an oncology setting: Initial evaluation of a communication skills training module. *Psychooncology* 2010;19:408–414. [PubMed: 19441006]
45. Back AL, Anderson WG, Bunch L, et al. Communication about cancer near the end of life. *Cancer* 2008;113:1897–1910. [PubMed: 18798531]
46. Mrig EH, Spencer KL. Political economy of hope as a cultural facet of biomedicalization: A qualitative examination of constraints to hospice utilization among U.S. end-stage cancer patients. *Social science & medicine* (1982) 2018;200:107–113. [PubMed: 29421457]
47. Sutherland N The meaning of being in transition to end-of-life care for female partners of spouses with cancer. *Palliative & Supportive Care* 2009;7:423–433. [PubMed: 19939305]
48. Ford DW, Nietert PJ, Zapka J, Zoller JS, Silvestri GA. Barriers to hospice enrollment among lung cancer patients: A survey of family members and physicians. *Palliative & supportive care* 2008;6:357–362. [PubMed: 19006590]
49. Wilkinson S, Kitzinger C. Thinking differently about thinking positive: A discursive approach to cancer patients' talk. *Social Science & Medicine* 2000;50:797–811. [PubMed: 10695978]
50. Wilkes LM, O'baugh J, Luke S, George A. Positive attitude in cancer: Patients' perspectives. *Oncology Nursing Forum* 2003;30:412–416. [PubMed: 12719741]
51. Prigerson HG, Bao Y, Shah MA, et al. Chemotherapy use, performance status, and quality of life at the end of life. *JAMA Oncology* 2015;1:778–784. [PubMed: 26203912]
52. Larson DG, Tobin DR. End-of-life conversations: Evolving practice and theory. *JAMA* 2000;284:1573–1578. [PubMed: 11000655]

Table 1.

Sample characteristics

Characteristic	Dyad, n (%)	
Site		
Western New York (URMC)	102 (72.3)	
Northern California (UCD)	39 (27.7)	
Cancer type		
Breast	21 (14.9)	
Other	120 (85.1)	
Patient-Caregiver Relationship		
Spouse	87 (61.7)	
Other	54 (38.3)	
	Patients, n (%)	Caregivers, n (%)
Gender		
Male	65 (46.1)	42 (29.8)
Female	76 (53.9)	99 (70.2)
Race		
White	126 (89.4)	125 (88.7)
Other	15 (10.6)	16 (11.3)
Education		
High school or less	43 (30.5)	38 (27.0)
Some college or more	98 (69.5)	103 (73.0)
Marital status		
Committed/Married	104 (73.8)	115 (81.6)
Divorced/Separated	15 (10.6)	9 (6.4)
Widowed	12 (8.5)	5 (3.5)
Never married	10 (7.1)	12 (8.5)
Age, M (SD)	66.3 (11.1)	60.1 (14.1)

Note. URMC: University of Rochester Medical Center; UCD: University of California – Davis

Table 2.

Frequency statistics n (%) on hospice enrollment as a function of patient-caregiver agreement on prognosis (future quality of life and life-expectancy)

	Agree: Good prognosis	Agree: Poor prognosis	Disagree
Future quality of life			
Enrolled in hospice	24 (50.0)	26 (78.8)	45 (75.0)
Not enrolled in hospice	24 (50.0)	7 (21.2)	15 (25.0)
Life-expectancy			
Enrolled in hospice	22 (52.4)	25 (86.2)	48 (68.6)
Not enrolled in hospice	20 (47.6)	4 (13.8)	22 (31.4)

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Table 3.

Relationship between patient-caregiver agreement on future quality of life and hospice enrollment

Predictor	OR	95% CI	p
UCD vs. URM	0.26	0.1, 0.64	<0.01
Breast cancer vs. other cancer	0.45	0.16, 1.31	0.14
Age, years	1.02	0.98, 1.06	0.26
Male vs. female gender	0.35	0.12, 0.99	0.048
Some college or more vs. other	2.45	0.94, 6.4	0.07
Dyads disagree vs agree on good future QoL	3.90	1.45, 10.49	<0.01
Dyads agree on worse future QoL vs agree on good future QoL	4.28	1.61, 11.39	<.001

Note UCD: University of California – Davis; URM: University of Rochester Medical Center

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Table 4.

Relationship between patient-caregiver agreement on life-expectancy and hospice enrollment

Predictor	OR	95% CI	p
UCD vs. URMC	0.20	0.08, .49	<.001
Breast cancer vs. other cancer	0.85	0.35, 2.07	0.71
Age, years	1.01	0.97, 1.05	0.57
Male vs. female gender	0.41	0.15, 1.09	0.07
Some college or more vs. other	2.54	1.08, 5.96	0.03
Dyads disagree vs agree on longer life-expectancy	3.15	1.35, 7.33	<0.01
Dyads agree on shorter vs agree on longer life-expectancy	7.99	2.4, 26.6	<0.001

Note UCD: University of California – Davis; URMC: University of Rochester Medical Center

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