

Development and Psychometric Evaluation of the Decisional Engagement Scale (DES-10): A Patient-Reported Psychosocial Survey for Quality Cancer Care

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In light of recent health care reforms, we have provided an illustrative example of new opportunities available for psychologists to develop patient-reported measures related to health care quality. Patient engagement in health care decision making has been increasingly acknowledged as a vital component of quality cancer care. We developed the 10-item Decisional Engagement Scale (DES-10), a patient-reported measure of engagement in decision making in cancer care that assesses patients' awareness of their diagnosis, sense of empowerment and involvement, and level of information seeking and planning. The National Institutes of Health's ResearchMatch recruitment tool was used to facilitate Internet-mediated data collection from 376 patients with cancer. DES-10 scores demonstrated good internal consistency reliability ($\alpha = .80$), and the hypothesized unidimensional factor structure fit the data well. The reliability and factor structure were supported across subgroups based on demographic, socioeconomic, and health characteristics. Higher DES-10 scores were associated with better health-related quality of life ($r = .31$). In concurrent validity analyses controlling for age, socioeconomic status, and health-related quality of life, higher DES-10 scores were associated with higher scores on quality-of-care indices, including greater awareness of one's treatments, greater preferences for shared decision making, and clearer preferences about end-of-life care. A mini-measure, the DES-3, also performed well psychometrically. In conclusion, DES-10 and DES-3 scores showed evidence of reliability and validity, and these brief patient-reported measures can be used by researchers, clinicians, nonprofits, hospitals, insurers, and policymakers interested in evaluating and improving the quality of cancer care.

Keywords: scale development, decision making, oncology, patient-reported outcomes, Affordable Care Act, health care reform

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Recent health care reforms will provide new opportunities for researchers to develop patient-reported measures related to health care quality. Historically, measurement science has been under-emphasized in health care research (Gabriel & Normand, 2012), and measures with poor psychometric properties limit statistical power to detect significant correlations and intervention effects (Lipse & Hurley, 2009), ultimately reducing the cost-effectiveness

of research funds spent to improve public health and well-being. Fortunately, several signs suggest a paradigm shift toward greater attention to patient-reported measures. Two initiatives of the National Institutes of Health (NIH)—the Patient Reported Outcomes Measurement Information System (Cella et al., 2010) and the Grid-Enabled Measures project (Moser et al., 2011)—have led to the development of efficient, psychometrically strong patient-reported measures related to health care quality. More recently, the Affordable Care Act (ACA) established the Patient-Centered Outcomes Research Institute (PCORI) to develop national priorities and a funding agenda for U.S. health care research. One of PCORI's five national research priorities is methodologic research, with a key emphasis on the development and use of patient-reported measures (Methodology Committee of the Patient-Centered Outcomes Research Institute [PCORI], 2012). As well, on January 1, 2015 (Chien & Rosenthal, 2013), the ACA began linking physicians' Medicare reimbursement rates to patient-reported survey measures of health care quality, with measures expected to evolve in the coming decades. Attention to these issues apparent in cancer care. For example, also as of January 1, 2015, the cancer center accreditation process began requiring evidence of the meaningful integration of patient-reported measures into rou-

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tine care (Wagner, Spiegel, & Pearman, 2013). Thus, it is an exciting time for psychologists to contribute to measuring health care quality.

Measures of health care quality fall into two broad camps, assessing the *process* and *outcomes* of health care. Herein, we focus on the former, particularly patient engagement in the process of making health care decisions. Patients who are more engaged in their health care decisions are more likely to make choices consistent with their values (Brown et al., 2012) and may experience better health and quality-of-life (QOL) outcomes (Atherton et al., 2013; Husson, Mols, & van de Poll-Franse, 2011; Vogel, Leonhart, & Helmes, 2009). Accordingly, patients have expressed a growing interest in actively engaging in their health care decisions (Chewning et al., 2012; Hubbard, Kidd, & Donaghy, 2008; Sullivan, 2003), and increasing patient engagement in decision making is a fundamental priority for health care research and care (Levit, Balogh, Nass, & Ganz, 2013; Committee on Approaching Death: Addressing Key End of Life Issues [Committee on Approaching Death], 2014; Patient-Centered Outcomes Research Institute, 2012; Reyna, Nelson, Han, & Pignone, 2015). As we will review, existing measures of decisional engagement are confined to specific elements of the content domain, leaving a pressing unmet need as health care reforms march forward. In this investigation, we argue for the importance of measuring patient engagement in decision making, review key indicators of decisional engagement in cancer care, and report on a measure developed for that purpose. In providing an illustrative example, this investigation is relevant to future studies of patient-reported measures involving other processes, outcomes, and patient populations. Given that cross-national computer-assisted telephone surveys are routinely being conducted to inform policy (Osborn, Moulds, Squires, Doty, & Anderson, 2014), our development of a brief, psychometrically strong measure of decisional engagement could be valuable to researchers, clinicians, nonprofits, hospitals, insurers, and policy-makers interested evaluating and improving health care quality.

Importance of the Health Care Decision-Making Process

Improving health care quality will require attention to the health care decision-making process. A nationally representative study of U.S. adults ages 40 and over (Zikmund-Fisher et al., 2010) found that over 80% had made at least one of nine basic medical decisions (e.g., surgery for back pain, medication for hypertension) in the preceding 2 years, a figure that increased with age and declining health. Moreover, adults are likely to face a secular trend toward an increasing number of health care decisions over the coming decades, given demographic aging, the increasing use of prescription drugs, and the continuous development of life-prolonging treatments (Levit et al., 2013; Committee on Approaching Death, 2014; Kantor, Rehm, Haas, Chan, & Giovannucci, 2015; May, Montori, & Mair, 2009; Zikmund-Fisher et al., 2010). With this increasing exposure to health care decisions, patients have expressed a growing interest in becoming more actively engaged in the decision-making process (Alston et al., 2012; Chewning et al., 2012; Hubbard et al., 2008; Sullivan, 2003), with approximately 75–80% of patients stating they prefer an active, collaborative role in their decisions (Merck, 2015; J. A. Singh et al., 2010; Wolters

Kluwer Health, 2015). In sum, health care decision making is a widespread population concern.

The health care decision-making process can be inherently stressful and, ultimately, carries implications for health care outcomes. Absorbing and weighing highly technical health information is cognitively demanding (Hesse, Beckjord, Rutten, Fagerlin, & Cameron, 2015; Pieterse, de Vries, Kunneman, Stiggebout, & Feldman-Stewart, 2013), and grappling with decisions that affect physical functioning and longevity can awaken emotionally burdensome thoughts about one's own mortality (Luce, 2005; Solomon & Lawlor, 2011; Sweeny, 2008). Low literacy, health literacy, and numeracy represent additional challenges that are further compounded by cultural differences between patients and clinicians (Coulter & Ellins, 2007). Furthermore, the cognitive and emotional challenges of health care decision making are exacerbated when decisions are made on a continuous basis, as is the case in chronic or serious illnesses, as each subsequent decision can cumulatively deplete cognitive and emotional resources (Vohs et al., 2008). Moreover, the decision-making process drives choices about treatments and health behaviors that can affect QOL and longevity (Frieden, 2010; Schroeder, 2007). Understandably, patients (Chewning et al., 2012; Hubbard et al., 2008; Sullivan, 2003) and numerous priority statements (Levit et al., 2013; Committee on Approaching Death, 2014; National Institutes of Health, 2009) have emphasized the importance of enhancing the health care decision-making processes. Accordingly, in being tasked by the ACA with developing national research priorities for improving U.S. health care, PCORI—with substantial input from patients, providers, and public health researchers and officials—identified health care decision making as its overarching theme (Hoerger, 2013, 2015).

The types of health care decisions encountered vary across patient populations, and in this investigation we begin by focusing on cancer, due to the prevalence of the disease, which is increasing due to aging of the population (Levit et al., 2013), well-documented toll of decision making (Reyna et al., 2015), and increasing recognition that translational psychological science is needed to reduce the burden of cancer (Green McDonald, O'Connell, & Suls, 2015). There are currently over 14.5 million Americans living with cancer (American Cancer Society, 2014). In conjunction with their physicians and families, patients with cancer routinely make decisions about their health and health care that might be grouped into three general arenas: treatments, health behaviors, and broader psychosocial concerns (Levit et al., 2013; Nekhlyudov, Levit, Hurria, & Ganz, 2014; Revenson & Pranikoff, 2005). Common treatment decisions include those about chemotherapy, radiation, surgery, experimental treatments, second opinions, palliative care, integrative treatments, and medications to control treatment side effects. These treatment decisions are often made on a continual basis due to multiple layers of uncertainty: the timing and extent of response to treatment; the impact of treatments on functional status and comorbid conditions; the type, severity, and duration of side effects experienced (e.g., nausea, fatigue, diarrhea, neuropathy); and whether patients can receive better care elsewhere. Decisions about specific health behaviors include adherence to medication recommendations, diet, exercise, and smoking behavior. Finally, patients also make a range of decisions about personal finance, work, and family responsibilities. Acknowledging that many health care interventions affect care in multiple ways, existing

evidence has suggested that increased patient engagement in the decision-making process may help to reduce the stress of decision making in cancer (Brown et al., 2012), improve health care outcomes (Atherton et al., 2013; Husson et al., 2011; Committee on Approaching Death, 2014; Vogel et al., 2009), provide cost savings (Oshima Lee & Emanuel, 2013), and reduce disparities (Siminoff, Graham, & Gordon, 2006; Trice & Prigerson, 2009). Moreover, the desire to more actively engage in health care decision making is particularly strong in samples of patients with cancer (Chewning et al., 2012). Thus, the importance of the health care decision-making process in cancer is well-documented, and brief measures of decisional processes could be valuable to researchers and policymakers alike.

Assessing Decisional Engagement in Cancer Care

A theoretically informed psychometrically strong measure of decisional engagement in cancer care could greatly facilitate progress in this domain, ultimately with implications for reducing the burden of decision making and improving health care outcomes. Countless examples in psychology (Carver, 1997; Costa & McCrae, 2008; Wechsler, 2008) and medicine (Cella & Stone, 2015; Morisky, Green, & Levine, 1986; Ware & Sherbourne, 1992) have demonstrated the potential for new, theoretically informed measures to catalyze related research, and that objective is all the more pressing given ongoing health care reforms (e.g., Chien & Rosenthal, 2013; Patient-Centered Outcomes Research Institute, 2012; Wagner et al., 2013). Some of the existing measures of decisional engagement employed in clinical practice are proprietary (e.g., Goldstein, Farquhar, Crofton, Darby, & Garfinkel, 2005) and, consequently, lack publically available data or known psychometric properties. Of the measures used in research, many were developed on an exploratory basis in the trenches of larger ongoing studies. While commendable, this sometimes has resulted in scales with low internal consistency reliability (Légaré et al., 2010; S. Singh, Butow, Charles, & Tattersall, 2010), potentially unnecessary item redundancy (i.e., inordinately high internal consistency reliability; Bennett et al., 2010; Edwards et al., 2003; Kriston et al., 2010), or unknown validity (Farin, Gramm, & Kosiol, 2011; Gagnon, Hébert, Dubé, & Dubois, 2006; Kriston et al., 2010; S. Singh et al., 2010). Moreover, the ad hoc nature of some prior scale development procedures led researchers to assess aspects of decisional engagement in piecemeal fashion (Scholl et al., 2011) without outlining the scope of the content domain. The most commonly used measure, the Control Preferences Scale (CPS; Degner, Sloan, & Venkatesh, 1997), is administered in dozens of studies annually and consists of a single-item rating of desired or actual involvement in the decision-making process (Kehl et al., 2015). Over 40 other studies have used a potpourri of homegrown, single-item ratings (Chewning et al., 2012; Degner et al., 1997). We sought to summarize the key components of the content domain for decisional engagement in order to develop a scale with reasonable psychometric properties that broadly assessed the construct.

Present Investigation

The present investigation was designed to develop and provide a preliminary evaluation of the 10-item Decisional Engagement

Scale (DES-10), a measure of cancer patients' engagement in the health care decision-making process. The research was conducted in two waves. In the first wave, we recruited patients with prostate cancer. According to the American Cancer Society (2014), prostate cancer is the most common cancer in the United States across the life span, affecting 60–80% of men who live into their 80s (Grönberg, 2003), and health care decision making is particularly complex. Contrary to common lay beliefs about cancer (Maliski, Heilemann, & McCorkle, 2002), prostate cancer often progresses slowly and, in most cases, would cause no harm if left untreated (Moyer & the U.S. Preventive Services Task Force, 2012). Moreover, several treatment options are often available, carrying different benefits, risks, and levels of uncertainty; all have the high potential for side effects, such as erectile dysfunction and urinary incontinence. Thus, decisions about whether and how to treat prostate cancer are often difficult and continuous. The second wave of data collection involved recruiting patients with a range of cancer diagnoses, including breast cancer, colon/rectal cancers, and hematologic cancers, allowing us to examine the robustness of the scale properties across patient groups. Given that many patients with cancer are quite ill, the DES-10 was developed with time economy in mind: the study procedures were brief to minimize the effects of participant fatigue, and the scale was kept to 10 items to promote eventual dissemination and uptake. The investigation was designed to examine (a) the internal consistency reliability of DES-10 scores, (b) the adequacy of a hypothesized single-factor solution, (c) the consistency of these psychometric properties across subgroups based on demographic and health characteristics, (d) the association between DES-10 scores and patient demographic, socioeconomic, and health characteristics, (e) the concurrent validity of DES-10 scores when compared with other indicators of the health care decision-making process, including when controlling for demographic and health covariates, and (f) the psychometrics of a mini three-item scale (DES-3) ideal for embedding within lengthy batteries and cross-national surveys.

Method

Scale Development

In developing the DES, the first step was to establish a content domain for decisional engagement. Psychosocial theories of health behavior (see Reyna et al., 2015; Sutton, 2001) have often attended to emotional/intuitive processes (e.g., Lerner, Li, Valdesolo, & Kassam, 2015; Sweeny, 2008), relational processes (e.g., Elwyn et al., 2014; Hibbard, Stockard, Mahoney, & Tusler, 2004; Ng et al., 2012), and cognitive/rationalistic processes (e.g., Carpenter, 2010; Fishbein, 2008) implicated in health behaviors, and provided an overarching frame. Next, we reviewed the literature on decisional engagement in cancer care. To focus on the most applicable studies, we did not consider articles and measures focused on pediatric cancer or specific to disease-defined noncancer populations. Prior reviews of the literature (Eveleigh et al., 2012; Hibbard et al., 2004; Hubbard et al., 2008; Scholl et al., 2011; Smith, Dixon, Trevena, Nutbeam, & McCaffery, 2009) have described a number of elements of decisional engagement. By consensus, we organized these elements into five content domains (see Table 1 for relevant literature) spanning the three overarching processes emphasized in theories of health behavior (e.g., Elwyn et al., 2014;

Table 1
 Key Elements of Decisional Engagement in Cancer Care

Process	Domain	Summary
Emotional	Diagnostic acceptance	The health care system has increasingly acknowledged that patient awareness and acceptance of the reality of their diagnosis can facilitate meaningful engagement in decision making. For example, from the 1960s to 1970s, the number of patients told their cancer diagnosis increased from 12% to 98% (Novack et al., 1979). Nonetheless, difficulties in understanding and emotionally processing one's diagnosis persist, suggesting that awareness and acceptance continue to occur on a continuum to this day (Mack et al., 2008; Weeks et al., 1998).
Relational	Empowerment	Power asymmetries are inherent in physician–patient interactions, meaning that to share in the decision-making process, patients need to feel empowered, confident, and efficacious in doing so (Gagnon et al., 2006; Maly et al., 1998; Sepucha et al., 2012). Interventions have aimed to empower patients by coaching them to be more activated, enhancing physicians' facilitative communication behaviors, or both (Hoerger et al., 2013).
	Active, timely involvement	At the core of decisional engagement is patients involvement in the process of actually weighing decisions about their health and health care (Barry & Edgman-Levitan, 2012; Hagerty et al., 2004; Krantz et al., 1980). Timing also matters. For complex or emotional decisions (e.g., those involving advanced care planning), early involvement in the decision-making process may have a greater benefit than delayed involvement (Temel et al., 2010).
Cognitive	Information seeking	For patients to actively engage in health care decision making, they need to be informed about risks, benefits, and other concerns (Fowler, Levin, & Sepucha, 2011; Hagerty et al., 2004; Sutherland et al., 1989). A host of interventions involving decision aids, question-prompt lists, and prioritization tools have been designed to help patients effectively seek information about their questions and concerns (Brandes et al., 2014; Hoerger et al., 2013).
	Planning	Decision making in cancer often involves planning for the future: choosing treatment regimens, scheduling tests, preparing for transitions in care (e.g., posttreatment survivorship, end-of-life care), and anticipating changes in work roles, family finances, and emotional adjustment (Revenson & Pranikoff, 2005). The forward-looking nature of these decisions suggests that planning is integral to many arenas of engagement in decision making (Back, Arnold, & Quill, 2003; Sørensen & Pinquart, 2001; Stricker et al., 2011).

Fishbein, 2008; Sweeny, 2008): *diagnostic acceptance* (emotional process), *empowerment* and *involvement* (relational processes), and *information seeking* and *planning* (cognitive processes). These five domains overlap conceptually; for example, diagnostic acceptance and information seeking both involve understanding one's health status, and involvement and planning both involve grappling with choices. Moreover, greater engagement in one area, such as acceptance, can facilitate engagement in another area, such as empowerment, and vice versa. Over 60 measures exist assessing decisional engagement using a single-item global rating or at least one of these five domains (Bennett et al., 2010; Chewing et al., 2012; Degner et al., 1997; Edwards et al., 2003; Farin et al., 2011; Gagnon et al., 2006; Goldstein et al., 2005; Hibbard et al., 2004; Hubbard et al., 2008; Kriston et al., 2010; Légaré et al., 2010; Mack et al., 2008; Maly, Frank, Marshall, DiMatteo, & Reuben, 1998; Scholl et al., 2011; Sørensen & Pinquart, 2001; S. Singh et al., 2010; Sutherland, Llewellyn-Thomas, Lockwood, Tritchler, & Till, 1989), though none were developed with the intent of broadly assessing all of them. A broad assessment of these five overlapping domains is needed to provide a representative indicator of one's overall level of decisional engagement.

The next step was to develop survey items corresponding to the five identified content domains. In studies involving college students or relatively healthy community samples, a common approach is to develop a large pool of candidate survey items, perhaps 5–10 times greater than that desired for the final version of the survey, and winnow down the number of survey items based on observed psychometric properties (e.g., Carver, 1997; Hall et al., 2014; Hoerger, Quirk, & Weed, 2011). Such an approach is common but less practical when involving patients with serious illnesses who may be significantly more prone to fatigue. In fact,

many studies involving patients with severe illnesses include no more than 50–70 items total (see Hoerger et al., 2013). Accordingly, we used the legacy approach (Burisch, 1984) to scale development. This involved carefully reviewing the item-level psychometric properties (e.g., item-total correlations, validity) of items from prior scales (in particular, Hagerty et al., 2004; Krantz, Baum, & Wideman, 1980; Mack et al., 2008; Maly et al., 1998; Sepucha et al., 2012; Sørensen & Pinquart, 2001; Sutherland et al., 1989). As an example, the Peace, Equanimity, and Acceptance in the Cancer Experience scale (Mack et al., 2008) includes two subscales, with the Peaceful Acceptance subscale showing clearer evidence of convergent and predictive validity; we adapted our diagnostic acceptance items from two items on that subscale that have good face validity and high item-total correlations ($r > .50$) with their overall subscale score. Based on those articles, we carefully developed or adapted two new items in each of the five content domains, which were compiled into a 10-item scale expected to provide a unifying assessment of decisional engagement (see Table 2 column 1). Given the conceptual overlap and potentially causal interrelationships among the five processes, we hypothesized that the 10 items would load on a single factor. While acknowledging the advantages of varying analytic approaches, such as item response theory, that can be used to develop large item banks for computer adaptive tests suitable for high-stakes academic and personnel selection, we drew on classical test theory to promote dissemination in clinical and research settings. Specifically, classical test theory uses statistics familiar to many readers (e.g., Cronbach's alpha, item-total correlations), uses straightforward scoring procedures, and yields measures that often perform comparably with those derived using other methods (e.g., DeVellis, 2006; Stark, Chernyshenko, & Drasgow, 2006). Drawing from

Table 2
 Psychometric Properties of the 10-Item Decisional Engagement Scale in a Sample of Patients ($N = 376$) in Cancer Care

Item	Domain	CITC
1. I am able to accept my diagnosis of cancer	Diagnostic acceptance	.45
2. I feel confident in my ability to make decisions about medical treatments ^a	Empowerment	.59
3. I would rather be given many choices about what is best for my health than to have my doctor make decisions for me ^a	Involvement	.47
4. I prefer to know as many details as possible about my illness and treatment	Information seeking	.45
5. I should be preparing for help or care I will need in the future	Planning	.30
6. I am at peace with my illness	Diagnostic acceptance	.47
7. I feel comfortable making medical decisions that are consistent with my values and preferences ^a	Empowerment	.61
8. I would prefer to discuss treatment goals and options sooner rather than later	Involvement	.46
9. I would prefer my doctor to give me detailed information about my treatments, including information on rare side effects	Information seeking	.32
10. I find myself trying to avoid planning for the future because it makes me think of negative things (reverse-coded)	Planning	.39
Cronbach's $\alpha = .80$		

Note. $N = 376$. Participants were instructed to "Read each statement and rate from 0–10 how well it describes you," using a scale from 0 (*disagree*) to 10 (*agree*). CITC = corrected item-total correlation.

^a Appropriate for a 3-item version (DES-3).

this perspective, we examined reliability, factor structure, invariance across demographics and health subgroups, and validity in a large heterogeneous sample of patients with cancer.

Participants

Participants were 376 patients in treatment for cancer who completed an Internet-mediated survey study. Inclusion criteria involved being at least age 18 and having a diagnosis of cancer. Exclusion criteria included being unable to read English or no longer being in active oncology care. The study was completed in two waves, with the first wave focusing on prostate cancer and the second wave expanded to include a range of diagnoses, most commonly breast cancer, colon/rectal cancers, and hematologic cancers (see Table 3 for demographic data). Given these cancer diagnoses, most participants were men. The sample was predominantly White, and most participants were married, had a college education, and had private insurance. Participants were ages 18–84 years ($M = 58.26$ years, $SD = 10.44$) and geographically dispersed across 44 U.S. states and internationally.

Procedures

This research was initiated at the University of Rochester Medical Center, James P. Wilmot Cancer Institute, with the approval of the local institutional review board. Participants were recruited using the NIH Clinical and Translational Science ResearchMatch (Harris et al., 2012) recruitment tool. ResearchMatch allows researchers at any of 112 institutions with Clinical and Translational Science Awards, or related clinical and translational research interests, to recruit patients from an online database of over 85,000 volunteers. Participants were also able to access and enroll in the study through links posted with permission on health education websites, discussion forums/listservs, and search engines. The study website was designed according to existing technical and ethical guidelines for Internet-mediated research (Hoerger & Currell, 2012). In particular, the website included a standard online consent form, contact information for project personnel, and the study survey. Participants were given the option of entering into a

\$100 lottery drawing as an incentive to participate. Data were collected from 2011–2012. Waves I and II were conducted close in time using identical procedures.

Measures

Decisional Engagement Scale. Items for the DES-10 are shown in Table 2. Participants were instructed to "read each statement and rate from 0–10 how well it describes you," using a scale ranging from 0 (*disagree*) to 10 (*agree*). The scale has a Flesch–Kincaid grade level of 8.1, meaning the items were reasonable for those completing middle school.

Demographics. Participants reported their gender, age, marital status, race/ethnicity, geographic residence, insurance status, education level, and level of financial strain. Financial strain was measured with a four-item Yes/No scale (Friedman, Conwell, & Delavan, 2007), which asks whether participants' current income is enough for various basic expenses, such as food and housing; responses were dichotomized (0 = *no financial strain* and 1 = *any financial strain*).

Health characteristics. Participants reported on the amount of time that had elapsed since diagnosis, their treatments, cancer stage, prognosis, and health-related quality of life (HRQOL). More specifically, participants reported the treatments they were currently receiving or planning to receive in the near future (i.e., no cancer-specific treatment, radiation, chemotherapy, surgery, and/or biologic/targeted therapy) or indicated that they were uncertain about their treatments. They classified the cancer stage as either an early stage (i.e., believed to be localized to one part of the body) or an advanced stage (i.e., metastasized/spread to other regions), or indicated that there was no longer evidence of disease (i.e., posttreatment follow-up care with active monitoring), or indicated that they were uncertain about the cancer stage. Participants reported their beliefs about prognosis by estimating the probability that they would live for 5 years or more: 0%, 1–25%, 26–74%, 75–99%, 100% (Hoerger et al., 2013). Subjective health was reported using the SF-1 (Ware & Sherbourne, 1992), a 5-point rating scale, ranging from 1 (*poor*) to 5 (*excellent*). The Functional Assessment of Cancer Therapy—General (FACT-G; Cella et al.,

Table 3
Patient Demographic Characteristics

Category	<i>n</i>	%
Recruitment population		
Wave I: Prostate cancer	212	56.4%
Wave II: Other cancers	164	43.6%
Breast cancer	57	15.2%
Colon and rectal cancers	51	13.6%
Hematologic cancers	28	7.4%
All other cancers	28	7.4%
Age (years)		
<40	9	2.4%
40–49	58	15.4%
50–59	143	38.1%
60–69	111	29.5%
70–79	50	13.3%
≥80	5	1.3%
Gender ^a		
Female	123	32.7%
Male	253	67.3%
Marital status		
Single/never married	28	7.5%
Married	294	78.2%
Divorced/separated	43	11.4%
Widowed	11	2.9%
Race and ethnicity		
White, non-Latino	354	94.1%
Other racial/ethnic group	22	5.9%
Geographic region ^b		
Northern U.S.	52	13.8%
Midwestern U.S.	71	18.9%
Southern U.S.	109	29.0%
Western U.S.	72	19.1%
International	72	19.1%
Health insurance status		
None	21	5.6%
Medicaid	10	2.7%
Medicare	91	24.2%
Private insurance	253	67.3%
Other insurance	62	16.5%
Education level		
High school or lower	35	9.5%
Some college	88	23.7%
College degree	126	34.0%
Graduate/professional degree	122	32.9%
Financial strain		
High strain	127	33.8%
Low strain	249	66.2%

Note. *N* = 376.

^a Gender varied by cancer diagnosis: prostate (0% female), breast (97% female), colon/rectal (63% female), hematologic (61% female), and other (68% female). ^b Regions were grouped using U.S. Census categories.

1993) Physical Well-Being scale (items 1–6) was used to assess the severity of cancer symptoms (e.g., nausea, lack of energy, pain) on a scale from 0 (*not at all*) to 4 (*very much*). Participants also reported the number of days in the past month mainly spent in bed, a key indicator of functional impairment and poor prognosis (Jette et al., 1986). Finally, they completed a 13-item disease burden checklist (Chapman et al., 2009) of past or present health conditions beyond cancer (e.g., diabetes, high blood pressure/hypertension, arthritis) and reported whether they had a history of any mental health treatments for depression, anxiety/posttraumatic stress disorder, or substance use (Chapman et al., 2009).

Health care decision making. The CPS (Degner et al., 1997; J. A. Singh et al., 2010) was used to measure participants'

decision-making preferences. On the CPS, participants are asked to report how they prefer to make decisions about their cancer treatments: (a) I prefer to leave all decisions regarding treatment to my doctor, (b) I prefer that my doctor make the final decision about which treatment, but seriously considers my opinion, (c) I prefer that my doctor and I share responsibility for deciding which treatment is best for me, (d) I prefer to make the final selection of my treatment after seriously considering my doctor's opinion, and (e) I prefer to make the final selection about which treatment I will receive. Responses were dummy coded to indicate whether participants preferred physicians to engage in paternalistic decision making (e.g., responses of a–b coded as "0") or some form of shared decision making (e.g., response of c–e coded as "1"). Preferences for shared decision making on the CPS have been shown to predict a more active role in actual medical decisions as well as better QOL (Atherton et al., 2013; Brom et al., 2014).

The End-of-life Preferences Scale (EOL-PS; Hoerger et al., 2013) was used to assess whether participants had identified their preferences for end-of-life care. The EOL-PS asks participants about the care they would prefer to receive if their physician informed them that further anticancer treatments were unlikely to be helpful. Participants rate the extent to which they would prefer each of three types of interventions: "Experimental treatments (e.g., experimental chemotherapy with unknown benefit for your disease)"; "Life support (e.g., breathing machine, tube for feeding, electric shock to the heart)"; and "Palliative care (e.g., comfort care, focused on quality of life but not a cure)." The same 5-point response scale was used for each item (1 = *definitely no*, 2 = *possibly no*, 3 = *unsure*, 4 = *possibly yes*, and 5 = *definitely yes*). For each item, responses were dummy coded to indicate whether participants were uncertain (e.g., responses of 2–4 coded as "0") or had clearly identified preferences (e.g., responses of 1 and 5 coded as "1"). Greater preference clarity is an indicator of a higher quality decision-making process and predicts a greater likelihood of receiving preference-concordant care, improved QOL near death, and a reduction in the decision burden experienced by family members (Billings, 2012; Committee on Approaching Death, 2014; Wright et al., 2008).

Data Cleaning

The data were screened for invalid responding using several approaches. Missing data were avoided methodologically by using JavaScript to ensure complete responding. Of 393 initial survey submissions, 17 were removed for the following reasons: repeat responding (*n* = 3, participants endorsed completing the study previously), careless responding (*n* = 1, participant endorsed completing the study carelessly/dishonestly), infrequent/bizarre responding (*n* = 12, participants endorsed a catch item, "I noticed that flowers were talking to me"; Hoerger et al., 2011), or a suspicious response speed (*n* = 1, participant completed the survey in under 5 min, compared with an average completion time of 32 min for the entire sample). The valid response rate of 96% (376/393 = 95.7%) is similar to prior studies (Hoerger et al., 2011).

Statistical Analyses

Descriptive statistics were used to summarize the sample characteristics and basic item and scale properties. Reliability analyses

examined Cronbach's alpha in the entire sample as well as in key patient subgroups based on health and sociodemographic characteristics. Acknowledging that internal consistency reliability does not always imply unidimensionality (Schmitt, 1996), confirmatory factor analysis (CFA) and multigroup CFA were used to examine the fit of the hypothesized single-factor solution, and to test the comparability of model fit across patient subgroups. These analyses were conducted in LISREL, Version 8.80, using the Satorra and Bentler (1988) method to correct for interval data. Guidelines for evaluating model fit advocate reporting multiple fit indices and suggest the following criteria for evidence of adequate model fit: a comparative fit index of .90 or higher, a non-normed fit index of .90 or higher, an incremental fit index of .90 or higher, a standardized root mean square residual of .08 or less, and a root mean square error of approximation of .10 or less (see Kenny, 2014, for a review).

Next, we examined demographic, socioeconomic, and health-related variation in DES-10 scores using Pearson correlations. One demographic variable (age), two socioeconomic variables, and four health-related variables were associated with DES-10 scores. Principal components analysis (PCA) was used as a data reduction strategy (Jolliffe, 2002) to group these variables into a smaller number of factors, easing interpretation and reducing the number of covariates incorporated into subsequent validity analyses. Specifically, PCA was used to group education level and financial strain into a single factor tapping socioeconomic status (SES), and to group the four health-related variables into a single-factor capturing HRQOL. All analyses checked for assumptions of normality, linearity, and multicollinearity as needed.

The concurrent validity of DES-10 scores was examined using analysis of covariance (ANCOVA), which controlled for age, SES, and HRQOL. The dependent variable was DES-10 scores. Independent variables, which were examined separately rather than simultaneously, included (a) preferences for shared versus paternalistic decision making on the CPS, (b) knowing versus not knowing one's current treatment, (c) having clearly identified end-of-life care preferences versus being unclear about these preferences, and (d) meeting all three of these criteria. Effect sizes were reported using Cohen's *d*, the standardized mean difference.

Finally, we set out to derive a 3–5 item mini version of the DES with reasonable internal consistency reliability (Cronbach's $\alpha \geq .70$). We examined the psychometrics of a five-item measure that included one item from each domain, but the internal consistency reliability of that scale (Cronbach's $\alpha = .68$) fell below our prespecified threshold. Therefore, we went back to the original 10 items and iteratively removed the item with the lowest corrected item-total correlation, until left with a three-item scale (the DES-3), which surpassed our minimum reliability threshold. The iterative item-deletion process was used because item-total correlations fluctuate as weaker items are removed from the scale; for example, Items 3 and 6 performed comparably on the DES-10, but Item 3 began to perform better on removing weaker items from the scale. Analyses present the internal consistency reliability (Cronbach's alpha) and concurrent validity, which was evaluated using the same procedures and covariates as for the DES-10.

Results

Patient Health Characteristics

Participants' health characteristics are summarized in Table 4. Participants were heterogeneous in terms of time since diagnosis, treatments, cancer staging, estimated prognosis, subjective health (SF-1 $M = 3.2$, $SD = 1.0$), and disease burden ($M = 1.4$ comorbid conditions, $SD = 1.5$). On the FACT-G (item $M = 1.2$, $SD = 0.9$), the most commonly reported concerns were lack of energy, side effects, and pain. About a third of participants spent at least one day in the past month mainly in bed, indicating poorer functional status. A substantial minority (41%) reported past or present mental health/substance use treatment.

Descriptives and Reliability

Scores on the DES-10 demonstrated good internal consistency in the present study. Corrected item-total correlations ranged from .30–.61, with items in the empowerment content domain performing best (Table 2, column 3). Cronbach's alpha was .80 for the entire sample, and none of the items detracted from the internal consistency of the measure. Subgroup analyses showed that Cronbach's alpha was acceptable (.73–.84) across different cancer diagnoses and stages (see supplemental materials, Table A1). Additional analyses showed that Cronbach's alpha was also acceptable (.71–.84) across subgroups based on other demographic and health characteristics (see Table A1).

CFA and Multigroup CFA

The single-factor model of decisional engagement fit the data well, both for the sample as a whole and for group-level analyses based on cancer diagnosis and staging (see Table 5), with 13 of 15 fit indices falling within the recommended range (sign test, $p = .007$). The single-factor model was also supported in group-level analyses based on a broader range of demographic, socioeconomic, and health-related factors (see supplemental materials, Table A2), with 66 of 70 fit indices in the recommended range (sign test, $p < .001$). Thus, the five overlapping content domains assessed a unifying construct, and the hypothesized single-factor solution was relatively robust across key subgroups based on participant demographics, SES, and illness characteristics.

Demographic, Socioeconomic, and Health Differences

Individuals who reported higher scores on the DES-10 were older ($r = .14$, $p = .007$), more educated ($r = .12$, $p = .02$), and less financially strained ($r = -.14$, $p = .05$). Likewise, higher SES (based on the PCA of education and financial strain) was associated with greater decisional engagement on the DES-10 ($r = .17$, $p = .001$).

Participants scoring higher on the DES-10 had a better self-reported prognosis ($r = .18$, $p = .001$), better subjective health ratings on the SF-1 ($r = .23$, $p < .001$), lower symptom burden on the FACT-G ($r = -.28$, $p < .001$), and were less likely to have a history of mental health/substance use treatments ($r = -.14$, $p = .008$). Similarly, better HRQOL (based on the PCA of these variables) was associated with higher scores on the DES-10

Table 4
Patient Health Characteristics

Category	<i>n</i>	%
Cancer stage ^a		
Early stage/localized	143	38.0%
Advanced stage/metastasized	116	30.9%
No evidence of disease, active follow-up	61	16.2%
Uncertain about stage	56	14.9%
Time since cancer diagnosis		
<3.0 months	35	9.3%
3.0–11.9 months	117	31.1%
1.0–4.9 years	160	42.6%
≥5.0 years	64	17.0%
Cancer treatments ^b		
No cancer-specific treatment	74	19.7%
Radiation	110	29.3%
Chemotherapy	109	29.0%
Surgery	103	27.4%
Biologic/targeted therapy	49	13.0%
Uncertain about treatment regime	26	6.9%
Prognostic beliefs about 5-year survival		
0% chance	16	4.3%
1–25% chance	30	8.0%
26–74% chance	75	19.9%
75–99% chance	137	36.4%
100% chance	118	31.4%
SF-1 subjective health rating		
Poor	23	6.1%
Fair	68	18.1%
Good	145	38.6%
Very good	109	29.0%
Excellent	31	8.2%
FACT-G symptom burden ^c		
Lack of energy	327	87.0%
Bothered by side effects	263	69.9%
Pain	207	55.1%
Health-related family role impairment	185	49.2%
Feel ill	175	46.5%
Nausea	101	26.9%
No concerns	21	5.6%
Days per month mainly in bed (prognostic indicator)		
0 days	250	66.5%
1–7 days	93	24.7%
8–14 days	24	6.4%
≥15 days	9	2.4%
Disease burden		
0 comorbid conditions	144	38.3%
1–2 comorbid conditions	155	41.2%
≥3 comorbid conditions	77	20.5%
Prior mental health treatments		
None	222	59.0%
Depression	123	32.7%
Anxiety/PTSD	65	17.3%
Substance use	11	2.9%

Note. *N* = 376. FACT-G = Functional Assessment of Cancer Therapy – General; PTSD = posttraumatic stress disorder; SF-1 = 1-Item Short-Form Health Survey.

^a This staging system is less sensitive for the subset of hematologic patients with leukemia, who mostly present after the cancer has spread to other organs; expectedly, the one leukemia patient in our sample selected Advanced Stage. ^b Total percentages surpass 100% due to combined treatment. ^c Values indicate the percentage of participants reporting as least 1 (a little bit) on the 0–4 rating scale.

($r = .31, p < .001$). Scores on the DES-10 were not associated with other demographic variables, cancer site, stage, or time since diagnosis. All remaining analyses controlled for age, SES, and HRQOL.

Concurrent Validity

The concurrent validity of DES-10 scores was supported in analyses comparing the DES-10 with three other indicators of decision quality (see Figure 1). As hypothesized, DES-10 scores were higher for those preferring shared decision making than those preferring paternalistic decision making on the CPS, $F(1, 371) = 13.62, p < .001$. Participants who could identify their cancer treatment also scored higher on the DES-10, $F(1, 371) = 5.94, p = .02$. As well, DES-10 scores were higher for participants with clear preferences regarding end-of-life care, $F(1, 371) = 22.14, p < .001$ (palliative care, $d = 0.40$; life support, $d = 0.34$; experimental treatments, $d = 0.46$; $ps < .003$). Participants meeting all three of these criteria scored higher on the DES-10 than those meeting two or fewer criteria, $F(1, 371) = 31.49, p < .001$. In summary, initial evidence supported the concurrent validity of DES-10 scores as an indicator of decisional engagement in cancer care.

Mini-Measure

Item selection produced a three-item mini-measure (DES-3; see Table 2, Items 2, 3, and 7) with a Cronbach's alpha of .75. DES-3 scores correlated ($r = .79, p < .001$) with the longer DES-10. As well, in ANCOVAs controlling for covariates, DES-3 scores were higher among participants preferring shared decision making on the CPS, $d = 1.29, F(1, 371) = 20.48, p < .001$, participants who could identify their cancer treatment, $d = 0.48, F(1, 371) = 5.53, p = .02$, participants with clear preferences for end-of-life care, $d = 0.42, F(1, 371) = 14.32, p < .001$, and participants meeting all three of these criteria, $d = 0.59, F(1, 371) = 25.70, p < .001$. These psychometric properties suggest that the DES-3 will suffice for situations where administration of the longer scale would be infeasible.

Discussion

The DES-10 is a psychometrically strong patient-reported measure of decisional engagement in cancer care that, in the wake of recent health care reforms, has the potential to make an important contribution toward building knowledge that can improve health care quality. In contrast to 50 years ago when cancer care was

Table 5
CFA and Multigroup CFA for the Single-Factor Solution

Model	CFI	NNFI	IFI	sRMR	RMSEA
CFA, entire sample	.92*	.89	.92*	.04*	.04*
Multigroup CFA, by cancer site	.97*	.96*	.97*	.08*	.09*
Multigroup CFA, by cancer stage	.96*	.95*	.96*	.09	.09*

Note. *N* = 376. Fit indices are defined in text. In Multigroup CFA, cancer site was classified as prostate or nonprostate due to low sample sizes in the hematologic and other cancer categories; all four cancer stage categories were examined simultaneously. CFA = confirmatory factor analysis; CFI = comparative fit index; IFI = incremental fit index; NNFI = non-normed fit index; RMSEA = root mean square error of approximation; sRMR = standardized root mean square residual.

* Indicates adequate fit according to existing guidelines.

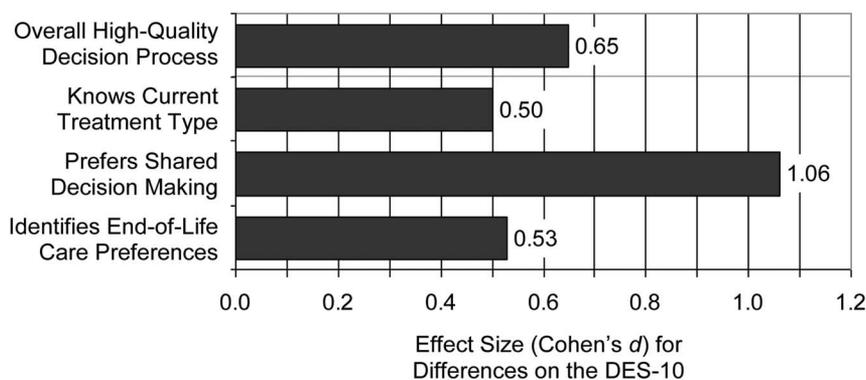


Figure 1. Concurrent validity of the 10-item Decisional Engagement Scale (DES-10). Patients who could identify their current cancer treatment, preferred shared decision making on the Control Preferences Scale, and had more clearly identified end-of-life care preferences scored higher on the DES-10. Analyses controlled for age, socioeconomic status, and health-related quality of life ($ps < .015$).

characterized by paternalistic decision making in which patients were rarely told their cancer diagnoses (Novack et al., 1979), patients are now facing an increasing number of health care decisions (May et al., 2009; Sullivan, 2003; Zikmund-Fisher et al., 2010) and seeking to become more actively engaged in those decisions (Alston et al., 2012; Chewning et al., 2012; Hubbard et al., 2008). Along with recent health care reforms (Chien & Rosenthal, 2013; PCORI, 2012; Wagner et al., 2013) and changing demographics, these secular trends motivated us to develop the DES-10 and DES-3. Scores on the DES-10 demonstrated reliability and unidimensionality, including across heterogeneous subgroups, and showed evidence of concurrent validity as a measure of patients' decisional engagement. Results also provided evidence for the concurrent validity of scores on the DES-3, suggesting that the mini-measure will be useful for situations when administration of a comprehensive-but-longer measure would be infeasible, such as cross-national studies aimed at informing health care policy (Osborn et al., 2014). The current research provides an illustrative example of the expanded opportunities available for psychologists to collaborate in developing patient-reported measures in this era of health care reform, and the DES-10 and DES-3 may be of use to researchers, health care systems, and policymakers seeking to measure and enhance patient care.

Findings supported the reliability of DES-10 scores, and CFA and multigroup CFA supported the hypothesized single-factor model of decisional engagement. Specifically, the internal consistency reliability was good by conventional standards (Cronbach's $\alpha = .80$), and each item correlated well with the summated composite (see Table 2). As well, the internal consistency reliability remained adequate ($\alpha > .70$) across subgroups based on cancer site, stage, and other demographic, socioeconomic, and health characteristics (see Table A1), and when examining a mini-measure, the DES-3. Moreover, CFA supported the unidimensionality of the DES-10, meaning that the five overlapping content domains represented a single unifying construct of decisional engagement, and multigroup CFA showed that the single-factor solution fit the data similarly across key patient subgroups (see Tables 5 and A2). Items 2 and 7 tapping the empowerment domain contributed most to the internal consistency reliability of the scale

(higher corrected item-total correlations), perhaps suggesting that relational processes that build patient confidence and efficacy most directly "hit the core" (Burisch, 1984) of the construct, best representing what it means to be meaningfully engaged in the health care decision-making process. Given the emphasis of public health research and policy on improving the quality of health care for all citizens and particularly those at elevated risk (Frieden, 2010; Levit et al., 2013; Committee on Approaching Death, 2014; Schroeder, 2007), it is important to highlight that the basic psychometric properties of DES-10 scores were comparable for Medicare patients, noncollege graduates, those with high financial strain, and those with significant illness burden and medical comorbidity (see Tables A1 and A2).

Several sociodemographic and health-related correlates of DES-10 scores were identified. In particular, older age, higher SES, and better HRQOL were associated with higher levels of decisional engagement on the DES-10. Health care decision making becomes more frequent with age (Zikmund-Fisher et al., 2010), and it is possible that repeated interactions with the health care system could socialize older adults to become more engaged (see Pinquart & Duberstein, 2004, for a more nuanced discussion). SES-related differences in aspects of decisional engagement have been documented elsewhere (Siminoff et al., 2006) and are thought to contribute to disparities in cancer morbidity and mortality. The relation between HRQOL and decisional engagement is potentially more complex. Decisional engagement can help to focus health care encounters on patients' most important needs (Brandes et al., 2014; Hoerger et al., 2013), supporting improved QOL (Atherton et al., 2013; Husson et al., 2011; Committee on Approaching Death, 2014; Temel et al., 2010; Vogel et al., 2009). As well, resource models of decision making (Vohs et al., 2008) emphasize that people have limited cognitive and emotional resources available for engaging in decision making, and it could be that individuals with lower QOL are already taxed in terms of their available resources, which could diminish their capacity to proactively engage in health care decision making. Thus, the relationship may be reciprocal. Accordingly, these findings suggest the need for longitudinal cohort studies and intervention studies examining potential pathways by which decisional engagement may affect

changes in QOL, or whether interventions to reduce emotional distress could foster decisional engagement (Anderson, 2003).

The present investigation also provides evidence for the validity of DES-10 and DES-3 scores as indicators of decisional engagement in cancer care, suggesting these measures may be of use to future researchers, nonprofit organization, health care systems, insurers, and policymakers. National and cross-national studies are increasingly focused on understanding consumer health care preferences and behaviors (Alston et al., 2012; Kantor et al., 2015; Merck, 2015; Osborn et al., 2014; Wolters Kluwer Health, 2015; Zikmund-Fisher et al., 2010), with the goal of guiding policy. Moreover, quality measures are being increasingly adopted by health care systems voluntarily as well as to increase reimbursement rates and meet accreditation standards (Chien & Rosenthal, 2013; Wagner et al., 2013). Evidence for the validity of DES-10 and DES-3 scores were upheld in analyses controlling for age, SES, and HRQOL. Participants who scored higher on the DES-10 and DES-3 were more likely to report preferring shared decision making on the CPS (Degner et al., 1997), a single-item scale widely used in this line of research (e.g., Brom et al., 2014; J. A. Singh et al., 2010). As well, although patient deficits in knowledge of their illness and treatments are well-documented (Committee on Approaching Death, 2014; Weeks et al., 1998), decisional engagement can help patients to be more informed (Oshima Lee & Emanuel, 2013; Barry & Edgman-Levitan, 2012), and, consistent with this view, the present study showed that participants with higher DES-10 and DES-3 scores were more likely to know their current treatment regime.

Similarly, decisional engagement is thought to help patients develop and articulate their treatment preferences (Epstein & Peters, 2009). Decision making about end-of-life care is cognitively challenging, emotionally burdensome, and often substantially delayed, which compromises patients' QOL and erodes finances (Levit et al., 2013; Committee on Approaching Death, 2014; Temel et al., 2010). This study found that participants with higher scores on the DES-10 were more likely to have identified clearer preferences for end-of-life care, including preferences regarding palliative care, life support, and experimental therapeutics. Thus, the DES-10 and DES-3 may be of use to health care systems and policymakers interested in improving QOL near the end of life as well as mitigating the societal toll of aggressive end-of-life care.

Study Limitations and Strengths

Several limitations of this research can be noted. All participants were recruited via the Internet, and it is possible that participant self-selection effects may have produced a sample more engaged with their health care than typical patients recruited directly at particular cancer centers. As well, the sample was overrepresented by males, mainly consisted of White, non-Latino American adults, and was confined to English-speaking participants. Future researchers are welcome to translate the DES-10 into other languages, and more research is needed to evaluate some psychometric properties, such as differential item functioning across key demographics, such as race, ethnicity, national origin, gender, and age. Although differential item functioning can be assessed comparably using classical test theory and item response theory approaches (Stark et al., 2006), our study was not designed to assess differential item functioning, because doing so would

require strategically recruiting large samples of participants in each demographic subgroup of interest. As well, we studied patient responses only, but family caregivers are often involved in cancer decision making, and future studies could explore the psychometrics of the DES with family caregivers. We also did not closely track each participant's referral source, and future researchers would be advised to collect this information to better characterize samples in Internet-mediated studies. Additionally, the scale was developed by clinician research scientists, and researchers seeking to develop other scales should consider incorporating input from a broad range of stakeholders (Hausman et al., 2013). Finally, all findings were cross-sectional and based on a limited battery of measures. Future studies should examine the test-retest reliability of DES-10 scores as well as the utility of the DES-10 in intervention studies aimed at measuring changes in decisional engagement. Observational studies of related constructs have shown test-retest correlations of approximately r equal to .70 over a timespan of several weeks to months (Scholl et al., 2011), even without disattenuating for imperfect internal consistency reliability, suggesting stability under ordinary circumstances. Importantly, intervention studies have also shown that it is possible to increase aspects of decisional engagement (Hibbard & Greene, 2013). Similar work with the DES-10 appears warranted.

These limitations were balanced by several noteworthy strengths. Foremost, this research is responsive to ongoing health care reforms rooted in increasing patient interest in actively engaging in health care decisions. Second, clinical populations are underutilized in many psychology studies (Croyle, 2015), including in scale development research, and the present investigation drew on a large sample of patients with cancer, over half of whom had comorbid medical diagnoses, and many with very severe cancer symptoms and poor prognoses. Third, analyses were attentive to subgroup variation in reliability and factor structure, supporting generalizability in heterogeneous populations of patients with cancer diagnoses.

These findings provide an illustrative example of the vital role psychologists can play in collaborating to advance measurement science in the context of health care research. Beyond decisional engagement, there is a need for the development of psychometrically strong patient-reported measures of other health care processes, such as the quality of patient-provider communication, the patient-provider relationship, and care coordination (Levit et al., 2013). There is also a need for outcome measures assessing satisfaction with care, QOL in specific patient populations, and satisfaction with particular health care decisions (PCORI, 2012). Community-based approaches that incorporate stakeholder input into the research process could be particularly valuable for identifying additional health care processes and outcomes of interest (PCORI, 2012). Based on estimates of the public health burden of health conditions in the United States (Frieden, 2010; Levit et al., 2013; Committee on Approaching Death, 2014; Schroeder, 2007), it would be useful for scale development studies to focus on patients with cancer, heart disease, diabetes, obesity, stroke, chronic obstructive pulmonary disease, and mental health diagnoses, as well as those with two or more comorbid chronic health conditions.

Conclusion

Results from a large heterogeneous sample of patients with cancer indicate that the DES-10 and DES-3 are a psychometrically strong patient-reported measure of decisional engagement in cancer care. These brief patient-reported measures could be used by researchers, clinicians, nonprofits, hospitals, insurers, and policy-makers interested evaluating and improving the quality of cancer care. This research also speaks to the valuable opportunities available for psychologists to contribute to health care measurement science in the wake of recent health care reforms and broader demographic and societal changes.

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Appendix A

Online Supplemental Materials

Table A1

Internal Consistency Reliability by Demographic, Socioeconomic, and Health Characteristics

Patient Subgroup	α
Cancer Site	
Prostate cancer	.81
Breast cancer	.74
Colon and rectal cancers	.77
Hematologic cancers	.76
All other cancers	.84
Cancer Stage	
Early stage / localized	.80
Advanced stage / metastasized	.78
Uncertain about stage	.85
No evidence of disease, active follow-up	.73
Age	
< 60	.78
≥ 60	.81
Gender	
Female	.77
Male	.81
Time Since Cancer Diagnosis	
< 1 year	.76
≥ 1 year	.82
Marital Status	
Married	.82
Unmarried	.72
Geographic Region	
Northern U.S.	.73
Midwestern U.S.	.82
Southern U.S.	.77
Western U.S.	.84
International	.79
Health Insurance Status	
None/Medicaid/Other	.80
Medicare	.80
Private insurance	.80
Education Level	
Non-college graduate	.76
College/graduate/professional degree	.84
Financial Strain	

High Strain	.81
Low Strain	.79
Cancer Treatments	
No cancer-specific treatment	.84
Radiation	.80
Chemotherapy	.79
Surgery	.71
Biologic/targeted therapy	.82
Uncertain about treatment regime	.79
Prognostic Beliefs about 5-year Survival	
≤ 25% chance	.83
26-74% chance	.81
≥ 75% chance	.76
SF-1 Subjective Health Rating	
Poor/Fair/Good	.81
Very good/Excellent	.71
FACT-G Symptom Burden	
Low (< median)	.76
High (≥ median)	.81
Days per Month Mainly in Bed (Prognostic Indicator)	
0 days	.78
≥ 1 day	.81
Disease Burden	
0 comorbid conditions	.75
≥ 1 comorbid condition	.82
Prior Mental Health Treatments	
No	.78
Yes	.81

Note. $N = 376$. Response options have been grouped into a smaller number of categories than those noted in Tables 2 and 3 in order to increase power within subsamples and simplify interpretation.

Table A2

Multigroup CFA for the Single-Factor Solution

Multigroup CFA, Grouped By	CFI	NNFI	IFI	sRMR	RMSEA
Age	.96*	.95*	.96*	.08*	.10*
Gender	.97*	.96*	.97*	.09	.09*
Time Since Cancer Diagnosis	.97*	.96*	.97*	.08*	.09*
Marital Status	.96*	.95*	.96*	.08*	.09*
Geographic Region	.97*	.96*	.97*	.10	.09*
Health Insurance Status	.97*	.96*	.97*	.08*	.09*
Education Level	.97*	.96*	.97*	.08*	.09*
Financial Strain	.97*	.96*	.97*	.08*	.09*
Cancer Treatment	.96*	.95*	.96*	.10	.10*
Prognostic Beliefs about 5-year Survival	.96*	.95*	.96*	.10	.10*
SF-1 Subjective Health Rating	.97*	.96*	.97*	.08*	.09*
FACT-G Symptom Burden	.97*	.96*	.97*	.08*	.09*
Days in Bed	.97*	.96*	.97*	.08*	.09*
Disease Burden	.97*	.96*	.97*	.07*	.09*
Prior Mental Health Treatment	.97*	.96*	.97*	.07*	.09*

Note. $N = 376$. Fit indices are defined in text. Category groupings were the same as those in Table A1, except that the latter two Cancer Treatment groups were excluded due to low sample size.

* Indicates adequate fit according to existing guidelines