



Published in final edited form as:

*Am J Hosp Palliat Care*. 2018 March ; 35(3): 431–439. doi:10.1177/1049909117715215.

## Awareness and Misperceptions of Hospice and Palliative Care: A Population-Based Survey Study

Ariel Shalev, BBA<sup>1</sup>, Veerawat Phongtankuel, MD, MS<sup>1</sup>, Elissa Kozlov, PhD<sup>1</sup>, Megan Johnson Shen, PhD<sup>1</sup>, Ronald D. Adelman, MD<sup>1</sup>, and M. C. Reid, MD, PhD<sup>1</sup>

<sup>1</sup>Department of Medicine, Weill Cornell Medicine, New York, NY, USA

### Abstract

**Background**—Despite the documented benefits of palliative and hospice care on improving patients' quality of life, these services remain underutilized. Multiple factors limit the utilization of these services, including patients' and caregivers' lack of knowledge and misperceptions.

**Objectives**—To examine palliative and hospice care awareness, misperceptions, and receptivity among community-dwelling adults.

**Design**—Cross-sectional study.

**Subjects**—New York State residents 18 years old who participated in the 2016 Empire State Poll.

**Outcomes Measured**—Palliative and hospice care awareness, misperceptions, and receptivity.

**Results**—Of the 800 participants, 664 (83%) and 216 (27%) provided a definition of hospice care and palliative care, respectively. Of those who defined hospice care, 399 (60%) associated it with end-of-life care, 89 (13.4%) mentioned it was comfort care, and 35 (5.3%) reported hospice care provides care to patients and families. Of those who defined palliative care ( $n = 216$ ), 57 (26.4%) mentioned it provided symptom management to patients, 47 (21.9%) stated it was comfort care, and 19 (8.8%) reported it was applicable in any course of an illness. Of those who defined hospice or palliative care, 248 (37.3%) had a misperception about hospice care and 115 (53.2%) had a misperception about palliative care.

**Conclusions**—Most community-dwelling adults did not mention the major components of palliative and hospice care in their definitions, implying a low level of awareness of these services, and misinformation is common among community-dwelling adults. Palliative and hospice care education initiatives are needed to both increase awareness of and reduce misperceptions about these services.

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Corresponding Author: Ariel Shalev, Weill Cornell Medical College, 525 East 68th Street, Box 39, New York, NY 10065, USA. [ars3003@med.cornell.edu](mailto:ars3003@med.cornell.edu).

#### Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Keywords

palliative care; hospice care; awareness; community-dwelling adults; misperceptions; palliative care receptivity

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## Introduction

Palliative and hospice care have been associated with improved patient symptom control<sup>1-3</sup> and quality of life<sup>4-8</sup> as well as increased satisfaction with care.<sup>9,10</sup> Palliative care aims to address the physical, psychological, and spiritual needs of patients living with serious illnesses with the goal of improving their quality of life.<sup>11,12</sup> Hospice care is a type of palliative care for patients in the last 6 months of life, and it cannot be delivered concurrently with curative treatment.<sup>11,13</sup> Despite the many documented benefits of palliative and hospice care, both types of care remain underutilized among patient populations critically in need of these forms of care.<sup>14,15</sup> Among patients admitted to the hospital, fewer than 5% are seen by a palliative care team<sup>16</sup> and less than half of all individuals who die in the United States receive hospice care.<sup>17,18</sup> With the number of Americans living with serious illnesses expected to double in the coming years,<sup>10</sup> promoting access to and utilization of palliative and hospice care services is increasingly important.

Multiple factors contribute to the underutilization of palliative and hospice services, one of which is individuals' lack of knowledge about these services.<sup>19-21</sup> Two large surveys of community-dwelling adults found that over 70% of participants self-reported low to no knowledge of palliative care.<sup>22,23</sup> Multiple studies have also found that patients and caregivers considering hospice are often unaware of basic information about hospice care such as how it is delivered and paid for.<sup>20,24-26</sup> However, few studies have examined specific key components of palliative and hospice care that community-dwelling adults are either aware or unaware of. Ascertaining this information could help to identify important targets for public education initiatives.

In addition to low knowledge levels of palliative and hospice care, negative misperceptions can adversely affect individuals' receptivity to these services. The majority of existing research has examined misperceptions in various patient populations.<sup>27-29</sup> One study examined adults who were HIV positive and found that participants often associated palliative care with end-of-life care, with 1 participant describing palliative care as "negative and scary ... like you're about to die."<sup>30</sup> However, studies have also found misperceptions among community-dwelling adults. In 1 study, over 30% of respondents agreed with the statements "hospice care is only about death" and "hospice care is seen as giving up."<sup>25</sup>

Given that previous studies have shown that greater knowledge of palliative and hospice care has been associated with greater receptivity toward these services,<sup>31-34</sup> improving awareness and dispelling misperceptions are critical to further acceptance of this care. However, key components of palliative and hospice care that community-dwelling adults are either aware of (or possibly unaware of) and which specific misperceptions individuals maintain about these types of care remain poorly defined. This study sought to examine community-dwelling adults' awareness of key components and misperceptions of both palliative and

hospice care. As a secondary objective, we sought to analyze whether certain participant characteristics were associated with greater receptivity to palliative services.

## Methods

### Study Design

We conducted a cross-sectional study analyzing data collected as part of Cornell Survey Research Institute's 2016 Empire State Poll. Institutional review board approval was obtained in 2016 by the survey research institute.

### Participants, Setting, and Recruitment

The Empire State Poll is an annual survey of 800 New York State residents aged 18 and over. The survey collects participants' demographic data that includes age, gender, race, education level, marital status, social ideology, and household income. Researchers can submit questions to be incorporated into the survey for a fee. Participants are chosen at random from both landline and cellular numbers in New York State obtained from marketing systems group. Of the 2875 calls made, only 800 were successful; 1185 phone numbers were inactive, 506 respondents were ineligible due to factors such as age and English proficiency, and 384 refused to participate. Data collection occurred between February and April 2016.

### Questionnaire

Three questions regarding palliative and hospice care were included in the survey. All 3 questions were read to participants over the phone during the survey and presented in the order that we have listed them here. Two open-ended questions assessed participants' awareness of hospice and palliative care. The first question asked "How would you define hospice care?" The second question asked, "Palliative care is a type of medical care that is gaining in popularity. How would you define palliative care?" The third question assessed receptivity to palliative care by asking participants if they would recommend palliative care services to a loved one. Participants were first read the following definition of palliative care obtained from the Center to Advance Palliative Care<sup>12</sup>: "Palliative care is specialized medical care for people with serious illnesses. It 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 is provided by a team of palliative care doctors, nurses and other specialists who work together with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided along with curative treatment." Participants were next asked, "How likely, if at all, would you be to consider palliative care for a loved one if they had a serious illness?" and then directed to rate their likelihood of recommending palliative care to a loved one as *very likely* = 1, *somewhat likely* = 2, *not too/not at all likely* = 3, and *do not know* = 4.

### Defining Knowledge and Misperceptions

We analyzed participants' open-ended responses by coding for awareness and misperceptions. Using the National Hospice and Palliative Care Organization and World

Health Organization's definitions of palliative and hospice care as a framework to code participants' level of awareness, we created a list of key components that define palliative and hospice care. A team of palliative care specialists (R.D.A., E.K., V.P., M.C.R., and M.J.S.) reviewed each definition and came to an agreed-upon coding scheme highlighting key components that defined each term. The coding scheme was designed a priori and not derived from themes within the participant's answers. For hospice care, the 10 key components were (1) it is delivered at the end of life, (2) it provides care to both patients and families, (3) it provides symptom management to patients, (4) it offers psychosocial and spiritual support, (5) it assists with goals of care, (6) it is delivered by an interdisciplinary team, (7) it is comfort care, (8) it offers bereavement services, (9) it affirms life and regards dying as a normal process, and (10) it seeks to improve quality of life. The key components for palliative care were the same with one exception: "hospice care is care delivered at the end of life" was replaced by "palliative care is applicable during any course of an illness." Any mention of 1 of the 10 components, whether through a personal anecdote or simply stated, was considered proof of a participant's awareness of that component. Each response was coded for the presence of these components by a pair of investigators (R.D.A., E.K., V.P., M.C.R., M.J.S., and A.S.) and disagreements were resolved by a third trained reviewer (A.S. and V.P.).

Responses were also coded in the same fashion for the presence of misperceptions regarding palliative and hospice care. We used content analysis to code for the presence of misperceptions in participant definitions of palliative and hospice care.<sup>35</sup> Misperceptions were answers provided by respondents to the definitional questions judged to be partially or totally incorrect by the reviewers based on the definitions used to create our key components. Misperceptions were further coded into subcategories. To create the subcategories, 4 investigators (E.K., V.P., A.S., and M.J.S.) independently reviewed and coded a sample of the responses and then came to an agreed-upon coding scheme derived from the data. Misperceptions of hospice care were coded into 3 categories: misperceptions about who is eligible for hospice care (people), misperceptions about where hospice care is delivered (setting), and "other" misperceptions. For example, misperceptions involving people often involved believing hospice was only provided to older adults. One participant remarked, "It's care of elderly people who are in need of services at home." Misperceptions involving setting included participants who stated that hospice care was only delivered at home. One example of this was a participant who responded by saying, "I think that's when someone lives in your house to be a caretaker." Misperceptions that did not fit the above categories were categorized as "other," and an example of this was a participant who stated "Keeps special people alive." Palliative care misperceptions were grouped into 3 categories: association with end of life, misperceptions about who is eligible for palliative care, and other.

### Statistical Analysis

We performed descriptive statistics of the entire sample. Furthermore, bivariate analyses of participants' receptivity to palliative care were conducted. We compared the subgroups who answered that they were very or somewhat likely to recommend palliative care for a loved one to the subgroups who were not (ie, did not endorse likelihood to use or recommend

palliative care) using  $\chi^2$  tests for categorical variables and Wilcoxon rank sum tests for continuous variables. Interrelater agreement was assessed by calculating percentage agreement. This was computed by identifying the number of discrepancies and dividing it by the opportunities for discrepancies then multiplying by 100. Statistical analyses were conducted using STATA MP 14.1 (College Station, Texas).

## Results

### Characteristics of the Study Cohort

Table 1 shows the characteristics of the entire sample (N = 800), the subset of participants (n = 664) who answered the hospice question, and the subset of participants (n = 216) who answered the palliative care question. Given the response rates, 136 (17%) participants said they did not know what the term “hospice care” meant, while 584 (73%) did not know what the term “palliative care” meant. The mean age for the entire sample was 47 years (SD = 17.0 years). A majority of the sample was White (n = 483, 60.4%), married (n = 377, 47.1%), had some college education or greater (n = 526, 65.7%), and reported an annual household income of \$50, 000 USD or greater (n = 492, 61.5%).

### Participants' Awareness of Hospice and Palliative Care

Figures 1 and 2 show the breakdown of hospice and palliative care responses by key components. For hospice care, out of the 664 participants who responded to the question, a majority (n = 399, 60%) associated it with end-of-life care. However, a small proportion of respondents described other key components of hospice care (in order of frequency): 89 (13.4%) mentioned it was a type of comfort care, 35 (5.3%) reported hospice care provides care to both patients and families, and only 22 (3.3%) stated that hospice care provides symptom management to patients. Less than 1% of respondents mentioned that hospice care assists with goals of care (n = 5), is delivered by an interdisciplinary team (n = 5), offers bereavement services (n = 5), or affirms life and regards dying as a normal process (n = 1).

Of the 216 participants who answered the palliative care question, the key components of palliative care most frequently mentioned were palliative care provides symptom management to patients (n = 57, 26.4%), constitutes a type of comfort care (n = 47, 21.9%), and is applicable at any course of an illness (n = 19, 8.8%). The 3 components of palliative care least mentioned were palliative care is delivered by an interdisciplinary team (n = 3), offers bereavement services (n = 2), and affirms life (n = 2).

### Misperceptions Regarding Hospice and Palliative Care

Of the 664 participants who responded to the hospice question, 248 (37%) responses were classified as containing 1 or more misperceptions. These misperceptions were categorized by setting (n = 128, 51.6%), people (n = 108, 43.5%), and other (n = 59, 26.2%) as outlined earlier. Of note, 6 of the misperceptions classified as other related hospice care to euthanasia (eg, an example of such a response is “*It is euthanasia*”).

For participants (n = 664) who responded to the hospice question, 299 (45%) stated a key component and did not express a misperception, 119 (18%) stated a key component but

expressed a misperception, 129 (19.4%) stated no key components but expressed a misperception, and 117 (17.6%) stated no key components and did not express a misperception (eg, an example of such a response is “*I think it’s great*”).

Of the 216 participants who responded to the palliative care question, 115 (53.2%) expressed at least 1 misperception. The most common misperception was associating palliative care with end-of-life care ( $n = 85, 73.9\%$ ), while a few participants ( $n = 8, 6.96\%$ ) associated palliative care with a type of care only for the elderly; the remainder of misperceptions ( $n = 22, 19.1\%$ ) were classified as other.

For participants who responded to the palliative care question, 59 (27.3%) stated a key component and did not express a misperception, 63 (29.2%) stated a key component but expressed a misperception, 42 (19.4%) stated no key components and did not express a misperception, and 52 (24.1%) stated no key components but expressed a misperception.

### Interrater Reliability

In all, 2.89% of responses needed to be resolved through consensus meetings.

### Receptivity to Palliative Care

When the entire cohort was provided with the definition of palliative care and asked if they would recommend this type of care to a loved one, 503 (62.9%) responded *very likely*, 224 (28%) responded *somewhat likely*, 69 (8.6%) responded *not too likely/not at all likely*, and 4 (0.5%) responded *do not know*.

### Bivariate Analyses of Variables Associated With Receptivity to Palliative Care

Table 2 shows the bivariate analyses of variables associated with receptivity to palliative care. Lower receptivity to palliative care was associated with being male ( $P < .001$ ), having a more conservative social ideology ( $P = .004$ ), having a lower household income ( $P = .043$ ), and having lower palliative care awareness ( $P = .038$ ).

## Discussion

Our study indicates that participants were unaware of many key components of palliative and hospice care, and their responses frequently contained misperceptions. Seventy-three percent and 17% of participants were unable to generate a response when asked to define palliative and hospice care, respectively. Awareness of hospice was not as poor as awareness of palliative care and 60% of respondents correctly associated hospice care with end-of-life care, however, other key aspects of hospice care were rarely mentioned.

Although further studies are needed to understand the factors affecting palliative and hospice care receptivity, our results shed light on several possible barriers to utilization of these services. Most participants could not define palliative care, this is significant, given the existing research linking knowledge of and receptivity to palliative and hospice care services.<sup>31–34</sup> In addition, many of the misperceptions that emerged from the data were ones that could deter people from considering these services. For example, misperceptions equating palliative with end-of-life care or hospice with elder care could give people the

impression that these services are not appropriate for themselves or their loved ones. Overall, our findings emphasize the need for palliative and hospice care education among the public to raise awareness, reduce misperceptions, and increase receptivity.<sup>23,24,31–33,36,37</sup>

Specific participant characteristics were associated with decreased palliative care receptivity. In specific, male gender, a more conservative social ideology, lower household income, and lower palliative care awareness were all associated with lower palliative care receptivity. While there are limitations to our analyses, it provides a framework to understand where to focus future palliative care education initiatives and resources. Although it is unclear why these disparities exist, further studies, both quantitative and qualitative, are needed to better understand whether these factors influence receptivity of palliative care.

One way to improve awareness and knowledge of palliative and hospice care among community-dwelling adults is to engage in community-based educational interventions, which have proven effective and have been well received. For example, an educational intervention in Indiana utilized community presentations to improve participants' advance care planning. Of the 960 community members involved, most felt they had gained useful resources with which to approach the topics of palliative and end-of-life care.<sup>38</sup> Another educational intervention targeting Latino caregivers found that familiarity with the concept of palliative care increased from 21% to 87%.<sup>39</sup> Given the poor awareness and prevalent misperceptions found in our study, implementing and understanding effective community-level educational interventions is a key part of improving knowledge of these services. In addition, the results of the current study could be utilized to inform the content of these interventions, for example, focusing on the components, purpose, and eligibility criteria of palliative and hospice care.

In addition to implementing effective community-level interventions, national initiatives focused on increasing awareness of palliative and hospice care should be expanded. While efforts to enhance public education regarding palliative and hospice care are limited, several novel solutions to address this gap are emerging. Activists and organizations are utilizing art and media to promote discussion regarding end of life and increase awareness of both palliative and hospice care. One example is *Before I Die*, a global public art project which invites participants to publically contemplate death by finishing the sentence "before I die I want to ..."<sup>40,41</sup> A similar initiative, the Conversation Project, is working to promote conversations about individual's end-of-life wishes through their Conversation Starter Kits, which are provided free on their Website in 9 languages and include prompts, questions, and facts that encourage and guide individuals as they contemplate their end-of-life preferences.<sup>42</sup> Another innovative project is *redesigning death*, a collaboration between Dr BJ Miller and the design company IDEO.<sup>43</sup> The project has had significant press, all with the goal of better engaging the public in end-of-life care awareness.<sup>43–45</sup> The educational outcomes of both projects have great potential as a model approach to improving public understanding of hospice and palliative care. Measuring their impact on participants' knowledge and receptivity to these types of care will be important to do.

Our study has limitations that warrant consideration. One limitation is the lack of follow-up questions. We found a very low level of awareness regarding hospice and palliative care and

a low response rate when participants were asked to define palliative care. Participants may have given more detailed and informed answers had we asked them to expand on their responses. In addition, the use of open-ended questions may not have best captured a person's awareness of the term since 1 study, utilizing a true/false format, found much higher levels of hospice knowledge.<sup>31</sup> Furthermore, participants were residents of New York State and their opinions and awareness level may not be representative of people living in other parts of the country. Finally, given the low number of participants who stated they were not likely to consider palliative care for a loved one, there is potential of a type II error to have occurred among the variables we examined.

In conclusion, our findings suggest that community-dwelling adults are unaware of many of the basic components of both palliative and hospice care. Misperceptions regarding hospice and palliative care are also highly prevalent. Our findings are in line with much of the existing research.<sup>25,26,28,30,31</sup> Future research is needed to build upon these findings by further exploring the effectiveness of educational interventions and public health initiatives as well as examining why certain populations are more or less receptive to these services.

## Acknowledgments

The authors would like to acknowledge the Cornell Survey Research Institute for their assistance in collecting participant data for this study.

### Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Dr. Reid is supported by grants from the National Institute on Aging (P30AG022845, K24AGO53462) and by the Howard and Phyllis Schwartz Philanthropic Fund.

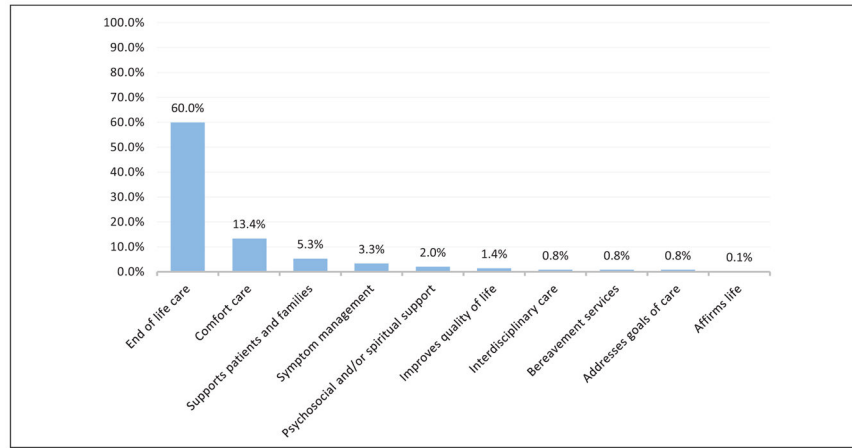
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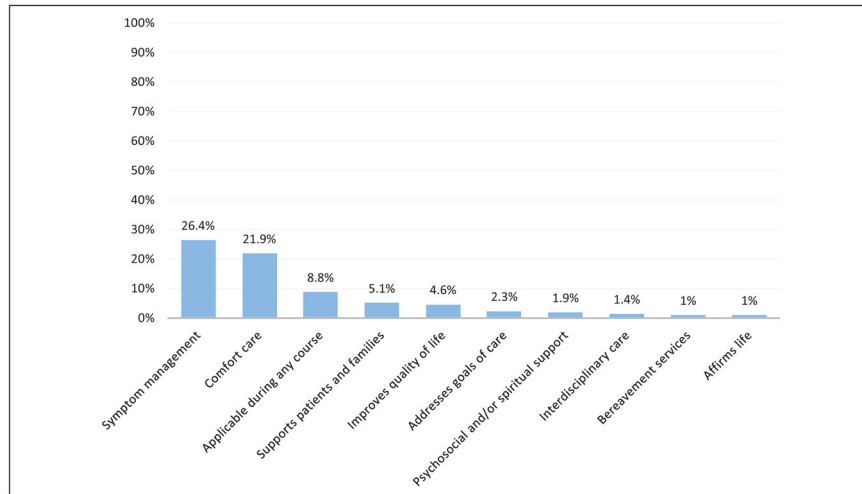
**Figure 1.** Participants' hospice awareness by key components (N = 664 respondents).

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**Figure 2.** Participants' palliative care awareness by key components (N = 216 respondents).

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**Table 1**

Characteristics of Empire Cohort and Subset of Participants Answering Hospice and Palliative Question.

<b>Demographic Characteristics</b>	<b>Entire Cohort (N = 800) N (%)</b>	<b>Subset Answering Hospice Question (N = 664) N (%)</b>	<b>Subset Answering Palliative Care Question (N = 216) N (%)</b>
<b>Age</b>			
Mean (SD)	47 (17)	49 (17)	52 (15)
Median	48	50	51.5
<b>Gender</b>			
Female	392 (49)	338 (50.9)	132 (61.1)
Male	408 (51)	326 (49.1)	84 (38.9)
<b>Marital status</b>			
Married	377 (47.1)	337 (50.7)	119 (55.4)
Divorced/Separated	78 (9.7)	61 (9.2)	20 (9.3)
Widowed	43 (5.4)	39 (5.9)	13 (6.0)
Single	293 (36.6)	219 (33.0)	59 (27.4)
Not reported	9 (1.2)	8 (1.2)	5 (1.9)
<b>Education level</b>			
High school or lower	252 (31.5)	165 (24.8)	29 (13.4)
Technical school	20 (2.5)	16 (2.4)	3 (1.4)
College or some college	377 (47.1)	338 (50.9)	113 (52.3)
Postgraduate school	149 (18.6)	143 (21.5)	71 (32.9)
Not reported	2 (0.3)	2 (0.3)	0 (0)
<b>Race/ethnicity</b>			
White	483 (60.4)	444 (66.9)	154 (71.3)
Black	133 (16.6)	106 (16)	26 (12.0)
Hispanic	41 (5.1)	11 (1.7)	3 (1.4)
Asian	37 (4.6)	24 (3.6)	8 (3.7)
Mixed/Other	106 (13.3)	79 (11.9)	25 (11.6)
<b>Political party</b>			
Democrat	299 (37.4)	245 (36.9)	83 (38.4)
Independent	313 (39.1)	257 (38.7)	79 (36.6)
Republican	156 (19.5)	135 (20.3)	44 (20.4)
Not reported	32 (4.0)	27 (4.1)	10 (4.6)
<b>Social ideology</b>			
Liberal	255 (31.9)	218 (32.8)	84 (38.9)
Moderate	290 (36.2)	235 (35.4)	62 (28.7)
Conservative	239 (29.9)	198 (29.8)	65 (30.1)
Not reported	16 (2.0)	13 (2.0)	5 (2.3)
<b>Household income</b>			
Under \$30 000	115 (14.4)	75 (11.3)	14 (6.5)
\$30 000–\$49 999	167 (20.9)	126 (19.0)	42 (19.4)
\$50 000–\$74 999	181 (22.6)	152 (22.9)	42 (19.4)

<b>Demographic Characteristics</b>	<b>Entire Cohort (N = 800) N (%)</b>	<b>Subset Answering Hospice Question (N = 664) N (%)</b>	<b>Subset Answering Palliative Care Question (N = 216) N (%)</b>
\$75 000–\$99 999	100 (12.5)	92 (13.8)	29 (13.4)
\$100 000+	211 (26.4)	198 (29.8)	83 (38.5)
Not reported	26 (3.2)	21 (3.2)	6 (2.8)

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**Table 2**

Bivariate Analysis of Variables Associated With Receptivity to Palliative Care.

Demographic Characteristics	Very or Somewhat Likely to Consider Palliative Care (N = 727)	Not Likely to Consider Palliative Care (N = 69)	P-Value
Age			.7446
Mean (SD)	47.3	48.0	
Gender			<.001
Female	370 (50.9)	19 (27.5)	
Male	357 (49.1)	50 (72.5)	
Race/ethnicity			.057
White	451 (62)	31 (44.9)	
Black	116 (16)	15 (21.8)	
Hispanic	36 (4.9)	5 (7.2)	
Asian	34 (4.7)	3 (4.3)	
Mixed/Other	90 (12.4)	15 (21.8)	
Marital status			.988
Married	343 (47.2)	32 (46.4)	
Divorced/separated/widowed	111 (15.3)	10 (14.5)	
Single	265 (36.4)	26 (37.7)	
Not reported	8 (1.1)	1 (1.4)	
Education level			.078
High school or lower	223 (30.7)	27 (39.2)	
College/some college/technical school	364 (50.1)	31 (44.9)	
Postgraduate school	139 (19.1)	10 (14.5)	
Not reported	1 (0.1)	1 (1.4)	
Political party			.183
Democrat	280 (38.5)	18 (26.1)	
Independent	278 (38.2)	33 (47.8)	
Republican	139 (19.2)	16 (23.2)	
Not reported	30 (4.1)	2 (2.9)	
Social ideology			.004
Liberal	240 (33)	11 (15.9)	
Moderate	266 (36.6)	24 (34.9)	
Conservative	208 (28.6)	31 (44.9)	
Not reported	13 (1.8)	3 (4.3)	
Household income			.043
Under \$30 000	106 (14.6)	9 (13)	
\$30 000–\$49 999	142 (19.5)	23 (33.3)	
\$50 000–\$74 999	161 (22.1)	18 (26.3)	
\$75 000–\$99 999	95 (13.1)	5 (7.2)	
\$100 000+	200 (27.5)	11 (15.9)	

<b>Demographic Characteristics</b>	<b>Very or Somewhat Likely to Consider Palliative Care (N = 727)</b>	<b>Not Likely to Consider Palliative Care (N = 69)</b>	<b>P-Value</b>
Not reported	23 (3.2)	3 (4.3)	
Palliative care awareness			.038
Participants who stated a palliative care component and did not express a misperception	57 (7.8)	2 (2.9)	
Participants who stated a palliative care component but expressed a misperception	62 (8.5)	1 (1.4)	
Participants who did not state a component of palliative care or a misperception	40 (5.5)	1 (1.4)	
Participants who stated an incorrect definition of palliative care and expressed a misperception	47 (6.5)	5 (7.2)	
Participants who did not respond to question	521 (71.7)	60 (87.1)	

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