

Does it matter what you call it? A randomized trial of language used to describe palliative care services

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Abstract

Introduction Integration of palliative care into oncology practice remains suboptimal. Misperceptions about the meaning of palliative care may negatively impact utilization.

Purpose We assessed whether the term and/or description of palliative care services affected patient views.

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Methods 2x2 between-subject randomized factorial telephone survey of 169 patients with advanced cancer. Patients were randomized into one of four groups that differed by name (supportive care vs. palliative care) and description (patient-centered vs. traditional). Main outcomes (0–10 Likert scale) were patient understanding, impressions, perceived need, and intended use of services.

Results When compared to palliative care, the term supportive care was associated with better understanding (7.7 vs. 6.8; $p=0.021$), more favorable impressions (8.4 vs. 7.3; $p=0.002$), and higher future perceived need (8.6 vs. 7.7; $p=0.017$). There was no difference in outcomes between traditional and patient-centered descriptions. In adjusted linear regression models, the term supportive care remained associated with more favorable impressions ($p=0.003$) and higher future perceived need ($p=0.022$) when compared to palliative care.

Conclusions Patients with advanced cancer view the name supportive care more favorably than palliative care. Future efforts to integrate principles of palliative medicine into oncology may require changing impressions of palliative care or substituting the term supportive care.

Keywords Palliative care · Supportive care · Advanced cancer · Communication · Oncology

Introduction

Palliative care services play an integral role in the multidisciplinary care of patients with advanced cancer and their families [1]. Specialized palliative care provided concurrently with standard oncology care decreases burdensome psychological symptoms, improves quality of life, decreases healthcare costs near death, optimizes timing of therapies, and may prolong life [2–9]. Support for integrating palliative care services into

standard oncology practice is growing. International organizations including the National Comprehensive Cancer Network, the American Society of Clinical Oncology, the European Society for Medical Oncology, the Institute of Medicine, and the World Health Organization are calling for a new paradigm of advanced cancer care that incorporates the principles and practice of palliative medicine [10–14]. The American Society of Clinical Oncology recently published a provisional clinical opinion stating that “combined standard oncology care and palliative care should be considered early in the course of illness for any patient with metastatic cancer and/or high symptom burden [15].”

To date, however, the provision of palliative care services to patients with advanced cancer remains suboptimal. Informational, emotional, and physical needs are frequently unmet among patients with incurable disease receiving standard oncology care [16–18]. The majority of specialized palliative care services are provided in the hospital when patients are sicker, families are under stress, and decision-making about goals of care is difficult [19–21].

One reason for inadequate use of palliative care may be misperceptions about the meaning and/or scope of palliative care services. Patients and providers may mistakenly equate palliative care with hospice or assume that palliative care services cannot be provided concomitantly with active treatment [22, 23]. The term *palliative care* may act as a barrier to early patient referrals because it is viewed as distressing by oncologists, who may be more likely to refer patients to a service called *supportive care* [24–27]. Whether patients hold similar views, however, is not known. A recently conducted consumer marketing survey suggests that a new description of palliative care may positively affect the public’s impressions of these services [28]. However, this issue has never been formally tested in patients with cancer who, because of their experience, may have very different attitudes toward palliative care. To date, there has been no systematic assessment of how the term supportive care (vs. palliative care) or the description of services affects the understanding and views of oncology patients.

Methods

Design overview

We conducted a randomized between-subject 2×2 factorial telephone survey of patients with advanced cancer to assess the impact of language used to describe outpatient palliative care services on patient understanding, impressions, perceived need, and intended use. Patients were randomized into one of four groups that differed by terminology (supportive care vs. palliative care) and description (patient-centered vs. traditional). This study did not require clinical trial registration because there was no intervention affecting health outcomes. The

University of Pittsburgh Institutional Review Board approved all study procedures.

Subjects and setting

From December 2011 to April 2012, we recruited patients from 20 participating medical oncologists practicing at two university-affiliated cancer treatment centers with outpatient palliative care clinics (referred to as the Cancer Pain and Supportive Care Clinic and the Palliative Care Outpatient Clinic) in Pittsburgh, PA. One additional medical oncologist was approached but declined to participate because he did not want the term palliative care used with his patients. Eligible patients were adults with advanced solid tumors, defined as stage IV, or refractory or recurrent hematologic malignancies. We included patients who had an appointment with their oncologist within the past 3 months or in the next 1 month, had a working telephone number, and were able to complete a 30-min interview without assistance. We excluded patients who were determined by their oncologist to be emotionally or physically unable to participate in a 30-min telephone interview.

Survey content

1. Language. Surveys used either the term palliative care or supportive care throughout [26]. The traditional description of these services used language from participating cancer center websites that is also found in many published descriptions of palliative care [28–30]. The patient-centered description used language that was preferred by the general public in a national consumer survey conducted by the Center to Advance Palliative Care and the American Cancer Society [28]. See Textbox 1 for complete descriptions.

Textbox 1. Traditional and patient-centered descriptions of palliative/supportive care

Traditional

Palliative care (or supportive care) is specialized medical care for patients with life-limiting illness. This type of care is focused on the management of symptoms such as pain, nausea, anxiety, and stress for patients with advanced cancer. The goal is to improve patient’s quality of life. Emphasis is placed on communication and coordinated care with the patient’s cancer doctors. Palliative care (or supportive care) is appropriate from the time of diagnosis with a life-limiting illness and can be provided together with other cancer treatments such as chemotherapy or radiation.

Patient-Centered

Palliative care (or supportive care) is specialized medical care for people with serious illness. This type of care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. Palliative care (or supportive care) is provided by a team of doctors, nurses, and other specialists who work with a patient’s cancer doctors to provide an extra layer of support. Palliative care (or supportive care) is appropriate at any age and at any stage in a serious illness and can be provided together with curative treatment.

2. **Outcome Measures.** All outcomes were measured on a 0 through 10 Likert scale. We assessed perceived understanding by asking patients to rate their overall understanding of what palliative (or supportive) care services offer (0—do not understand at all to 10—completely understand). Similar to the Center to Advance Palliative Care/American Cancer Society survey, we measured impressions by asking patients to rate how favorable their overall impressions of palliative (or supportive) care services were (0—not at all favorable to 10—most favorable). We assessed perceived need and intended use by asking patients how strongly they agreed or disagreed with the following statements (0—strongly disagree to 10—strongly agree): “Palliative (or supportive) care services would be helpful to me or my family now” (current perceived need); “Palliative (or supportive) care services would be helpful to me or my family in the future” (future perceived need); “I am likely to ask my oncologist if I can see a palliative (or supportive) care doctor” (patient-initiated intended use); and “I would be willing to see a specialized palliative (or supportive) care doctor if my oncologist recommended it” (oncologist-initiated intended use).
3. **Open-ended responses.** Prior to describing palliative/supportive care to patients, we asked patients to describe in their own words what they thought palliative (or supportive) care was.
4. **Demographic and clinical characteristics.** Age, gender, and cancer diagnosis were abstracted from the medical record. The survey included questions about patient demographics, clinical characteristics, and prior experience with palliative/supportive care.

All survey questions were pilot-tested for clarity and ease of administration over the phone prior to use. The complete survey is included as an appendix (ESM).

Enrollment

Participating medical oncologists identified up to 30 patients each (range 6 to 30) who met eligibility criteria and had an appointment in the past 3 months or upcoming 1 month by reviewing their clinic schedules from this specified time frame. We mailed eligible patients an explanation of the study that included an interview guide to visualize responses and a toll-free opt out phone number. Two interviewers (RM and LV) trained in telephone interview techniques contacted patients by phone within 3 weeks of mailing the informational letter and up to a maximum of five times each. Interviews were conducted by phone either immediately after verbal consent or during a subsequent telephone call scheduled at a convenient time. All participants provided verbal consent.

Randomization

We used computer-generated block randomization stratified by age (>65 or ≤ 65 years of age), sex, and interviewer to ensure equal distribution of subjects into one of four groups: (1) palliative care/patient-centered description, (2) palliative care/traditional description, (3) supportive care/patient-centered description, and (4) supportive care/traditional description. Patients were randomized immediately following verbal consent and before beginning the interview.

Power calculation

We estimated that a sample size of 152 participants (38 per group) would yield 85 % power (two-sided, $\alpha=0.05$) to detect a difference of one point in our main outcome measures [28]. We anticipated a 50 % enrollment rate based on prior experience with patient telephone surveys and aimed to identify 304 eligible participants.

Analysis

We generated descriptive statistics of patient demographic and clinical characteristics. We used mean (standard deviation) to describe normally distributed continuous variables and median (median absolute deviation) to describe continuous variables with a skewed distribution. We used ANOVA F tests, Kruskal–Wallis tests, and Chi-squared test to compare demographic and clinical variables by randomized groups. We used two-way ANOVA to test for interaction between the factors (term and description) and to compare mean outcome measures by the two factors (term and description). We conducted a series of univariate regression models to determine which individual covariates were associated with each outcome. Terminology (supportive care vs. palliative care), description (patient-centered vs. traditional), and additional variables with a p value <0.1 in univariate analyses were included in final multivariate regression models.

We used qualitative description to analyze narrative responses [31]. Three investigators (RM, LV, and YS) used constant comparative methods to develop a coding framework [32, 33]. All disagreements were discussed and resolved by consensus. The codebook was then applied to all responses by a single investigator (LV) who was blinded to randomization group. After coding was completed, we used Chi-squared tests to compare response categories by randomization group (palliative care vs. supportive care).

All analyses were conducted in R. (R Foundation for Statistical Computing, Vienna, Austria, 2011).

Results

Enrollment and randomization

Patient enrollment is summarized in Fig. 1. Of the 338 subjects identified as eligible, 272 patients or family members were reached by telephone, 177 patients were randomized, and 169 completed the survey.

Patient characteristics

There were no significant differences in age ($p=0.199$), gender ($p=0.127$), or cancer diagnosis ($p=0.1$) between participants and nonparticipants. Participant characteristics are summarized in Table 1. The most common cancer diagnoses were breast (54/169, 32 %) and lung (31/169, 18 %). Eleven percent of patients (18/169) reported they had seen a specialized palliative/supportive care provider in the past. There were no significant differences in demographic or clinical characteristics between randomization groups.

Main outcomes

Main outcomes by randomization group are summarized in Table 2. There were no significant interactions between term (supportive care vs. palliative care) and description (*patient-centered vs. traditional*). The term supportive care (vs. palliative care) was associated with better understanding (7.7 vs. 6.8; $p=0.021$), more favorable impressions (8.4 vs. 7.3; $p=0.002$), and higher future perceived need of services (8.6 vs. 7.7; $p=0.017$), but not with higher current perceived need (5.0 vs. 4.7; $p=0.548$) or intended use (self-initiated, 6.3 vs. 5.8; $p=0.372$; oncologist-initiated, 8.8 vs. 8.4; $p=0.177$).

Fig. 1 Consort diagram detailing patient flow through the study including recruitment, randomization, and completion. *Dagger* patients were reached, requested to call back, and were unable to reach on subsequent attempts. *Single asterisk* patients were reached, requested call back after randomization and were unable to reach on subsequent attempts. *Double asterisks* after randomization, patient was not reached during scheduled interview ($N=1$), patient died ($N=1$), was determined to be unable to complete without assistance ($N=2$), and interviewer deviated from standard script and decision was made not to be in final analysis ($N=1$)

Outcomes did not differ by description (patient-centered vs. traditional) of palliative/supportive care services.

Univariate regression results are included in the appendix (ESM). In final multivariate models adjusted for term (supportive care vs. palliative care), description (patient-centered vs. traditional), and all significant variables ($p<0.1$) in univariate analyses, the term supportive care (vs. palliative care) remained associated with more favorable impressions ($p=0.003$) and higher future perceived need ($p=0.022$) of services. See Table 3.

Qualitative results

Patient responses to the question “can you please describe in your own words what you think palliative care (or supportive care) is?” are presented in Table 4. A higher percentage of patients expressed confusion about what palliative care meant as compared to what supportive care meant ($p=<0.001$). Patients were more likely to describe supportive care as involving psychological, mental, or social support ($p=<0.001$) or opportunities for medical communication/information exchange ($p=0.001$) and more likely to describe palliative care as end-of-life care ($p=0.006$).

Discussion

In a randomized trial of language used to describe palliative care services, patients with advanced cancer reported more favorable impressions and higher future perceived need for supportive care (vs. palliative care). To our knowledge, this study is the first systematic comparison of attitudes toward *the term* palliative vs. supportive care among patients with cancer. Patients were more likely to interpret supportive care as a

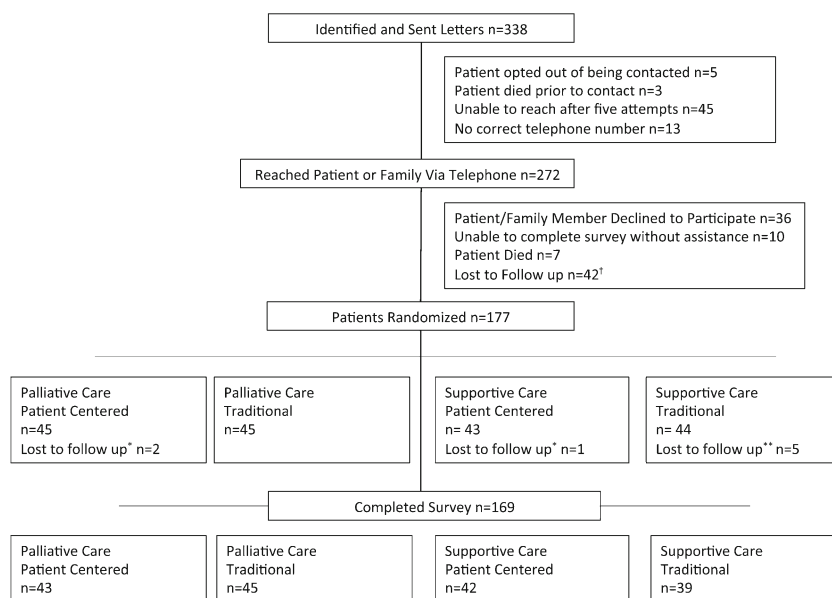


Table 1 Demographic and clinical characteristics overall and by randomized group^a

Participant characteristics	All participants N=169	Palliative care, patient-centered N=43	Palliative care, traditional N=45	Supportive care, patient-centered N=42	Supportive care, traditional N=39	p value
Age, mean (SD)	62.3 (11.6)	62.3 (10.1)	63.1 (9.2)	60.7 (13.6)	62.9 (13.4)	0.78
Female	107 (63.3)	27 (62.8)	28 (62.2)	27 (64.3)	25 (64.1)	0.9966
Race						0.251
Caucasian	161 (95.3)	39 (90.7)	43 (95.6)	42 (100.0)	37 (94.9)	
Education						0.998
≤High school						
Diploma/GED	50 (29.6)	12 (27.9)	13 (28.9)	16 (38.1)	9 (23.1)	
>High school						
Diploma/GED	119 (70.4)	31 (72.1)	32 (71.1)	26 (61.9)	30 (76.9)	
Average household income						0.875
<\$30,000	33 (19.5)	9 (20.9)	10 (22.2)	8 (19.1)	6 (15.4)	
≥\$30,000	97 (57.4)	22 (51.2)	27 (60.0)	25 (59.5)	23 (59.0)	
Declined to answer	39 (23.1)	12(27.9)	8 (17.8)	9 (21.4)	10 (25.6)	
Religion						0.545
Catholic/Christian	150 (88.8)	39 (90.7)	42 (93.4)	38 (90.5)	31 (79.5)	
Jewish	7 (4.1)	2 (4.7)	0 (0.0)	3 (7.1)	2 (5.1)	
Other religion	6 (3.6)	1 (2.3)	2 (4.4)	0 (0.0)	3 (7.7)	
Non/agnostic	5 (3.0)	1 (2.3)	1 (2.2)	1 (2.4)	2 (5.1)	
Importance of religion						0.851
Very important	125 (74.0)	32 (74.4)	35 (77.8)	31 (73.8)	27 (69.2)	
Somewhat important	31 (18.3)	6 (14.0)	8 (17.8)	8 (19.0)	9 (23.1)	
Not important	13 (7.7)	5 (11.6)	2 (4.4)	3 (7.1)	3 (7.7)	
Self-reported quality of life						0.490
Excellent	26 (15.4)	6 (14.0)	6 (13.3)	8 (19.0)	6 (15.4)	
Very good	58 (34.3)	15 (34.9)	17 (37.8)	17 (40.5)	9 (23.1)	
Good	56 (33.1)	16 (37.2)	15 (33.3)	12 (28.6)	13 (33.3)	
Fair	21 (12.4)	3 (7.0)	5 (11.1)	3 (7.1)	10 (25.6)	
Poor	8 (4.7)	3 (7.0)	2 (4.4)	2 (4.8)	1 (2.6)	
Seen palliative/supportive						0.132
Care provider	18(10.7)	2 (4.7)	7 (15.6)	7 (16.7)	2 (5.1)	
Cancer diagnosis						0.860
Gastrointestinal	22 (13.0)	4 (9.3)	4 (11.9)	5 (11.9)	9 (23.1)	
Genitourinary	18 (10.7)	4 (9.5)	7 (15.5)	3 (7.1)	4 (10.3)	
Gynecologic	2 (1.2)	1 (2.3)	1 (2.2)	0 (0.0)	0 (0.0)	
Brain	2 (1.2)	1 (2.3)	1 (2.2)	0 (0.0)	0 (0.0)	
Breast	54 (32)	13 (30.9)	13 (28.9)	16 (38.1)	12 (30.8)	
Hematologic	19 (11.2)	5 (11.9)	5 (11.1)	6 (14.3)	3 (7.7)	
Lung	31 (18.3)	7 (16.7)	7 (15.6)	8 (19.0)	9 (23.1)	
Sarcoma	12 (7.1)	6 (14.3)	3 (6.7)	2 (4.8)	1 (2.6)	
Skin	7 (4.7)	2 (4.7)	2 (4.4)	2 (4.8)	1 (2.6)	
Other	2 (1.2)	0 (0.0)	2 (4.4)	0 (0.0)	0 (0.0)	
Months since cancer diagnosis, median (MAD) ^b	46 (54.9)	30 (32.6)	46 (54.9)	52 (63.8)	52 (47.4)	0.164
Months receiving oncologist's care, median (MAD) ^b	24 (27.4)	20 (20.8)	17 (22.2)	36 (40.0)	24 (26.7)	0.551

MAD median absolute deviation

^a All numbers are reported as N (%) except where indicated otherwise^b p values calculated with Kruskal–Wallis test due to skewed data. All others were calculated with ANOVA F test or Chi-squared tests

Table 2 Understanding, impressions, perceived need, and intended use of palliative care services overall and by randomized group^a

	All subjects (<i>N</i> =169)	Palliative care, patient-centered (<i>N</i> =43)	Palliative care, traditional (<i>N</i> =45)	Supportive care, patient-centered (<i>N</i> =42)	Supportive care, traditional (<i>N</i> =39)	Supportive vs. palliative <i>p</i> value	Patient-centered vs. traditional <i>p</i> value
Understanding	7.3 (2.6)	6.7 (3.0)	7.0 (2.6)	7.7 (2.2)	7.8 (2.2)	0.027	0.660
Impressions	7.8 (2.4)	7.0 (3.0)	7.5 (2.2)	8.5 (2.0)	8.3 (2.1)	0.002	0.636
Current perceived need	4.9 (3.3)	4.1 (3.3)	5.3 (3.3)	5.0 (3.4)	5.1 (3.2)	0.547	0.194
Future perceived need	8.1 (2.3)	7.5 (2.7)	8.0 (2.3)	8.7 (1.9)	8.5 (1.9)	0.018	0.601
Self-initiated intended use	6.0 (3.5)	5.4 (3.6)	6.1 (3.8)	6.3 (3.5)	6.2 (3.1)	0.375	0.638
Oncologist-initiated intended use	8.6 (2.0)	8.3 (2.0)	8.4 (2.2)	8.9 (2.0)	8.7 (1.7)	0.179	0.746

^a All numbers are reported as mean (SD)

service that provides medical communication and information as well as psychological, mental, and social support, whereas they were more likely to equate palliative care with end-of-life services.

Our findings raise concerns as to how patients perceive the term palliative care. Unfamiliarity and/or negative associations with the term palliative care may result in less favorable impressions and lower perceived need for these services. The reasons underlying these more negative perceptions are not entirely clear. In our study, over half of the patients did not know what palliative care meant. This finding builds on prior research demonstrating a lack of familiarity with the term among oncology nurses [23] and the general public [28], as well as among patients with cancer [22]. Palliative care also lacks a standard definition in the supportive and palliative

oncology literature [29, 34]. In the absence of a clear understanding of what palliative care means, patients may invoke prior experiences of palliative care with friends or loved ones. The fact that most patients receive palliative care late in their disease course [19, 20] may play into perceptions that this service is for patients at the end of life, leading to a lower perceived need for palliative care among patients who are not at this stage. Patients may develop a misunderstanding about palliative care from their oncologists, who often think of it as end-of-life care [25]. Finally, the fact that palliative care is so closely tied to hospice—for example in the USA, the subspecialty board certification is for Hospice and Palliative Medicine—may contribute to this view. Hospice care has been available for a longer period of time and continues to be a more familiar concept [22, 28]. Patients who are not

Table 3 Multivariate analysis of understanding, impressions, perceived need, and intended use of palliative care services^a

	Overall understanding	Impressions	Current perceived need	Future perceived need	Self-initiated intended use	Oncologist-initiated intended use
Gender, male	-0.605 (0.202)	-0.585 (0.174)	-	-	-	-
Race, white	-	-0.122 (0.899)	-	-	-	-
Education, some college education or college degree	-	-	-	0.466 (0.311)	-	-
Income, >\$30,000 annually	1.637 (0.001)	1.190 (0.012)	-	0.617 (0.198)	-	-
Christian religion	-1.092 (0.095)	-	-	-	-	-
Quality of life	-	-	-0.381 (0.118)	-	-	-
Seen palliative/supportive care provider	-	-	2.22 (0.007)	-	2.332 (0.009)	-
Cancer diagnosis ^b	0.886 (0.077)	-	-	-	-	-
Months since cancer diagnosis	0.001 (0.740)	0.003 (0.346)	-0.004 (0.310)	-	-	-
Months receiving oncologist's care	-	-	-0.007 (0.331)	-	-	-
Supportive vs. palliative care terminology	0.644 (0.124)	1.247 (0.003)	0.403 (0.426)	0.934 (0.022)	0.449 (0.403)	0.415 (0.183)
Patient-centered vs. traditional description	0.150 (0.717)	0.163 (0.684)	0.609 (0.232)	0.208 (0.604)	0.231 (0.667)	-0.100 (0.746)

^a All values presented as correlation coefficient (*p* value). All analyses adjusted for supportive care vs. palliative care terminology, patient-centered vs. traditional descriptions, and additional variables that were significant (*p*<0.1) in univariate analysis

^b Dichotomized as breast cancer vs. all other types cancer

Table 4 Patient's responses to the question "can you please describe in your own words what you think palliative care/supportive care is?"

Patient response themes	All patients (N=169) ^a	Palliative care (N=88)	Supportive care (N=81)	<i>p</i> value ^b
I don't know	46	45	1	<0.001
"I have no idea." "I'm not sure."				
Psychological/mental/social support	42	2	40	<0.001
"I think it is care that would provide mental health services if you are stressed, like support groups." "To help me get through bad times and to understand that people go through the same things. To help, to talk, to get through bad stuff, having family members and friends and doctors."				
Symptom/additional medical care	45	27	18	0.285
"Care that is designed to keep you as pain free as possible and as well as possible." "Healthcare not directly related to cancer but to other side issues with medications and nutritional stuff."				
Medical communication/information exchange	17	2	15	0.001
"Its follow ups and you're able to speak to a nurse to answer general questions." "I imagine they would help you if you have any questions."				
End-of-life care	13	12	1	0.006
"When people are at the end of their life, like hospice care, that kind of thing." "I think that I have always assumed that it was end-stage medical care."				
Activities of daily living/financial/home support	13	4	9	0.190
"Assistance with living at home." "Its when they help you with your medicine and things. They help pay for it. People come in and take care of you."				
Unspecified additional care/support	16	5	11	0.137
"I don't know, care to help me I think it would be." "Somebody to help you out whenever you have problems."				

^a Numbers total to more than 169. One patient response included 3 themes, 21 included 2 themes, and 147 included 1 theme

^b *p* values computed with Chi-squared test

eligible for hospice may not think of palliative care as an option.

While we had hypothesized that using recently developed patient-centered language to describe palliative/supportive care services may improve understanding, impressions, perceived need, and intended use, we found no such association between descriptions and these outcomes [28]. Our findings differ from the national marketing survey sponsored by the American Cancer Society and the Center to Advance Palliative Care in which the public rated newer patient-centered language more positively [28]. This finding may result from the fact that our study involved patients with advanced cancer who likely have greater familiarity with these services than the general public. In addition, our study also utilized a more stringent randomized design than the marketing survey, which may also account for our different results. Patients reported being more willing to seek palliative/supportive care services when recommended by their oncologist. This finding highlights the importance of trust between patients and oncologists in the setting of life-threatening illness, which may lead to a hesitancy to question oncologists' advice or independently

engage with additional providers. While referral from an oncologist is not required for a palliative care clinic visit at many cancer centers and efforts have been made to increase patient-driven requests for palliative care [10], improved integration of palliative care services will require the active participation and support of oncologists.

These findings have practical implications. Lack of patient familiarity with the term palliative care creates an opportunity for palliative care clinicians to define palliative care services for patients, particularly in outpatient oncology settings where subspecialty palliative care clinics are growing rapidly and have many unique features from hospital and hospice-based palliative care programs. However, the fact that patients were most likely to associate the true scope of outpatient palliative care services with the term supportive care suggests that substituting this term may decrease barriers to service use. Recognizing that many patients equate palliative care with death and dying, oncologists may also choose to substitute the term supportive care and/or directly elicit and address patient concerns when recommending these services [24–26, 35–37]. Of note, addressing barriers to service use should not be

confused with changing the nature of services provided. It is possible that any name applied to palliative care services will eventually be associated with end-of-life care. [38] Additional work is needed to ensure that descriptions of palliative care in research and clinical settings are clear and reflect evolving definitions of the field [39].

Our study has several limitations. First, just over half of the identified patients completed the study. However, our enrollment rate compares favorably to other published telephone surveys and there were no significant demographic differences between participants and nonparticipants [40, 41]. Second, the majority of respondents were Caucasian. Previous research suggests that awareness of palliative care may be even lower among more racially/ethnically diverse groups [22]. Third, we conducted this study at two cancer centers with well-established palliative care programs. Our findings may not generalize to other centers with less established palliative care services. Fourth, the name of outpatient palliative care clinics at these cancer centers may have influenced participant responses, though a minority of participants had used these services. Finally, because we were not able to directly measure service use it is not clear to what extent these findings will translate into clinically meaningful differences.

In summary, it is important to consider how patients perceive the terms palliative vs. supportive care, as language may significantly affect understanding, impressions, and use. Providing early palliative care services as part of a multidisciplinary approach can enhance the quality of life and perhaps even prolong survival for patients with advanced cancer. Changing impressions of the term palliative care, or substituting the term supportive care, may help to extend the reach of these services.

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