Published in final edited form as:

J Psychosoc Oncol. 2018 ; 36(1): 1–18. doi:10.1080/07347332.2017.1357666.

Unpacking cancer patients' preferences for information about their care

Erin M. Ellis, PhD, MS, MPH^a and Ashley Varner, MSW, MBA^b

^aBehavioral Research Program, National Cancer Institute, Rockville, Maryland, USA;

^bDeCesaris Cancer Institute, Anne Arundel Medical Center, Annapolis, Maryland, USA

Abstract

Objective: Patient-centered decision making requires cancer patients be actively involved and feel sufficiently informed about their care, but patients' preferences for information are often unrecognized or unmet by their oncologist, particularly for more distressing topics. This study examined cancer patients' preferences for information about three care-related topics: (1) diagnostic information, (2) treatment costs, and (3) prognosis. We tested whether factors known to influence information preferences (psychological distress, control preferences, and financial distress) were differently associated with information preferences for each topic.

Methods: Cancer patients (N = 176) receiving ongoing treatment completed a questionnaire that assessed their out-of-pocket treatment costs, psychological distress, preferences for control over their medical decisions, and the amount of information they desired and received from their oncologists about the three topics.

Results: Patients' preferences were less often met for treatment cost information than for the other topics, $p < 0.001$, with half wanting more cost information than they received. One-third of patients also wanted more prognostic information than they received. Patients' preferences for diagnostic information did not differ as a function of financial burden, distress, or control preferences, $ps > 0.05$. Preferences for cost information were greater among patients who preferred more control over their medical decisions, $p = 0.016$. Patients' preferences for prognostic information were greater among those desiring more control and with lower distress, $ps < 0.05$. Financial burden was not associated with information preferences.

Conclusion: Appreciating the variability in information preferences across topics and patients may aid efforts to meet patients' information needs and improve outcomes.

Keywords

cancer/oncology treatment; information preferences

Introduction

Actively involving cancer patients in treatment decisions is a central facet of patient-centered decision-making models, and is advocated by leading professional organizations and funding agencies. For instance, the American Society of Clinical Oncology endorses patient-centered individualized care as a primary element of services for patients with advanced cancer (Bickel et al., 2016; Peppercorn et al., 2011), and the Institute of Medicine's *Crossing the Quality Chasm* report identified patient-centered decision making as one of the fundamental approaches to improving the quality of health care in the United States (Richardson et al., 2001). Likewise, the vision of the Patient-Centered Outcomes Research Institute—one of several patient-centered Affordable Care Act initiatives—is to conduct research that helps patients and the public to make better-informed health care decisions (Patient Protection and Affordable Care Act, 2010, Section 3506; Patient Centered Outcomes Research Institute, 2017).

This type of patient-centered decision making requires patients be actively involved and feel sufficiently informed about their care; however, patients' preferences for information are often unrecognized or unmet by their oncologist (e.g., Kiesler & Auerbach, 2006; Pardon et al., 2011; Russell & Ward, 2011). These information preferences may vary across care-related topics and patient characteristics, but a few studies have assessed preferences for information beyond the topics of diagnosis and treatment. This study sought to extend our understanding of patients' information preferences by comparing how much information patients wanted about several aspects of their care, and examining patient characteristics associated with these topic-specific preferences.

Most patients rely on their healthcare team as the primary source of (potentially complex) medical information about their diagnosis, medical procedures, and treatment options (Longo et al., 2009; Reyna, Nelson, Han, & Pignone, 2015). Particularly, in cases of clinical equipoise (i.e., no single objectively superior treatment option), the provision of information often becomes a key goal of the physician–patient relationship (Kiesler & Auerbach, 2006; Reyna et al., 2015). Evidence suggests meeting patients' preferences for information can—but does not always—increase perceptions of control, reduce anxiety, improve treatment compliance, and potentially improve clinical outcomes (Jefford & Tattersall, 2002). Not all patients want to be fully informed and involved in treatment decision making though (Ankem, 2006), and providing patients with more information than they want may impair overall comprehension (Reyna et al., 2015) and cause emotional distress (Kiesler & Auerbach, 2006). On the other hand, providing less information than patients want is associated with lower patient engagement and poorer health-related quality of life (Husson, Mols, & van de Poll-Franse, 2011). Thus, regardless of the direction of the mismatch, when there is incongruence between how much information patients want and how much they receive, it can have negative effects on patient outcomes (Kiesler & Auerbach, 2006). Patients may have optimal care experiences when their providers are able to assess or anticipate their unique information preferences.

Patients' preferences for information may vary across different topics. They may want to feel fully informed about some aspects of their care, but desire less—or even avoid—

information that can be more distressing to discuss or think about (Ankem, 2006; Sweeny, Melnyk, Miller, & Shepperd, 2010). For instance, nearly half of the patients worry about the cost of their treatment, and an even larger proportion worries about related concerns, such as missing work (Martin et al., 2014; Meisenberg et al., 2015; Zafar & Abernethy, 2013). Relatedly, discussing prognosis and life expectancy can be distressing and difficult for a patient and loved ones (Innes & Payne, 2009). In an effort to avoid psychological distress, patients may desire less information about their prognosis and treatment costs than about their diagnosis and treatment side effects (e.g., Elkin, Kim, Casper, Kissane, & Schrag, 2007). However, because these topics are also the hardest for oncologists to discuss with their patients, even preferences for a small amount of information about prognosis or treatment costs may go unmet, and discordance between the amount of information desired and received may be high (Fine, Reid, Shengelia, & Adelman, 2010).

Preferences for information may also vary across patients based on sociodemographic, clinical, and other psychological characteristics (e.g., Ankem, 2006; Jefford & Tattersall, 2002). Although there is evidence that age, marital status, education level, gender, cancer type, and stage of disease influence information preferences, the direction and significance of the associations are inconsistent across studies (Russell & Ward, 2011; Zeguers et al., 2012). Likewise, the evidence of the effects of anxiety and depression on information preferences is mixed, with some studies finding positive associations between distress and information preferences (Davison & Breckon, 2012; Fujimori & Uchitomi, 2009; Mesters, van den Borne, De Boer, & Pruyn, 2001), whereas other studies suggest higher baseline depression and anxiety may motivate avoidance of distressing information (Baile et al., 2000; Sweeny et al., 2010).

There is also mixed evidence for the associations between control preferences and information preferences. Some studies have speculated about and found evidence for a positive association between patients' desire for control and their information needs (Degner et al., 1997; Kiesler & Auerbach, 2006), whereas other studies have found no association between preferences for control and information; even patients who prefer to take a passive approach to their medical decisions want to feel fully informed (Manson, 2010; ter Hoeven et al., 2011). Finally, patients' financial distress may influence their preferences for information about treatment costs, but a few studies have examined the direction of this association. One possibility is that patients experiencing greater financial distress may desire more cost information so they can consider costs in future treatment decisions; alternatively, patients experiencing financial distress may find this information distressing and avoid it. Given that the financial burden facing cancer patients is growing (Zafar & Abernethy, 2013), it is becoming increasingly important to understand patients' information preferences related to the cost of treatments.

The current study

The primary aim of the current study was to compare patients' preferences for information, as well as discordance between preferred and received information, about the following topics: diagnosis and treatment (e.g., treatment options and side effects), costs of treatments, and prognosis. Given that patients may be motivated to avoid distressing information about

prognosis and costs, we hypothesized they would prefer less information about these topics than about diagnosis and treatment options, but that these topics would also produce greatest discordance because of the barriers that exist to oncologists and patients discussing these topics.

A secondary aim was to examine the patient characteristics associated with these topic-specific information preferences, focusing on depression/anxiety, control preferences, and financial burden. Conceptually, these factors have been linked to the motivation to acquire information, as well as the ability to effectively process and use this information for decision making (e.g., Ferrer, Klein, Lerner, Reyna, & Keltner, 2015). Moreover, we hypothesized that their associations with information preferences would be topic-specific, making them particularly relevant for the current study. For instance, we hypothesized that depression would be associated with prognostic information preferences, whereas financial burden would be associated with preferences for treatment cost information.

Despite a growing literature documenting patients' preferences for information, little work has examined these preferences in a topic-specific fashion. Summary or general measures of information preferences may mask important differences in preference concordance about challenging yet important topics (e.g., treatment costs), as well as the participant characteristics associated with these preferences. Greater understanding of such complexities may help inform efforts to meet patients' information needs, thereby facilitating patient-centered decision making.

Methods

Participants and procedure

A convenience sample of cancer patients ($N = 176$) in the state of Maryland (United States) currently receiving treatment at one community cancer center completed an anonymous paper and pencil survey (see section Measures) in the waiting room before one of their clinic appointments. Consistent with procedures used in prior surveys at the cancer center, nurses trained to answer participants' questions invited all patients to participate with no restrictions based on diagnosis, treatment type, or other care-related criteria. Recruitment lasted approximately one week. The center's institutional review board deemed the survey exempt. The survey took approximately 15 minutes to complete and patients were not remunerated for their participation.

Participants ranged in age from 28 to 87 years ($M = 63.0$, $SD = 12.3$); two-thirds (64%) were female; and two-thirds (68%) were married or living with a partner. Participants' median household income was between \$50,001 and \$100,000, and all participants had health insurance (40% had both Medicare and commercial insurance).

Measures

Treatment costss—Participants reported how much they spent on five treatment-related costs each month: (1) medical visits, (2) prescriptions, (3) vitamins and complementary treatments, (4) household help, and (5) other costs. These items were summed to create an estimate of their total monthly out-of-pocket costs related to their cancer illness and

treatment. This cost variable was positively skewed (skewness = 4.18); thus, a square root transformation was used to create a normally distributed variable (skewness = 1.93) that was used in the analyses described below.

Psychological distress—The 4-item Patient Health Questionnaire (PHQ-4) is a well-validated assessment of symptoms of depression and anxiety (Kroenke, Spitzer, Williams, & Löwe, 2009). Depression and anxiety were each assessed with two items; separate scales were calculated as the sum of the respective items ($\alpha = 0.89$). A combined psychological distress scale was also calculated as the sum of all four items ($\alpha = 0.88$). Results using the combined scale are reported, but findings were identical when depression and anxiety were analyzed separately.

Control preferences—Patients' desire for control over their medical decisions was assessed with a modified version of the Control Preferences Scale (Degner, Sloan, & Venkatesh, 1996). Four items assessed the extent to which patients preferred that their doctor controls the decision (1) with and (2) without their input, and the extent to which they preferred to control the decision themselves (3) with and (4) without doctor input. A control preferences scale was created as the mean score on the four items with the first two reverse-coded; thus, higher values represented a preference for greater patient control.

Information preferences—Patients' information preferences were assessed with a 7-item scale modified to include cost information (Pardon et al., 2011). Three items assessed preferences for diagnostic and treatment information: (1) diagnosis characteristics; (2) treatment side effects; and (3) treatment effectiveness). Two items assessed treatment costs to (4) society and (5) oneself, and two items were related to prognosis: (6) chances of cure and (7) life expectancy. Each item began with "I want information about..." and used a 4-point scale ranging from none to a lot (see Table 3).

Received information—Patients reported how much information they received from their doctor about the same seven topics. Each item began with "So far, my doctor has provided me with information about..." and used a 4-point scale ranging from *none* to *a lot*.

Preference concordance—To examine the match between desired and received information for each topic, we subtracted the amount of information that patients received from the amount desired. Thus, a score of zero represented a perfect match; negative scores represented the receipt of more information than desired, and positive scores reflected the receipt of less information than they desired.

Clinical and participant characteristics—Clinical characteristics (e.g., date of diagnosis and cancer type), health insurance coverage, and demographic information (e.g., age and gender) were also assessed.

Data analysis strategy—Variables were recoded such that higher scores reflected higher levels of each construct, and were standardized ($M = 0$, $SD = 1$) to facilitate comparisons between predictors that utilized different metrics. Linear regression was used to test the relations of participant characteristics, monthly treatment costs, psychological distress, and

control preferences to the amount of information participants desired about the various treatment topics. When participant characteristics produced significant main effects on the outcome variable, they were included as covariates in subsequent analyses; their inclusion did not substantively change any patterns of reported results.

Results

Clinical characteristics of participants

Most participants (75%) were diagnosed with cancer in the past 3 years. One-third of participants were being treated for breast cancer (38% of total sample; 57% of female participants). Of the remaining two-thirds of participants, the most common cancer diagnoses were: prostate (13% of total sample; 37% of male participants); lung (12%); lymphoma (8%); colorectal (6%); and other cancers that each represented 4% or less of participants, including myeloma, uterine, ovarian, pancreatic, esophageal, and others. One-third of participants were currently receiving radiation treatment (32%), and 49% were receiving intravenous (45%) and/or oral (7%) chemotherapy. Over half (56%) of participants had surgery as part of their cancer treatment, and of those participants, 66% were also currently receiving either chemotherapy or radiation. One-quarter of participants had no monthly out-of-pocket medical expenses; those who did spent between \$4 and \$12,025 per month on medical care (median = \$200; see Table 1 for all participants' characteristics).

Preferences for information

Most patients (81–88%) wanted “a lot” of information about their diagnosis and treatment options, as well as information about their prognosis (see Table 1). Compared to these topics, patients were less likely to want “a lot” of information about the financial costs of their cancer treatment, $F(2, 155) 61.60, p < 0.001$. Half of the patients (49%) wanted “a lot” of information about the costs that they would incur, and 16% did not want any information on this topic. Even fewer patients (31%) wanted “a lot” of information about the costs of their treatment to society, and 26% did not want any.

Match between preferences and received information

Of the three information categories, participants' preferences for information were most closely met for general diagnosis and treatment information, with more than 71% of participants receiving the amount they wanted, and less than 20% receiving less than they wanted (see Table 2). The poorest match existed in the realm of financial costs of treatment, with nearly half (49%) of the patients wanting more information than they received about costs to themselves, and 41% wanting more information about costs to society. Approximately one-third of participants (31–39%) also wanted more prognosis information than they received.

Predictors of information preferences

Married patients wanted more information than single patients about diagnostic and treatment information, as did those with higher incomes and those who had been diagnosed with cancer longer, $ps < 0.05$ (see Table 3). Younger and married participants also wanted

more information about treatment costs, $ps < 0.05$. No other participant or clinical characteristics predicted information preferences.

Adjusting for the significant covariates described above, the amount of information that patients wanted about their diagnosis and treatment options did not differ as a function of their psychological distress, control preferences, or treatment costs, $ps > 0.05$ (see Table 3). Regardless of these characteristics, nearly all patients wanted a lot of general information about their disease and treatment options.

Patients' psychological distress was only associated with their information preferences surrounding prognosis and life expectancy. As patients' distress increased, they wanted less information about these topics, $ps < 0.05$ (see Table 4). Patients' desire for control over their medical decisions was associated with their preferences for information about both the cost of their care and prognosis. Those who wanted more control also wanted more information about costs to themselves, costs to society, chances of a cure, and their life expectancy, $ps < 0.05$. Patients who had greater monthly expenses wanted more information about the costs of their care to society, $\beta = 0.16$, $p = 0.006$, 95% CI (0.040, 0.29). Otherwise, treatment costs were not associated with information preferences.

Discussion

Most patients desired a lot of information about all aspects of their cancer care although they wanted the least amount of information about the costs of their treatment compared to the other topics. For most patients, their oncologists met their information needs for diagnostic and treatment information, but were less likely to provide the desired amount of information about treatment costs and prognosis. Despite the fact that patients wanted the least amount of information about the cost of their care, this was the information topic for which oncologists were least likely to meet their patients' information needs.

These findings are consistent with prior evidence that patients' information preferences are more likely to be met for diagnosis and treatment information compared to information about prognosis, palliative care, and treatment costs (Henrikson, Tuzzio, Loggers, Miyoshi, & Buist, 2014; Pardon et al., 2011). These emotionally laden and potentially distressing topics are the hardest for both patients and oncologists to discuss (e.g., Pardon et al., 2011). Nonetheless, most patients want to have a discussion with their oncologist about their prognosis and life expectancy (e.g., Fujimori & Uchitomi, 2009; Russell & Ward, 2011), and many also want to discuss treatment costs (e.g., Kaser, Shaw, Marven, Swinburne, & Boyle, 2010; Tseng, Waitzfelder, Tierney, 2010). To the extent that discomfort and distress deter such discussions, reducing the stigma surrounding these topics and facilitating patient-provider conversations are important points of intervention (e.g., Blumenthal-Barby et al., 2015; Innes & Payne, 2009; McFarlane, Riggins, & Smith, 2008). These findings also suggest that patients' information preferences about topics beyond diagnostic and treatment information ought to be assessed and monitored explicitly, as it is these other topics for which patients want more information than they receive.

In the current study, no patient characteristics (clinical, demographic, or psychosocial) were associated with information preferences consistently across all topics. Patients' preferences for information about their diagnosis and treatments were consistently high regardless of their distress, control preferences, or treatment costs. On the other hand, their information preferences surrounding other facets of their care were associated with both psychological distress and control preferences. These findings extend prior evidence of a positive association between overall information needs and control preferences by demonstrating this association for topic-specific information about cost and prognosis, but not diagnostic information (Ankem, 2006; Davison & Breckon, 2012).

Participants who reported greater psychological distress wanted less information about their prognosis, including the chance of a cure and their life expectancy. This information topic can be distressing, and these findings are consistent with prior evidence that distress and anxiety motivate the active avoidance of distressing information as a means of protecting oneself from further mental discomfort (Case, Andrews, Johnson, & Allard, 2005). For instance, in some studies, patients with greater anxiety wanted less information about their disease, treatments, and prognosis (Zeguers et al., 2012). However, not all studies find similar negative relations between distress and preferences for information (Davison & Breckon, 2012; Fujimori & Uchitomi, 2009; Innes & Payne, 2009; Mesters et al., 2001).

Indeed, evidence suggests preferences for prognostic information are complex. Prognostic awareness among cancer patients is often quite low (Applebaum et al., 2014), and not all patients want to be fully informed of their prognosis (El-Jawahri et al., 2014; Enzinger, Zhang, Schrag, & Prigerson, 2015). Patients may convey this preference for not knowing explicitly to their oncologist, and/or indirectly avoid some or all prognostic information through nonverbal communication or biased interpretation of the information (Applebaum et al., 2014; Clayton, Butow, Arnold, & Tattersall, 2005; Daugherty & Hlubocky, 2008; Enzinger et al., 2015; White et al., 2016). These avoidance approaches may help explain why interventions aimed at improving patient–physician communication are often ineffective in improving patients' prognostic awareness (Back, Arnold, & Tulsky, 2009; Wittenberg-Lyles, Goldsmith, Sanchez-Reilly, & Ragan, 2008), as well as the discrepancies between what oncologists report telling patients about their prognosis, and what patients report hearing (Fried, Bradley, & O'Leary, 2003). Although this study included an assessment of patients' active avoidance of information, it did not capture the many other indirect ways patients avoid prognostic information, and this remains an important research question for future work.

Because of the cross-sectional design of the current study, the directionality of the association between information preferences and psychological distress cannot be inferred. Elucidating whether depression motivates or results from greater knowledge of prognosis is an important area for future work, particularly given other cross-sectional work showing greater prognostic awareness is related to less depression (Innes & Payne, 2009). Thus, depression-related avoidance of prognostic information may exacerbate existing depressive symptoms. Confirming the direction of these associations may facilitate intervention efforts aimed at both reducing depression and improving prognostic awareness.

Contrary to prior findings (e.g., Tseng et al., 2010), patients' out-of-pocket treatment costs had little overall effect on their information preferences, with the exception of information about costs to society. These findings may reflect the relatively affluent study population. All participants had health insurance and 40% had more than one type. Moreover, oral chemotherapies are some of the most expensive cancer treatments and a relatively small proportion of the current sample used them. Thus, participants' financial distress may have been lower than in prior studies, thereby reducing the perceived need to acquire cost information to make treatment decisions. Alternatively, the current findings suggest that patients' preferences for cost information should be assessed directly, rather than inferring preferences based on their level of financial distress. Future research ought to examine other factors that may influence these information preferences.

Implications for care delivery

The current findings highlight the complexity of patients' information preferences, which vary from topic to topic, across individuals, and presumably, over time. Despite this, information preferences are rarely assessed—or accurately inferred—by physicians (Elkin et al., 2007; Oostendorp et al., 2016; Pardon et al., 2011), and patients face barriers, such as low self-efficacy and embarrassment, to initiating these conversations themselves (e.g., Furber, Murtagh, Bonas, Bankart, & Thomas, 2014; Kiesler & Auerbach, 2006). Thus, a more proactive, systematic, and comprehensive approach to assessing and meeting patients' information preferences is needed.

Best practices recommend structured formats to guide difficult discussions between patients and providers (Bernacki & Block, 2014), and decision aids and question prompts have been utilized for this purpose in the context of palliative care (Baile et al., 2000; Bernacki & Block, 2014; Clayton, Butow, Arnold & Tatter-sall, 2007). Applied to the assessment of information preferences, care teams may have patients complete questionnaires or decision aids prior to a clinic visit and distribute the results to the team, either electronically or otherwise (e.g., Bernacki & Block, 2014; Blumenthal-Barby et al., 2015; Davison et al., 2002; Davison, Szafron, Gutwin, & Visvanathan, 2014). Importantly, this decision aid would assess topic-specific information preferences, thereby validating the importance of each for patient well-being, and also would assess psychosocial constructs known to be associated with information preferences.

Any assessment of patients' information preferences will only be useful to the extent that these preferences are shared with healthcare workers most capable of providing the requested information to patients. Relatedly, given that too much information can be overwhelming and paralyzing for patients, information needs to be provided in conjunction with the support needed to use this information for decision making. Patients desire a spectrum of information about their care that extends beyond their diagnosis and treatment options to various nonmedical concerns, and relying on oncologists to meet all of these needs may not be optimally efficient or effective (Bernacki & Block, 2014). Instead, a team approach that brings together subject matter experts across a variety of care-related topics (e.g., financial counselors, nurses, social workers, and palliative care experts) may be more capable of meeting patients' diverse needs. Central to the success of this model is strong

communication among team members; full utilization of information technology, such as electronic health records (EHRs), could be key to these efforts. While this approach would likely overcome some of the barriers associated with assessing and meeting patients' information preferences, several structural barriers remain, including the limitations of existing EHR systems and insurance reimbursement policies that contribute to the time constraints felt by oncologists.

Limitations and future directions

This study sought to examine patients' information preferences in a more nuanced manner; the findings provide preliminary evidence that the amount of information that patients both desired and received depended on the topic and patient characteristics. However, there may be alternative explanations for the current findings that warrant consideration. Given that the survey was cross-sectional, causality cannot be established, and the association between psychosocial constructs and information preferences may be bidirectional, particularly in the case of depression and anxiety. Also, there may be related individual differences to consider as predictors of information preferences, including information avoidance (Case et al., 2005), coping styles (Kiesler & Auerbach, 2006), and beliefs that prognosis and cost should not be considered in treatment decision making (Antiel, Curlin, James, & Tilburt, 2013). Aspects of the patient-provider relationship may also influence information preferences, suggesting future studies may also benefit from a multilevel or interpersonal approach (Fine et al., 2010).

Caution should be taken when generalizing the current findings to other populations of cancer patients who may be less affluent, more reliant on oral chemo-therapies, have more diverse types of cancer, or residing in countries other than the United States. Relatedly, cancer stage was not assessed in the current study, so we could not assess its relation to information preferences and concordance. Given that there is conflicting evidence of the effects of clinical characteristics on information preferences (Kiesler & Auerbach, 2006; Martin et al., 2014), future work should examine whether the current findings generalize to more diverse cancer patient populations, and whether cancer stage or other clinical measures (e.g., prognosis or receipt of palliative care) are related to information preferences. Preferences for information are likely to change throughout treatment and diagnosis and the current study only assessed information concordance in the past month. In future work, this time frame could be extended and examined longitudinally. Finally, given that information preferences are rarely assessed in clinical environments, researchers should also examine the minimal level of probing needed to accurately predict patients' preferences. Can healthcare workers determine topic-specific preferences with just one or two questions?

Conclusions

These findings underscore the importance of examining cancer patients' information preferences in a topic-specific fashion. Nearly all patients wanted and received diagnostic and treatment information regardless of their control preferences or levels of distress. Patients wanted less information about treatments costs and prognosis, but discordance between desired and received information was highest for these topics, likely reflecting

stigma, discomfort, and other barriers to discussing these topics. Moreover, patients' control preferences and distress were more consequential for these topics. Together, these findings suggest measuring topic-specific information preferences is particularly crucial as we strive to develop clinical tools and team approaches toward efficiently identifying and meeting patients' individualized care needs.

Acknowledgments

The authors would like to thank Pat Klesh for her data entry efforts and contributions to the success of this program of work.

References

References

- Ankem K (2006). Factors influencing information needs among cancer patients: A meta-analysis. *Library & Information Science Research*, 28, 7–23.
- Antiel RM, Curlin FA, James KM, & Tilburt JC (2013). The moral psychology of rationing among physicians: The role of harm and fairness intuitions in physician objections to cost-effectiveness and cost-containment. *Philosophy, Ethics, and Humanities in Medicine*, 8, 13.
- Applebaum AJ, Kolva EA, Kulikowski JR, Jacobs JD, DeRosa A, Lichtenthal WG, et al. (2014). Conceptualizing prognostic awareness in advanced cancer: A systematic review. *Journal of Health Psychology*, 19, 1103–1109. [PubMed: 24157936]
- Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, & Kudelka AP (2000). SPIKES— A six-step protocol for delivering bad news: Application to the patient with cancer. *The Oncologist*, 5, 302–311. [PubMed: 10964998]
- Back AL, Arnold RM, & Tulsky JA (2009). *Mastering communication with seriously ill patients: Balancing honesty with empathy and hope*. New York, NY: Cambridge University Press.
- Bernacki RE, & Block SD (2014). Communication about serious illness care goals: A review and synthesis of best practices. *JAMA Internal Medicine*, 174, 1994–2003. [PubMed: 25330167]
- Bickel KE, McNiff K, Buss MK, Kamal A, Lupu D, Abernethy AP, et al. (2016). Defining high-quality palliative care in oncology practice: An American Society of Clinical Oncology/American Academy of Hospice and Palliative Medicine guidance statement. *Journal of Oncology Practice*, 12, e828–e838. [PubMed: 27531376]
- Blumenthal-Barby JS, Robinson E, Cantor SB, Naik AD, Russell HV, & Volk RJ (2015). The neglected topic: Presentation of cost information in patient decision aids. *Medical Decision Making*.
- Case DO, Andrews JE, Johnson JD, & Allard SL (2005). Avoiding versus seeking: The relationship of information seeking to avoidance, blunting, coping, dissonance, and related concepts. *Journal of the Medical Library Association*, 93, 353–362. [PubMed: 16059425]
- Clayton JM, Butow PN, Arnold RM, & Tattersall MHN (2005). Discussing life expectancy with terminally ill cancer patients and their carers: A qualitative study. *Support Cancer Care*, 13, 733–742.
- Clayton JM, Butow PN, Tattersall MHN, Devine RJ, Simpson JM, Aggarwal G, et al. (2007). Randomized controlled trial of a prompt list to help advanced cancer patients and their caregivers to ask questions about prognosis and end-of-life care. *Journal of Clinical Oncology*, 25, 715–723. [PubMed: 17308275]
- Daugherty C, & Hlubocky FJ (2008). What are terminally ill cancer patients told about their expected deaths? A study of cancer physicians' self-reports of prognosis disclosure. *Journal of Clinical Oncology*, 26, 5988–5993. [PubMed: 19029419]
- Davison BJ, & Breckon E (2012). Factors influencing treatment decision making and information preferences of prostate cancer patients on active surveillance. *Patient Education and Counseling*, 87, 369–374. [PubMed: 22177658]

- Davison BJ, Gleave ME, Goldenberg SL, Degner LF, Hoffart D, & Berkowitz J (2002). Assessing information and decision preferences of men with prostate cancer and their partners. *Cancer Nursing*, 25, 42–49. [PubMed: 11838719]
- Davison BJ, Szafron M, Gutwin C, & Visvanathan K (2014). Using a web-based decision support intervention to facilitate patient–physician communication at prostate cancer treatment discussions. *Canadian Oncology Nursing Journal*, 24, 241–247.
- Degner LF, Kristjanson LJ, Bowman D, Sloan JA, Carriere K, & O’Neil J, et al. (1997). Information needs and decisional preferences in women with breast cancer. *JAMA*, 277, 1485–1492. [PubMed: 9145723]
- Degner LF, Sloan JA, & Venkatesh P (1996). The control preferences scale. *The Canadian Journal of Nursing Research*, 29, 21–43.
- El-Jawahri A, Traeger L, Park ER, Greer JA, Pirl WF, Lennes I, et al. (2014). Associations among prognostic understanding, quality of life, and mood in patients with advanced cancer. *Cancer*, 120, 278–285. [PubMed: 24122784]
- Elkin EB, Kim SHM, Casper ES, Kissane DW, & Schrag D (2007). Desire for information and involvement in treatment decisions: Elderly cancer patients’ preferences and their physicians’ perceptions. *Journal of Clinical Oncology*, 25, 5275–5280. [PubMed: 18024875]
- Enzinger AC, Zhang B, Schrag D, & Prigerson HG (2015). Outcomes of prognostic disclosure: Associations with prognostic understanding, distress, and relationship with physicians among patients with advanced cancer. *Journal of Clinical Oncology*, 33, 3809–3816. [PubMed: 26438121]
- Ferrer RA, Klein WMP, Lerner JS, Reyna VF, & Keltner D (2015). Emotions and health decision making: Extending the Appraisal Tendency Framework to improve health and health care In Roberto C & Kawachi I (eds.) *Behavioral economics and public health*. New York, NY: Oxford University Press.
- Fine E, Reid MC, Shengelia R, & Adelman RD (2010). Directly observed patient–physician discussions in palliative and end-of-life care: A systematic review of the literature. *Journal of Palliative Medicine*, 13, 595–603. [PubMed: 20491550]
- Fried TR, Bradley EH, & O’Leary J (2003). Prognosis communication in serious illness: Perceptions of older patients, caregivers, and clinician. *Journal of the American Geriatric Society*, 51, 1398–1403.
- Fujimori M, & Uchitomi Y (2009). Preferences of cancer patients regarding communication of bad news: A systematic literature review. *Japanese Journal of Clinical Oncology*, 39, 201–216. [PubMed: 19190099]
- Furber L, Murtagh GM, Bonas SA, Bankart JG, & Thomas AL (2014). Improving consultations in oncology: The development of a novel consultation aid. *British Journal of Cancer*, 110, 1101–1109. [PubMed: 24548856]
- Henrikson N, Tuzzio L, Loggers E, Miyoshi J, & Buist D (2014). Patient and oncologist discussions about cancer care costs. *Supportive Care in Cancer*, 22, 961–967. [PubMed: 24276955]
- Husson O, Mols F, & van de Poll-Franse LV (2011). The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: A systematic review. *Annals of Oncology*, 22, 761–772. [PubMed: 20870912]
- Innes S, & Payne S (2009). Advanced cancer patients’ prognostic information preferences A review. *Palliative Medicine*, 23, 29–39. [PubMed: 18952746]
- Jefford M, & Tattersall MHN (2002). Informing and involving cancer patients in their own care. *The Lancet Oncology*, 3, 629–637. [PubMed: 12372725]
- Kaser E, Shaw J, Marven M, Swinburne L, & Boyle F (2010). Communication about high-cost drugs in oncology—the patient view. *Annals of Oncology*, 21, 1910–1914. [PubMed: 20332139]
- Kiesler DJ, & Auerbach SM (2006). Optimal matches of patient preferences for information, decision-making and interpersonal behavior: Evidence, models and interventions. *Patient Education and Counseling*, 61, 319–341. [PubMed: 16368220]
- Kroenke K, Spitzer RL, Williams JBW, & Löwe B (2009). An ultra-brief screening scale for anxiety and depression: The PHQ-4. *Psychosomatics*, 50, 613–621. [PubMed: 19996233]

- Longo DR, Ge B, Radina ME, Greiner A, Williams CD, Longo GS, et al. (2009). Understanding breast-cancer patients' perceptions: Health information-seeking behaviour and passive information receipt. *Journal of Communication in Healthcare*, 2, 184–206.
- Manson NC (2010). Why do patients want information if not to take part in decision making? *Journal of Medical Ethics*, 36, 834–837. [PubMed: 20826868]
- Martin M, Fouad M, Oster R, Schrag D, Urmie J, Sanders S, et al. (2014). What do cancer patients worry about when making decisions about treatment? Variation across racial/ethnic groups *Supportive Care in Cancer*, 22, 233–244. [PubMed: 24037412]
- McFarlane J, Riggins J, & Smith TJ (2008). SPIKES: A six-step protocol for delivering bad news about the cost of medical care. *Journal of Clinical Oncology*, 26, 4200–4204 [PubMed: 18757335]
- Meisenberg BR, Varner A, Ellis E, Ebner S, Moxley J, Siegrist E, et al. (2015). Patient attitudes regarding the cost of illness in cancer care. *The Oncologist*, 20, 1199–1204. [PubMed: 26330457]
- Mesters I, van den Borne B, De Boer M, & Pruyn J (2001). Measuring information needs among cancer patients. *Patient Education and Counseling*, 43, 255–264.
- Oostendorp LM, Ottevanger P, van de Wouw A, Honkoop A, Los M, van der Graaf WA, et al. (2016). Patients' preferences for information about the benefits and risks of second-line palliative chemotherapy and their oncologist's awareness of these preferences. *Journal of Cancer Education*, 31, 443–448. [PubMed: 25985960]
- Pardon K, Deschepper R, Vander Stichele R, Bernheim J, Mortier F, & Schallier D, et al. (2011). Are patients' preferences for information and participation in medical decision-making being met? Interview study with lung cancer patients. *Palliative Medicine*, 25, 62–70. [PubMed: 20621948]
- Patient-Centered Outcomes Research Institute. (2017). About Us. Retrieved from <http://www.pcori.org/about-us>
- Patient Protection and Affordable Care Act of 2010, Pub.L. 111–148, 124 Stat. 119, codified as amended at 42 U.S.C. § 3506
- Peppercorn JM, Smith TJ, Helft PR, DeBono DJ, Berry SR, Wollins DS, et al. (2011). American Society of Clinical Oncology Statement: Toward individualized care for patients with advanced cancer. *Journal of Clinical Oncology*, 29, 755–760. [PubMed: 21263086]
- Reyna VF, Nelson WL, Han PK, & Pignone MP (2015). Decision making and cancer. *American Psychologist*, 70, 105–118. [PubMed: 25730718]
- Richardson WC, Berwick DM, Bisgard J, Bristow L, Buck C, & Cassel C (2001). Crossing the quality chasm: A new health system for the 21st century: Institute of Medicine. Washington, DC: National Academy Press.
- Russell BJ, & Ward AM (2011). Deciding what information is necessary: Do patients with advanced cancer want to know all the details? *Cancer Management and Research*, 3, 191–199. [PubMed: 21792328]
- Sweeny K, Melnyk D, Miller W, & Shepperd JA (2010). Information avoidance: Who, what, when, and why. *Review of General Psychology*, 14, 340–353.
- terHoeven CL, Zandbelt LC, Fransen S, de Haes H, Oort F, Geijssen D, et al. (2011). Measuring cancer patients' reasons for their information preference: Construction of the Considerations Concerning Cancer Information (CCCI) questionnaire. *Psycho-Oncology*, 20, 1228–1235. [PubMed: 20821376]
- Tseng C, Waitzfelder BE, & Tierney EF, et al. (2010). Patients' willingness to discuss trade-offs to lower their out-of-pocket drug costs. *Archives of Internal Medicine*, 170, 1502–1504. [PubMed: 20837840]
- White DB, Ernecoff NC, Buddadhumaruk P, Hong S, Weissfeld L, Curtis JR, et al. (2016). Prevalence of and factors related to discordance about prognosis between physicians and surrogate decision makers of critically ill patients. *JAMA*, 315, 2086–2094. [PubMed: 27187301]
- Wittenberg-Lyles EM, Goldsmith J, Sanchez-Reilly S, & Ragan SL (2008). Communicating a terminal prognosis in a palliative care setting: Deficiencies in current communication training protocols. *Social Science & Medicine*, 66, 2356–2365. [PubMed: 18321625]
- Zafar SY, & Abernethy AP (2013). Financial toxicity, Part I: A new name for a growing problem. *Oncology*, 27, 80–81. [PubMed: 23530397]

Zeguers M, de Haes HCJM, Zandbelt LC, terHoeven CL, Franssen SJ, Geijsen DD, et al. (2012). The information needs of new radiotherapy patients: How to measure? Do they want to know everything? And if not, why? *International Journal of Radiation Oncology Biology Physics*, 82, 418–424.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 1.

Participant characteristics.

	<i>n</i> (%)
Female	112 (64.4)
Age: <i>M</i> (<i>SD</i>)	62.88 (12.29)
Marital status	
Single	15 (8.6)
Married/living together	119 (68.0)
Other (widowed, divorced, separated)	41 (23.4)
Income	
\$0-\$20,000	14 (8.8)
\$20,001-\$50,000	29 (18.1)
\$50,001-\$100,000	52 (32.5)
\$100,001-\$150,000	37 (23.1)
\$150,001-\$200,000	17 (10.6)
Over \$200,000	11 (6.9)
# years since diagnosis: <i>M</i> (<i>SD</i>)	2.34 (2.96)
Cancer type	
Breast	64 (37.7)
Prostate	22 (12.9)
Lung	21 (12.4)
Lymphoma	13 (7.7)
Colorectal	11 (6.5)
Other	39 (22.9)
Treatments received for current diagnosis	
Surgery	101 (57.1)
Intravenous chemotherapy	79 (44.6)
Oral chemotherapy	13 (7.3)
Radiation	56 (31.6)
Hormone therapy	28 (15.8)
Other	13 (7.3)
Receiving >1 treatment	43 (24.3)
Treatment costs per month	
\$0	42 (23.7)
\$1-\$200	71 (40.1)
\$201-\$500	29 (16.4)
>\$500	36 (19.8)

Table 2.

Patients' information preferences about topics related to their care (scale range = 1–4), and the proportion who wanted less, the same, or more information than they received.

	Mean (SD)	Preferences met	Preferences not met	
			Wanted less	Wanted more
General information				
Diagnosis (name, characteristics)	3.79 (0.65)	77.0%	8.1%	14.9%
Treatment options' side effects	3.75 (0.66)	71.6%	8.6%	19.8%
Treatment options' effectiveness	3.71 (0.71)	75.0%	8.8%	16.3%
Cost information				
Treatment options' financial costs to society	2.59 (1.18)	52.2%	7.0%	40.8%
Treatment options' financial cost to me	3.08 (1.11)	47.4%	3.9%	48.7%
Prognosis information				
Chances of cure	3.80 (0.58)	65.6%	3.8%	30.6%
Life expectancy	3.66 (0.78)	56.3%	5.0%	38.6%

Table 3.

Patient and clinical characteristics associated with the amount of information patients desire about topics related to their care.

	General information			Cost information		Prognosis information	
	Diagnosis characteristics	Treatments' side effects	Treatments' effectiveness	Costs to society	Cost to me	Chances of cure	Life expectancy
Age	-0.0043	-0.040	0.017	-0.10	-0.15*	-0.060	0.017
Gender (ref: female)	0.12	0.13	0.15	0.17	0.13	0.064	0.14
Marital status (ref: single)	0.47*	0.30	0.42*	0.18	0.37*	0.16	-0.11
Income	0.25**	0.22*	0.21*	0.12	0.13	0.11	0.021
Treatment type (ref: surgery only)							
Chemotherapy	-0.30	-0.14	-0.038	-0.15	-0.066	0.021	0.084
Radiation	0.00	0.097	0.29	-0.21	-0.17	0.022	0.38
>1 treatment	0.079	0.16	0.29	-0.18	-0.38	0.00	0.42
Time since diagnosis	0.0034	0.040	0.14*	0.18	0.13	0.012	0.051

* $p < 0.05$.

** $p < 0.01$ (ref = reference category).

Associations between psychological distress, control preferences, monthly treatment expenses, and the amount of information patients desire about care-related topics.

Table 4.

	General information			Cost information		Prognosis information		
	Diagnosis characteristics	Treatments' side effects	Treatments' effectiveness	Treatments' costs to society	Treatments' cost to me	Chances of cure	Life expectancy	
Psychological distress	-0.029 (-0.19,0.14)	-0.0020 (-0.17, 0.18)	-0.058 (-0.26,0.14)	0.045 (-0.14,0.23)	-0.054 (-0.23, 0.12)	-0.24* (-0.44, -0.045)	-0.25* (-0.46, -0.032)	
Control preferences	0.039 (-0.080, 0.16)	0.03 (-0.079, 0.13)	0.046 (-0.16,0.072)	0.17* (0.002, 0.33)	0.15* (0.0046,0.30)	0.13* (0.0018, 0.26)	0.18* (0.034,0.32)	
Monthly expenses	-0.024 (-0.17,0.12)	-0.030 (-0.20,0.13)	0.026 (-0.12, 0.17)	0.16** (0.040, 0.29)	-0.12 (-0.26, 0.026)	-0.13 (-0.37, 0.11)	-0.11 (-0.38,0.15)	

Note: Standardized beta coefficients, adjusted for patient and clinical predictors that produced significant main effects (see Table 2).

* $p < 0.05$.

** $p < 0.01$.