Original Article

Knowledge of Palliative Care Among American Adults: 2018 Health Information National Trends Survey

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Abstract

Context. Palliative care will play an important role to alleviate disease suffering and improve quality of life for cancer patients and their family caregivers.

Objective. We examined the knowledge penetration of palliative care in a nationally representative sample of U.S. adults.

Methods. We used the 2018 National Cancer Institute's Health Information National Trends Survey to determine the proportion of respondents who had knowledge of palliative care as well as the depth and sources of their knowledge. We used the Pearson chi-square test and a multivariable logistic regression model to assess the association of respondents' basic demographic characteristics as well as health status and having knowledge of palliative care.

Results. We identified 3194 respondents (weighted sample size: 229,591,005) who met the inclusion criteria. About 71% (2097) of all respondents had no knowledge of palliative care and 84.5% of Hispanic respondents had no knowledge of palliative care. Multivariable analyses indicated the middle-aged (50−64 years old, odds ratio, 1.58; 95% CI, 1.15−2.19, $P = 0.006$) and elder population (65 years or older, odds ratio, 1.70, 95% CI, 1.30−2.22, $P < 0.001$) have a significantly better knowledge of palliative care than those under age 50. Common misconceptions existed in respondents, even those who had self-reported adequate knowledge of palliative care.

Conclusion. The proportion of adults who have knowledge of palliative care is low in the U.S. Greater efforts are needed to promote palliative care and reduce the misconceptions of palliative care in the general population. J Pain Symptom Manage 2019;58:39−47.

Key Words

Palliative care, knowledge, misconception, HINTS

Introduction

The number of palliative care programs has experienced rapid growth in the past 2 decades, [1,2] and this nationwide high-speed growth in palliative care is well supported by the mounting evidence in the literature that shows promising clinical and economic benefits of palliative care for patients diagnosed with terminal illness.[3−6] Rooted in this empirical evidence, the Institute of Medicine released a consensus report in 2014 to recommend delivery of palliative care early in the course of treatment for any serious illness.[7] The American Society of Clinical Oncology (ASCO) released a guideline in 2016 that further endorsed the early integration of palliative care services into the care for patients diagnosed with advanced cancer.[8] The 2018 National Comprehensive Cancer Network

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(NCCN) Clinical Practice Guideline in Oncology recommends screening all cancer patients, regardless of the disease stage or necessity of other therapies, for palliative care needs.[9]

Expanding access to and use of palliative care and enhancing clinical practice through guidelines, therefore, could have a profound effect on the quality of life of patients diagnosed with terminal illness as well as their family caregivers while containing the escalating health care expenditures that are spent in caring for these patients.[10] Whether this recent expansion of palliative care facilities and release of clinical guidelines supporting palliative care from prestigious medical associations have increased awareness of palliative care and facilitated the dissemination of the knowledge of palliative care, a relatively new medical specialty, to the public is still unknown. Previous studies have examined the use of palliative care among terminally ill patients.[11,12] However, these analyses focused on the patients who had been seen by physicians and were seeking health care for the existing terminal illness. Previous studies have reported many barriers to accessing the palliative care use, such as patient and family reluctance,[13] fear,[14] misconception,[15,16] ignorance and lack of awareness of resources,[13] worrisome on inferior survival,[17] communication difficulties,[18] and so on. Increasing the knowledge and overall awareness of palliative care in public is crucial for reducing or eliminating these barriers.

To address this gap in the literature and better understand the public awareness of palliative care, we sought to determine the current prevalence of adults having self-reported either inadequate or adequate knowledge of palliative care and characterize selected sociodemographic factors of these adults, in a nationally representative sample. We also examined whether the general public who had self-reported adequate knowledge of palliative care could answer correctly the questions regarding the goals of palliative care and common misconceptions of palliative care. In addition, we sought to learn whether the individuals were overconfident on their knowledge of palliative care by assessing the differences on these answers from respondents who had inadequate and adequate knowledge of palliative care. In addition, we sought to learn what were the first and trusted information sources for the general public to search for the knowledge of palliative care.

Methods

Data

We used data from the National Cancer Institute (NCI)'s Health Information National Trends Survey (HINTS) administrated by the NCI's Division of Cancer Control and Population Sciences. The HINTS collects nationally representative data about the changes in the rapidly evolving field of health communication through different communication channels. In this study, we used 2018 HINTS 5 Cycle 2 data set, and this is the first year the HINTS data ask respondents about their knowledge of palliative care. This HINTS 5 Cycle 2 survey data were collected from January 2018 to May 2018.

Study Population

There were 3504 survey respondents who completed the HINTS 5 cycle 2 survey. Respondents were excluded from the study if the question about knowledge of palliative care was not answered ($N = 59$), or if their basic demographic information was missing, including age, sex, race, education, marital status, employment, and region ($N = 142$). Respondents were also excluded if their health-related information was not reported, including health insurance, general health status, personal cancer history, and family cancer history ($N = 251$). The final study sample included 3194 respondents (weight sample: 229,591,005) (Supplemental Table 1).

Study Variables

The outcome variables of our study were extracted from the five question sets in Section F: Palliative care of the HINTS 5 cycle 2 survey. The original questions from the survey were listed in Supplemental Table 2.

Knowledge of Palliative Care (HINTS 5: Question Set F1). The primary outcome of interest in the study was whether respondents knew about palliative care. In the HINTS data, the respondents were asked, "How would you describe your level of knowledge about palliative care?" and response options were "I've never heard of it," "know a little bit about palliative care," and "I know what palliative care is and could explain it to someone else." We classified study respondents into three groups based on their answers: "no knowledge," "inadequate knowledge," and "adequate knowledge," respectively.

For respondents who had some knowledge of palliative care, either inadequate or adequate, 11 questions were asked to assess whether respondents knew what was the goal of palliative care, whether there was any misunderstanding of palliative care, or what were the information sources for respondents to seek palliative care knowledge:

Goal of Palliative Care (HINTS 5: Question Set F2). The questionnaire listed four goals of palliative care, including 1) "Help friends and family to cope with a

patient's illness," 2) "Offer social and emotional support," 3) "Manage pain and other physical symptoms," 4) "Give patients more time at the end of life." Respondents used a four-point Likert scale, "strongly agree," "somewhat agree," "somewhat disagree," "strongly disagree," and "don't know," to express how much they agreed or disagreed with each of the goals of palliative care.

Misconceptions of Palliative Care (HINTS 5: Question Set F5). The same four-point Likert scale was also used to assess respondents' knowledge on five common misconceptions of palliative care, including "Accepting palliative care means giving up," "It is a doctor's obligation to inform all patients with cancer about the option of palliative care," "If you accept palliative care, you must stop other treatments," "Palliative care is the same as hospice care," "When I think of "palliative care," I automatically think of death."

Information Source of Palliative Care Knowledge (HINTS 5: Question Sets F3 and F4). Respondents were asked to choose one of five information sources to be the first and most trust source to seek information about palliative care. These five sources listed in the survey were printed materials (e.g., newspapers, magazines), health care provider (doctor, nurse, social worker), conversations with people you trust (friends, relatives, or coworkers), Internet (Google or another search engine, WebMD, or another medical web site), social media (Facebook, Instagram, Twitter). Because the number of respondents who selected "Internet" or "Social Media" was very limited, we combined these two sources into one group labeled other online resources.

Sociodemographic and Health-Related Variables. Respondents' social demographics collected from multiple questions in HINTS include age, sex, race/ethnicity, education level, marital status, family income, employment status, and census region. The respondent's age was grouped into three categories: 18–49 years, 50–64 years, and 65 years or older. The race/ethnicity information was classified into four race/ethnicity groups: non-Hispanic white, non-Hispanic black, Hispanic, and other. The health-related variables included respondents' access to health care and respondent's personal and family history of cancer.

Statistical Analysis

We conducted bivariate analysis using the Pearson chi-square test to assess the association between respondents' basic demographic characteristics as well as health status and respondents' knowledge of palliative care. To examine the factors associated with having knowledge or no knowledge of palliative care, we conducted a multivariable logistic regression model, controlling for statistically significant or clinically meaningful characteristics. All statistical tests were two sided, and all analyses were performed using SAS version 9.4 software (SAS Institute, Cary, NC). Sampling weights calculated from the HINTS complex sample design were used in the statistical analysis using SAS. By using the HINTS sample weights in statistical analysis, we were able to estimate how many individuals in the U.S. were represented by the HINTS 5 cycle 2 respondents. We used the SURVEYFREQ procedure to derive nationally representative estimates on the bivariate analysis and to generate standard errors, and SURVEYLOGISTIC procedure for the multivariable logistic model. The full multivariable logistic model included all the sociodemographic and health-related variables, and the reduced multivariable logistic model only included the variables that had $P < 0.10$ in the univariate analysis. Statistical significance was defined as $P < 0.05$. This study was deemed exempt from review by the Institutional Review Board at the University of Florida.

Results

Demographics and Health Characteristics

Among 3194 study respondents, 2097 (71%) had no knowledge of palliative care. We compared knowledge of palliative care by respondents' demographic and health characteristics (Table 1). Compared with the population aged 18–49 years, the middle aged (50–64 years old) and elder population (65 years or older) had a significantly better knowledge of palliative care (inadequate knowledge: 21.6%, 22.7% vs. 14.4%; adequate knowledge: 11.9%, 11.3%, vs. 10.1%) ($P = 0.01$). Female respondents also had better knowledge of palliative care than male respondents (inadequate knowledge: 21.3% vs. 14.7%; adequate knowledge: 14.8% vs. 6.7%) ($P < 0.001$). We found that 84.5% of Hispanic respondents had no knowledge of palliative care, the highest among all racial/ethnic groups. The other factors associated with better knowledge of palliative care include a college education or higher, being married, high household income, being employed, having health insurance, or having a personal or family history of any cancer.

Logistic Regression Model

The results of logistic regression model with the full list of covariates are shown in Table 2. A higher odds of having knowledge of palliative care were observed in respondents who were middle-aged or elder (50–64 years: odds ratio [OR], 1.58; 95% CIs, 1.15–2.19, $P = 0.006$; 65 years or older: OR, 1.70, 95% CI, 1.30–2.22, $P < 0.001$), female (OR, 2.19,

Table 1
Sociodemographic Characteristics of Survey Respondents: HINTS 2018

	Knowledge of Palliative Care				
Study Sample	Total	No Knowledge	Inadequate Knowledge	Adequate Knowledge	
Unweighted population	3194	2097	668	429	
Weighted population	229,591,005	163,082,838	41,552,928	24,955,240	
Characteristics	No. (Col, %)	No. (Row, %)	No. (Row, %)	No. (Row, %)	*P*-value
Age group					0.001
18–49	1013 (51.2)	685 (75.5)	186 (14.4)	142 (10.1)	
50–64	1046 (29.8)	657 (66.5)	240 (21.6)	149 (11.9)	
65+	1135 (19.0)	755 (66.1)	242 (22.7)	138 (11.3)	
Gender					<0.001
Male	1298 (48.7)	964 (78.6)	222 (14.7)	112 (6.7)	
Female	1896 (51.3)	1133 (63.9)	446 (21.3)	317 (14.8)	
Race/ethnicity					<0.001
Non-Hispanic white	1861 (60.8)	1098 (65.5)	481 (22.6)	282 (11.9)	
Non-Hispanic black	408 (10.0)	310 (75.0)	60 (14.3)	38 (10.7)	
Hispanic	425 (14.8)	334 (84.5)	53 (9.2)	38 (6.3)	
Other	500 (14.4)	355 (77.9)	74 (10.9)	71 (11.2)	
Education					<0.001
Less than high school	240 (8.4)	220 (91.7)	13 (7.1)	7 (1.2)	
High school graduate	566 (21.6)	461 (86.0)	80 (11.2)	25 (2.8)	
Some college	962 (40.6)	662 (71.0)	186 (18.3)	114 (10.8)	
College or higher	1426 (29.4)	754 (54.1)	389 (26.1)	283 (19.8)	
Marital status					<0.001
Single	578 (31.2)	420 (80.0)	94 (13.5)	64 (6.4)	
Divorced/widowed/separated	991 (16.2)	653 (68.8)	199 (20.4)	139 (10.7)	
Married	1625 (52.6)	1024 (66.4)	375 (20.1)	226 (13.5)	
Family income					
Less than $20,000	518 (15.8)	422 (85.7)	60 (10.6)	36 (3.7)	<0.001
$20,000 to < $35,000	391 (10.7)	273 (74.7)	71 (17.5)	47 (7.8)	
$35,000 to < $50,000	379 (12.2)	265 (78.8)	69 (11.9)	45 (9.3)	
$50,000 to < $75,000	542 (16.8)	364 (73.5)	113 (15.7)	65 (10.9)	
$75,000 or more	1054 (36.3)	560 (59.9)	296 (24.8)	198 (15.2)	
Unknown	310 (8.2)	213 (70.5)	59 (17.8)	38 (11.7)	
Employment					
Employed	1605 (57.7)	985 (68.6)	356 (18.4)	264 (13.0)	0.004
Not employed	1589 (42.3)	1112 (74.4)	312 (17.7)	165 (8.0)	
Census region					0.280
Northeast	480 (17.9)	297 (67.2)	111 (19.9)	72 (12.9)	
Midwest	577 (21.2)	385 (73.8)	126 (18.0)	66 (8.2)	
South	1372 (37.3)	900 (69.2)	284 (19.0)	188 (11.8)	
West	765 (23.6)	515 (74.4)	147 (15.3)	103 (10.3)	
Health insurance					<0.001
Yes	3027 (91.4)	1962 (69.4)	652 (19.1)	413 (11.4)	
No	167 (8.6)	135 (88.0)	16 (7.3)	16 (4.8)	
General health					<0.001
Excellent	386 (15.1)	217 (65.4)	84 (18.9)	85 (15.8)	
Very good	1184 (35.3)	704 (65.2)	300 (21.7)	180 (13.0)	
Good	1115 (34.8)	796 (75.6)	200 (15.6)	119 (8.8)	
Fair	419 (12.1)	317 (82.4)	66 (12.1)	36 (5.5)	
Poor	90 (2.7)	63 (68.7)	18 (25.2)	9 (6.1)	
Diagnosed with cancer					0.026
Yes	539 (9.2)	341 (64.5)	108 (18.8)	90 (16.8)	
No	2655 (90.8)	1756 (71.7)	560 (18.0)	339 (10.3)	
Family history of any cancer					0.016
Yes	2303 (70.8)	1432 (68.4)	521 (19.6)	350 (12.0)	
No	643 (21.3)	470 (76.7)	108 (14.2)	65 (9.2)	
Not sure	248 (7.9)	195 (79.4)	39 (15.0)	14 (5.6)	

95% CI, 1.67–2.88, $P < 0.001$), having education higher than high school (some college: OR, 4.40, 95% CI, 1.63–11.87, $P = 0.004$; college or higher: OR, 8.88, 95% CI, 3.42–2308, $P < 0.001$), and not single (married: OR, 1.54, 95% CI, 1.03–2.30, $P = 0.036$; other: OR, 1.61, 95% CI, 1.05–2.46, $P = 0.029$). The respondents' characteristics associated with lower odds of having knowledge of palliative care were Hispanics (OR, 0.53; 95% CI, 0.30–0.95, $P = 0.033$), or races other than non-

Table 2
Predictors of Knowledge of Palliative Care Using Logistic Regression, Full Model and Reduced Model

	Full Model		Reduced Model	
Characteristics	OR (95% CI)	*P*-value	OR (95% CI)	*P*-value
Age group				
18–49	1.00		1.00	
50–64	1.56 (1.11–2.19)	0.012	1.58 (1.15–2.19)	0.006
65+	1.97 (1.36–2.85)	0.001	1.70 (1.30–2.22)	<0.001
Gender				
Male	1.00		1.00	
Female	2.23 (1.71–2.92)	<0.001	2.19 (1.67–2.88)	<0.001
Race/ethnicity				
Non-Hispanic white	1.00		1.00	
Non-Hispanic black	0.88 (0.53–1.47)	0.621	0.89 (0.53–1.51)	0.666
Hispanic	0.54 (0.30–0.96)	0.036	0.53 (0.30–0.95)	0.033
Other	0.66 (0.46–0.95)	0.028	0.64 (0.45–0.89)	0.010
Education				
Less than high school	1.00		1.00	
High school graduate	1.42 (0.48–4.18)	0.518	1.69 (0.59–4.81)	0.319
Some college	3.63 (1.28–10.32)	0.017	4.40 (1.63–11.87)	0.004
College or higher	6.31 (2.31–17.21)	0.001	8.88 (3.42–23.08)	<0.001
Marital status				
Single	1.00		1.00	
Divorced/widowed/separated	1.47 (1.00–2.17)	0.053	1.54 (1.03–2.30)	0.036
Married	1.32 (0.88–1.99)	0.174	1.61 (1.05–2.46)	0.029
Family income				
Less than $20,000	1.00			
$20,000 to <$35,000	1.52 (0.79–2.91)	0.207		
$35,000 to <$50,000	1.13 (0.66–1.93)	0.643		
$50,000 to <$75,000	1.32 (0.76–2.30)	0.320		
$75,000 or more	1.99 (1.11–3.58)	0.022		
Unknown	1.55 (0.84–2.87)	0.157		
Employment				
Not employed	1.00			
Employed	1.29 (0.94–1.76)	0.115		
Census region				
Northeast	1.00			
Midwest	0.82 (0.56–1.21)	0.311		
South	1.03 (0.71–1.51)	0.864		
West	0.85 (0.55–1.33)	0.469		
Health insurance				
Yes	1.00			
No	1.58 (0.81–3.10)	0.178		
General health				
Excellent	1.00		1.00	
Very good	0.94 (0.68–1.30)	0.701	0.94 (0.67–1.32)	0.710
Good	0.79 (0.53–1.18)	0.239	0.75 (0.50–1.12)	0.160
Fair	0.57 (0.34–0.94)	0.030	0.50 (0.31–0.82)	0.006
Poor	1.84 (0.51–6.56)	0.342	1.50 (0.44–5.16)	0.509
Diagnosed with cancer				
No	1.00			
Yes	1.15 (0.85–1.55)	0.367		
Family history of any cancer				
No	1.00		1.00	
Yes	1.35 (1.00–1.08)	0.053	1.36 (0.99–1.86)	0.056
Not sure	1.43 (0.78–2.63)	0.245	1.38 (0.77–2.48)	0.277

Hispanic black or white (OR, 0.64; 95% CI, 0.45–0.89, $P = 0.010$). Neither personal nor family history of cancer was associated with having knowledge of palliative care.

Knowledge of Palliative Care

Among respondents who had inadequate or adequate knowledge, we observed significant differences in their understanding of the goal of palliative care (Table 3) and their misconceptions about palliative care (Table 4), but no difference was observed in the information source where these respondents planned to seek knowledge of palliative care (Table 5). When comparing the knowledge about the goals of palliative care among respondents who had inadequate knowledge, higher proportions of respondents who had adequate knowledge of palliative care strongly agreed that palliative care helps friends and family to cope with a patient's illness (60.1% vs. 45.8%, $P = 0.005$), offers social and emotional support

Table 3
Survey Respondents' Knowledge of Goal of Palliative Care

	Total		Inadequate Knowledge		Adequate Knowledge		
Goal of Palliative Care	*N*	Col.%	*n*	Col.%	*n*	Col.%	*P*-value
Help friends and family to cope with a patients illness							0.005
Strongly agree	568	51.2	297	45.8	271	60.1	
Somewhat agree	381	35.6	265	38.7	116	30.4	
Somewhat disagree	35	3.6	21	3.4	14	3.9	
Strongly disagree	30	2.1	15	2.0	15	2.3	
Unknown	83	7.5	70	10.1	13	3.3	
Offer social and emotional support							<0.001
Strongly agree	645	57.9	334	49.0	311	72.6	
Somewhat agree	329	31.8	233	37.4	96	22.5	
Somewhat disagree	24	1.9	19	2.5	5	0.8	
Strongly disagree	14	0.8	10	0.9	4	0.6	
Unknown	85	7.7	72	10.2	13	3.4	
Manage pain and other physical symptoms							0.001
Strongly agree	805	72.8	442	67.9	363	80.8	
Somewhat agree	199	19.3	146	20.9	53	16.7	
Somewhat disagree	21	1.3	18	1.9	3	0.2	
Strongly disagree	5	0.3	4	0.4	1	0.2	
Unknown	67	6.3	58	8.8	9	2.1	
Give patients more time at the end of life							<0.001
Strongly agree	336	28.9	192	26.8	144	32.5	
Somewhat agree	269	26.2	183	29.7	86	20.2	
Somewhat disagree	199	20.3	117	18.8	82	22.8	
Strongly disagree	155	10.9	70	7.3	85	16.9	
Unknown	138	13.7	106	17.4	32	7.5	

(72.6% vs. 49.0%, $P < 0.001$), manages pain and other physical symptoms (80.8% vs. 67.9%, $P = 0.001$), and strongly disagreed that palliative care gives patients more time at the end of life (16.9% vs. 7.3%, $P < 0.001$) (Table 3).

Respondents who had adequate knowledge of palliative care were also more likely to strongly disagree on the common misconceptions of palliative care than those who had inadequate knowledge, such as "accepting palliative care means giving up" (67.0% vs. 46.6%, $P < 0.001$), "It is doctors obligation to inform all patients with cancer about the option of palliative care" (8.7% vs. 2.2%, $P = 0.002$), "accepting palliative care means stop other treatments" (52.6% vs. 40.5%, $P < 0.001$), "palliative care is the same as hospice care" (39.4% vs. 18.0%, $P < 0.001$), and "thinking of palliative care makes me automatically think of death" (40.1% vs. 22.3%, $P < 0.001$) (Table 4).

Both respondents having inadequate and adequate knowledge considered the health care provider as the primary source to seek knowledge of palliative care (inadequate knowledge: 52.1% vs. adequate knowledge: 59.1%), and the online sources, including Internet and social media, were the second popular choices (32.9% vs. 26.5%) (Table 5). Around 7% of respondents did not know any sources to learn more about palliative care. All these respondents considered the health care provider as the most trusted source to seek knowledge of palliative care (78.0% vs. 81.8%) (Table 5).

Discussion

Our study using the NCI HINTS 2018 data indicates that the proportion of adults who have knowledge of palliative care is low in the U.S. More than 70% of respondents had no knowledge of palliative care, and only 10% of respondents had self-reported adequate knowledge of palliative care and were confident to explain the palliative care to the others. However, not all these respondents with self-reported adequate knowledge of palliative care could answer correctly on the questions asking for the goals of palliative care, and around half of these respondents still had a misconception about palliative care. In this study, we examined many factors associated with having knowledge of palliative care, and we found a significant gender and racial variation in having knowledge of palliative care. Having a college or higher education is also one of the most significant predictors associated with having knowledge of palliative care. In addition, health care providers are the first and major information source for respondents to seek knowledge of palliative care, and the Internet and social media sites are also popular sources.

The high prevalence of respondents who had no knowledge of palliative care suggested that the general public was largely unaware of this beneficial approach to treating pain and symptoms from chronic and life-limiting illnesses. About one-third of respondents across all age groups had no knowledge of palliative

Table 4
Survey Respondents' Misconceptions of Palliative care

Misconceptions of Palliative Care	Total		Inadequate Knowledge		Adequate Knowledge		*P*-value
	n	Col.%	*n*	Col.%	*n*	Col.%	
Accepting palliative care means giving up							<0.001
Strongly agree	25	2.4	12	1.9	13	3.1	
Somewhat agree	132	11.7	88	12.5	44	10.2	
Somewhat disagree	232	25.4	171	30.3	61	17.3	
Strongly disagree	638	54.3	338	46.6	300	67.0	
Unknown	70	6.3	59	8.7	11	2.4	
It is a doctor's obligation to inform all patients with cancer about the option of palliative care							0.002
Strongly agree	618	52.9	360	51.5	258	55.1	
Somewhat agree	283	28.4	189	30.5	94	25	
Somewhat disagree	51	4.4	27	3.7	24	5.7	
Strongly disagree	47	4.6	16	2.2	31	8.7	
Unknown	98	9.6	76	12.1	22	5.5	
If you accept palliative care, you must stop other treatments							<0.001
Strongly agree	50	3.4	25	2.9	25	4.2	
Somewhat agree	98	9.9	62	9.7	36	10.1	
Somewhat disagree	252	24.0	144	22.9	108	25.8	
Strongly disagree	513	45.1	281	40.5	232	52.6	
Unknown	184	17.7	156	24.0	28	7.2	
Palliative care is the same as hospice care							<0.001
Strongly agree	89	5.5	41	4.7	48	6.8	
Somewhat agree	257	25.4	156	24.1	101	27.5	
Somewhat disagree	251	26.1	163	28.1	88	22.8	
Strongly disagree	312	26.0	139	18.0	173	39.4	
Unknown	188	16.9	169	25.0	19	3.4	
When I think of palliative care, I automatically think of death							<0.001
Strongly agree	99	7.7	51	6.6	48	9.5	
Somewhat agree	337	33.8	221	35.0	116	31.7	
Somewhat disagree	261	23.6	175	27.7	86	16.6	
Strongly disagree	328	29.0	158	22.3	170	40.1	
Unknown	72	6.0	63	8.3	9	2.1	

care, and this rate increased to 80% in never married adults, 85% in low-income group, 91.7% in adults with less than high school education. Commissioned by the Center to Advance Palliative Care, the 2011 Public Opinion Research on Palliative Care showed that 70% of Americans did not have any knowledge of palliative care.[19] Almost seven years past, this rate of no knowledge of palliative care remained unchanged. Low awareness of palliative care in the general public may contribute to the low usage of palliative care in clinical practice. Reville et al. noted that the use of palliative care was only 8% of all lung cancer patients in a university hospital.[11] Kumar et al. also reported an 8.6% use of palliative care in three outpatient medical oncology clinics.[12] Increasing the publicity of palliative care may facilitate effective delivery of palliative

Table 5
Survey Respondents' Information Source of Seeking Knowledge of Palliative Care

Information Source	Total		Inadequate Knowledge		Adequate Knowledge		*P*-value
	n	Col.%	*n*	Col.%	*n*	Col.%	
The first source							0.404
Printed materials	13	0.9	6	0.6	7	1.5	
Health care provider	635	54.7	359	52.1	276	59.1	
Conversations with people you trust	76	6.5	54	6.7	22	6.0	
Online (Internet and social media)	295	30.5	202	32.9	93	26.5	
Unknown	78	7.4	47	7.7	31	6.9	
The most trusted source							0.231
Printed materials	13	1	5	0.6	8	1.8	
Health care provider	876	79.5	527	78.0	349	81.8	
Conversations with people you trust	75	6.5	45	5.9	30	7.3	
Online (Internet and social media)	81	8.5	58	10.1	23	5.9	
Unknown	52	4.5	33	5.4	19	3.2	

care and improve patient and family caregivers' engagement in this relatively new approach to care.

Health care providers are now the major information source for people seeking knowledge of palliative care as shown in our study; hence, developing a multichannel promotion strategy, such as involving the integration of social media platforms, may expedite the penetration of palliative care knowledge. As shown in a recent study, the number of palliative care–related Twitter posts has increased by 62.3% over a two-year period and majority of discussion about palliative care in these Twitter posts was positive.[20] The fastest-growing social media platforms, such as Facebook and Twitter, will bring many opportunities for palliative care.[21–23] To reduce the knowledge gap in palliative care, some experiences can be learned from the other disciplines in which there are enormous confusion and misinformation abounds, such as HIV and influenza vaccinations. Many effective interventions have been developed to promote the awareness in these disciplines, such as structured home visits and counseling, community discussion and involvement, patient-involved teaching sessions, and street outreach programs.[24–27] Some of these educational interventions may be adapted to meet the needs of palliative care.

In general, most respondents with self-reported knowledge of palliative care were able to recognize the some but not all the palliative care goals. As shown in our study, 80% survey respondents either strongly agreed or somewhat agreed that palliative care will help friends and family to cope with a patient's illness, offer social and emotional support, and manage pain and other physical symptoms. These major goals have been well perceived by the general public who has ever learned about palliative care. Surprisingly, more than 50% respondents in the survey believed that palliative care can give patients more time at the end of life. Although the goal of palliative care is not to extend the life expectancy of patients diagnosed with the advanced disease but to improve the quality of life, many clinical studies reported significant survival benefits of palliative care among patients diagnosed with terminal illness.[28–30] These findings from these research studies may have influenced the public perception of palliative care. However, reasonable expectation of receiving palliative care should still be better quality of life other than extended survival time.[31]

The examination of respondents' depth and breadth of palliative care knowledge revealed the pressing need for national efforts to propagate correct knowledge about palliative care. Previous research studies have reported that many misconceptions about palliative care existed in patients diagnosed with terminal illness and their family caregivers, including (but not limited to) considering palliative care as the end-of-life care,[32,33] association with inferior survival,[34] and limiting access to treatment.[35] Our findings highlighted the presence of misconception among respondents who have self-reported knowledge of palliative care. Even for those who felt confident in their knowledge of palliative care, around 15% respondents agreed that palliative care means giving up or stop other treatments, 30% respondents agreed that palliative care is the same as hospice care, and 40% respondents linked palliative care with automatically thinking of death. Our finding implies that the respondents who have self-reported adequate knowledge were overconfident on their knowledge of palliative care.

Our study has limitations. First, the information on the cancer stage for respondents who had a personal or family history of cancer was not collected in the HINTS data set. Although palliative care offers benefits in improving the quality of life for cancer patients at all stages of cancer, the most critical use of palliative care is for patients with advanced cancer and their caregivers. Thus, the knowledge of palliative care should be better in this subgroup compared with those who had no advanced cancer. Moreover, we do not have longitudinal data to measure whether knowledge of palliative care in the U.S. population has improved or not over the past decade. This is the first time HINTS included questions asking for respondents' knowledge of palliative care; therefore, future studies using HINTS released in the coming years will be needed to measure the temporal pattern of knowledge of palliative care.

By using a national representative study sample, this analysis provides insights on the prevalence of individuals who had knowledge of palliative care and the depth of their knowledge. Two-thirds of respondents in the national survey had no knowledge of palliative care, and many respondents who were confident in their knowledge of palliative care could not answer the basic questions of palliative care correctly. The recent nationwide growth of the palliative care facilities will contribute to the dissemination of palliative care knowledge in the public; however, a time lag should be expected. To meet the increasing demand of palliative care and facilitate knowledge dissemination, a further expansion of palliative care facilities should be encouraged. In addition, more research is needed to develop and broaden information sources for the public to search for knowledge of palliative care, not limited to their health care providers but also more easily accessible through online platforms.

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Appendix

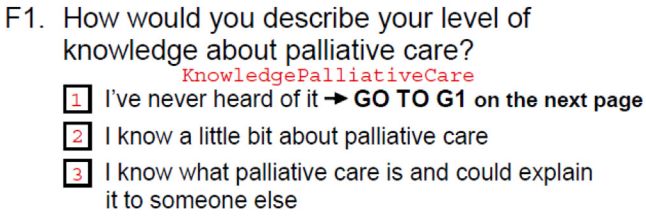
Supplemental Table 1
Study Sample Selection Criteria

Step	Selection Criteria	Included	Excluded
0	Total sample size	3504	
1	If answer on knowledge about palliative care is missing	3445	59
2	Excluded if age is missing	3362	83
3	Excluded if sex is missing	3322	40
4	Excluded if race is missing	3322	0
5	Excluded if education is missing	3306	16
6	Excluded if marital status is missing	3306	0
7	Excluded if employment is missing	3303	3
8	Excluded if region is missing	3303	0
9	Excluded if health insurance is missing	3252	51
10	Excluded if general health status is missing	3227	25
11	Excluded if answer on "ever had cancer" is missing	3226	1
12	Excluded if answer on "family ever had cancer" is missing	3194	32
13	Final data set (weighted sample size)	3194 (229,591,005)	

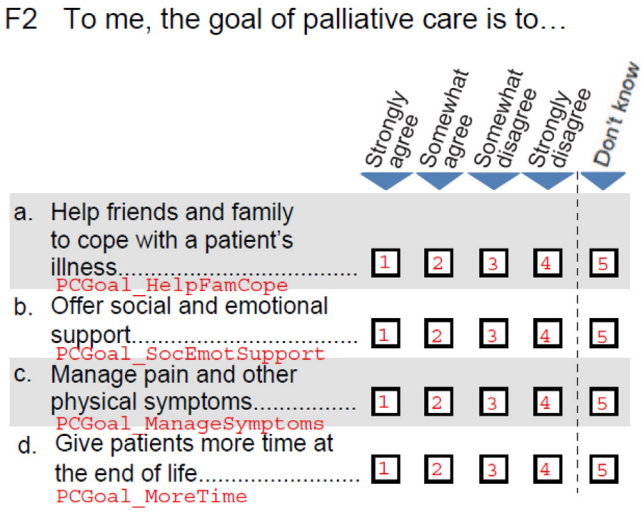
Supplemental Table 2

Screenshot of Original Palliative Care Questions From the HINTS 5 Cycle 2 Survey

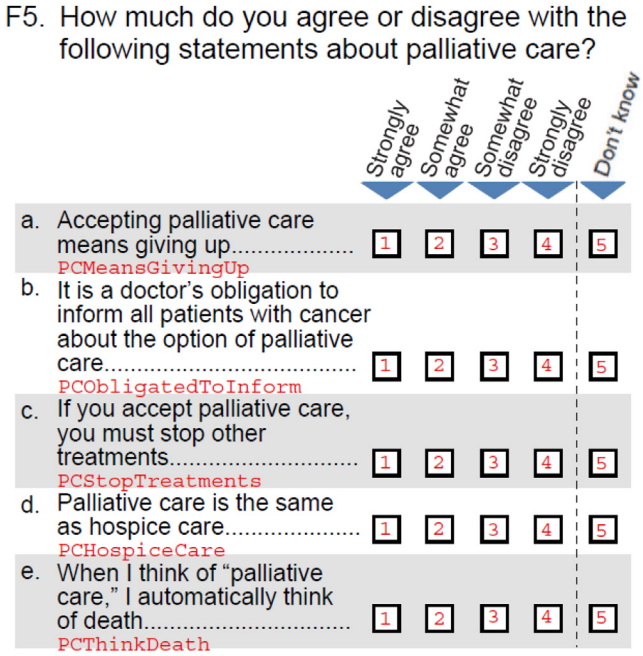
Knowledge of palliative care.



Goal of palliative care.



Misconceptions of palliative care.



Information source of palliative care knowledge.

F3. Imagine you had a strong need to get information about palliative care. Where would you go first to get information?

PCStrongNeedInfo

Mark only one.

- [1] Printed materials (for example, newspapers, magazines)
- [2] Health care provider (doctor, nurse, social worker)
- [3] Conversations with people you trust (friends, relatives, or co-workers)
- [4] Internet (Google or another search engine, WebMD or another medical website)
- [5] Social Media (Facebook, Instagram, Twitter)

PCStrongNeedInfo_IMP

F4. Imagine you had a strong need to get information about palliative care. Which of the following would you most trust as a source of information about palliative care?

PCTrustInfo

Mark only one.

- [1] Printed materials (for example, newspapers, magazines)
- [2] Health care provider (doctor, nurse, social worker)
- [3] Conversations with people you trust (friends, relatives, or co-workers)
- [4] Internet (Google or another search engine, WebMD or another medical website)
- [5] Social Media (Facebook, Instagram, Twitter)

PCTrustInfo_IMP