

## Original Article

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# Palliative care knowledge, information sources, and beliefs: Results of a national survey of adults in the USA

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**Objective.** Despite its established benefits, palliative care (PC) is not well known among patients and family/caregivers. From a nationally representative survey, we sought to assess the following associated with PC: knowledge, knowledge sources, and beliefs.

**Methods.** Data were drawn from the Health Information National Trends Study (HINTS 5 Cycle 2), a cross-sectional, survey of non-institutionalized adults aged 18+ years in the USA. Data were weighted and assessed by proportional comparison and multivariable logistic regression.

**Results.** A total of 3504 respondents were identified, and approximately 29% knew about PC. In the adjusted model, less PC knowledge was associated with: lower age (those aged <50), male gender, lower education (<high school graduation or high school graduate), and non-internet users. A little over half (55%) of respondents accessed healthcare providers first for PC information, and 80% considered providers the most trusted source of PC information. Most of the participants strongly/somewhat agreed that the goal of PC is to help friends and family cope with a patient's illness (90.6%), offer social and emotional support (93.4%), and manage pain and other physical symptoms (95.1%). Similarly, a majority (83.3%) strongly/somewhat agreed that it is a doctor's obligation to inform all patients with cancer about the option of PC.

**Significance of results.** PC knowledge was generally low (1-in-3 respondents knew of PC), with significant differences according to age, gender, education, and internet use. These data provide a baseline from which PC education policies and interventions may be measured.

**Introduction**

Approximately 90 million Americans currently live with chronic, life-threatening illnesses, and this number is expected to double in the next 25 years (Center to Advance Palliative Care, [nd](#)). People with chronic and debilitating illnesses and those nearing the end of their lives have different and often more complex needs than younger and healthier people. This creates a need for longer-term comprehensive care in addition to shorter-term curative treatments. Palliative care (PC) is intended to complement curative treatment and can be offered early in the course of a serious illness (Center to Advance Palliative Care, [nd](#)). This contrasts with hospice care, a sub-type of PC that is reserved for the last 6 months of an individual's life when only comfort care is indicated in the USA. The goal of PC is to improve the quality of life for both the patient and the caregiver. When a patient experiences chronic and life-threatening illness, PC helps by preventing and relieving suffering through early identification and treatment of pain (physical, psychosocial, and spiritual) (World Health Organization, [nd](#)). It also offers a support system to help the family/caregivers cope during the patient's illness (World Health Organization, [nd](#)). Integrating PC into the continuum of care increases patient and family satisfaction, improves the quality of care, can extend survival, and may lower costs (Morrison et al., [2008](#); Temel et al., [2011](#); Zimmermann et al., [2014](#); Bakitas et al., [2015](#); El-Jawahri et al., [2017](#)). Despite these benefits, the proportion of patients with PC-eligible conditions who receive such care is unknown.

However, reports indicate that approximately six million Americans could benefit from PC (Center to Advance Palliative Care, [nd](#)). Even though the number of US hospitals offering PC services has increased over the past decade (Bruera and Hui, [2012](#)), studies show that many patients who would benefit from PC either receive it too late in their illness for significant benefit

or not at all (Kozlov et al., 2015; Gidwani et al., 2016). One means to increase PC utilization is to have eligible patients and/or caregivers advocate for such service on their own behalf (complementary to clinician-based interventions designed to increase compliance with care and prescribing guidelines). Other means to increase PC utilization include increasing a referral to PC services by providers, enhancing the PC workforce, investing in the field's science base, and increasing the availability of PC services in US hospitals and nursing homes (Meier, 2011; Ferrell et al., 2017).

To develop interventions that promote PC utilization among the general public, we must have a better understanding of access barriers. One likely barrier is low public knowledge and awareness of PC. Research in other contexts has shown that patient knowledge of health services drives service utilization, and that patients accept or seek services which they know are relevant to their conditions (Grossman and Kaestner, 1997). While studies regarding patients' knowledge of PC are sparse, one community study in the USA found knowledge to be generally low (mean score of 5.25 of a possible 13 using the Palliative Care Knowledge Scale) (Kozlov et al., 2018). In addition, most people incorrectly equate PC to hospice, itself associated with end of life; so, they may be unwilling to accept a referral for PC (Schreibis-Baum et al., 2016; Slomka et al., 2016). If patients and family members understand the true aim and benefits of PC, they may be more likely to ask providers for a referral and may subsequently be more willing to participate in a program. Increased knowledge of PC among patients and family members may remove misconceptions and improve patient willingness to utilize this valuable and evidence-based service.

Prior research regarding the knowledge of PC has been primarily conducted among healthcare providers, individuals in a community context, or populations outside the USA (Morita et al., 2006; Kassa et al., 2014; Wilson et al., 2016; Dimoula et al., 2018; Kozlov et al., 2018). Clearly, more research is needed to clarify the depth of individual knowledge about PC, especially among those actively seeking care. Therefore, the aims of this study were to use a nationally representative survey to (1) quantify PC knowledge and examine factors that are associated with PC knowledge, (2) identify sources of PC information among those knowledgeable about PC, and (3) assess beliefs about PC among those who have knowledge about PC.

## Methods

### Data source and sample

The Health Information National Trends Study (HINTS) is a nationally representative survey mailed to civilian non-institutionalized adults aged 18 years and older. It has been conducted yearly by the National Cancer Institute (NCI) since 2003. A two-stage sampling strategy was used: households using addresses were selected using a random sample, and within each household, one adult was selected. HINTS 5 (Cycle 2) was conducted from January 26 to May 2, 2018, and the overall weighted response rate was approximately 33%. Extensive details on the study design, methods, and sampling plan of the HINTS can be found at <https://hints.cancer.gov/> and elsewhere (Finney Rutten et al., 2012).

### Measures

PC knowledge was assessed with the HINTS question "How would you describe your level of knowledge about palliative care?"

Responses included: (i) I know a little bit about PC, (ii) I know what PC is and could explain it to someone else, and (iii) I've never heard of it. For the logistic regression analysis, both responses (i) and (ii) were combined as having any knowledge about PC.

To assess sources of health information about PC, the following item was used "Imagine you had a strong need to get information about PC. Where would you go first to get information?" Responses to this item were grouped into four categories: (i) printed materials (newspapers and magazines), (ii) healthcare provider (doctor, nurse, and social worker), (iii) interpersonal sources [conversations with people you trust] (friends, relatives, or coworkers), and (iv) internet/social media (Google or another search engine, WebMD or another medical website, Facebook, or Instagram).

To assess trust in sources of PC health information, respondents were asked this question in HINTS: "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?" Responses were grouped into the same four categories as above: (i) printed materials, (ii) healthcare provider, (iii) interpersonal sources, and (iv) internet/social media.

Beliefs about PCs were assessed with two set of questions that were asked in the HINTS. The first question was assessed with these statements: (a) PC goal is to help friends and family to cope with a patient's illness, (b) PC goal is to offer social and emotional support, (c) PC goal is to manage pain and other physical symptoms, and (d) PC goal is to give patients more time at the end of life. Responses to each question were coded as (a) strongly agree or somewhat agree, (b) strongly disagree or somewhat disagree, and (c) don't know.

The second question was assessed with these statements: (i) accepting PC means giving up, (ii) it is a doctor's obligation to inform all patients with cancer about the option of PC, (iii) if you accept PC, you must stop other treatments, (iv) PC is the same as hospice care, and (v) when I think of PC, I automatically think of death. Responses to each question were coded as (a) strongly agree or somewhat agree, (b) strongly disagree or somewhat disagree, and (c) don't know.

Sociodemographic characteristics and other covariates with their categorizations included in the study were: age, gender, race/ethnicity, marital status, education, household income, employment status, health insurance, regular provider, general health, number of healthcare visits within past year, internet use, history of cancer, family history of cancer, and census region (Table 1). A HINTS original coding scheme was retained or recoded when necessary for analytical purposes.

### Statistical analysis

Analyses were performed using SAS (Version 9.4) procedures which incorporate survey sampling weights to account for the complex sampling design used in the HINTS and to provide representative estimates of the US population (SAS Institute Inc., Cary, NC). Jackknife weights, provided by HINTS, were used for calculating standard errors. Weighted, unadjusted prevalence estimates (%) and 95% confidence intervals were used to assess PC knowledge, sources of PC information, trusted sources of PC information, and beliefs about PC. A weighted, multivariable logistic regression model examined the factors (age, gender, race/ethnicity, marital status, education, household income, health insurance, regular provider, general health, internet use, and history of cancer) that were associated with PC knowledge. Statistical

**Table 1.** Characteristics of survey respondents, HINTS 5 Cycle 2 (N = 3,504)

	N	Weighted %	95% CI
<b>Level of knowledge about palliative care</b>			
I know a little bit about palliative care	712	18.0	15.9–19.9
I know what palliative care is and could explain it to someone else	450	10.8	9.4–12.2
I've never heard of it	2,283	71.2	69.0–73.5
<b>Age</b>			
65+	1,240	19.4	19.1–19.7
50–64	1,113	30.4	28.4–32.4
35–49	658	26.7	24.3–29.0
18–34	406	23.6	20.8–26.3
<b>Gender</b>			
Female	2,054	51.2	50.9–51.5
Male	1,394	48.8	48.5–49.1
<b>Race</b>			
Non-Hispanic White	1,983	59.7	58.7–60.7
Non-Hispanic Black	444	9.9	9.5–10.5
Hispanic	461	14.7	14.2–15.3
Non-Hispanic Other	263	7.6	7.4–8.1
Missing	353	7.8	6.4–9.2
<b>Marital status</b>			
Married/living with a partner	1,747	52.4	51.1–53.8
Divorced/widowed/separated	1,103	17.2	15.9–18.6
Never been married	605	30.2	30.0–30.6
<b>Education</b>			
College graduate	1,508	28.8	28.5–29.0
Some college	1,039	39.9	38.2–41.6
High school graduate	631	22.3	20.7–23.9
Less than high school	275	9.0	7.4–10.6
<b>Employed</b>			
Yes	1,720	57.7	54.7–60.6
No	1,741	42.3	39.4–45.3
<b>Household income</b>			
\$100,000 or more	846	26.7	24.2–29.2
\$75,000 to \$99,999	405	12.7	10.6–14.7
\$50,000 to \$74,999	607	17.5	15.2–19.7
\$20,000 to \$49,999	907	25.4	22.8–28.0
\$0 to \$19,999	627	17.8	15.4–20.1
<b>Health insurance</b>			
Yes	3,256	91.5	91.4–91.5
No	183	8.5	8.5–8.6

(Continued)

**Table 1.** (Continued.)

	N	Weighted %	95% CI
<b>Regular provider</b>			
Yes	2,470	65.5	62.9–68.2
No	983	34.5	31.8–37.1
<b>General health</b>			
Excellent/very good	1,698	50.6	48.1–53.1
Good	1,216	34.5	32.4–36.6
Fair/poor	558	14.9	13.0–16.8
<b>Number of healthcare visits past 12 months</b>			
None	507	19.2	16.6–21.8
1–3 times	1,732	50.4	47.3–53.5
4+ times	1,229	30.4	27.8–33.0
<b>Use internet</b>			
Yes	2,745	82.8	80.6–85.0
No	758	17.2	15.0–19.4
<b>History of cancer</b>			
Yes	593	9.4	9.3–9.4
No	2,898	90.6	15.0–19.4
<b>Family history of cancer</b>			
Yes	2,463	69.7	55.4–84.0
No	697	21.8	16.7–26.9
Not sure	276	8.3	5.9–10.7
Missing	4	0.2	0.0–20.2
<b>Census region</b>			
Northeast	526	17.8	17.8–17.8
West	820	23.6	23.6–23.6
Midwest	638	20.1	21.0–21.0
South	1,520	37.7	37.6–37.7

HINTS, Health Information National Trends Study.  
Totals may not add to sample size because of missing data.

significance was set at  $p < 0.05$ , and all tests were two-tailed. The analysis was performed in December 2018.

### Results

A total of 3,504 respondents were included in this study. The majority were non-Hispanic whites (59.7%), married or living with a partner (52.4%), had health insurance (91.5%), had a regular provider (65.5%), and used the internet (82.8%). Approximately 29% reported having knowledge about PC (18.0% knew a little about it and 10.8% knew enough to be able to explain it to others; Table 1).

There were differences in the characteristics of respondents based on whether or not they had heard about PC (Table 2). Results from the adjusted logistic regression showed that respondents who were less likely to have any knowledge about PC were mostly those 18–34 years old (aOR = 0.38; 95% CI = 0.25, 0.56) or

**Table 2.** Unadjusted and adjusted odds ratios of having any knowledge about PC, HINTS 5 Cycle 2

	Odds ratio (95% CI)	
	Crude	Adjusted
<b>Age</b>		
65+	Reference	Reference
50–64	0.96 (0.74, 1.23)	0.80 (0.56, 1.11)
35–49	0.81 (0.64, 1.04)	0.57 (0.41, 0.79)
18–34	0.48 (0.33, 0.70)	0.38 (0.25, 0.56)
<b>Gender</b>		
Female	Reference	Reference
Male	0.48 (0.38, 0.59)	0.45 (0.34, 0.59)
<b>Race</b>		
Non-Hispanic White	Reference	Reference
Non-Hispanic Black	0.64 (0.41, 1.00)	0.93 (0.55, 1.59)
Hispanic	0.37 (0.23, 0.59)	0.57 (0.32, 1.03)
Non-Hispanic Other	0.56 (0.40, 0.77)	0.63 (0.39, 1.02)
Missing	0.50 (0.34, 0.73)	0.84 (0.46, 1.51)
<b>Marital status</b>		
Married/living with a partner	Reference	Reference
Divorced/widowed/separated	0.86 (0.66, 1.12)	1.23 (0.90, 1.67)
Never been married	0.51 (0.36, 0.74)	0.94 (0.61, 1.45)
<b>Education</b>		
College graduate	Reference	Reference
Some college	0.48 (0.36, 0.63)	0.58 (0.42, 0.81)
High school graduate	0.19 (0.13, 0.29)	0.26 (0.17, 0.40)
Less than high school	0.11 (0.05, 0.25)	0.23 (0.08, 0.64)
<b>Household income</b>		
\$100,000 or more	Reference	Reference
\$75,000 to \$99,999	0.73 (0.47, 1.14)	1.02 (0.60, 1.75)
\$50,000 to \$74,999	0.50 (0.33, 0.76)	0.69 (0.45, 1.06)
\$20,000 to \$49,999	0.42 (0.32, 0.55)	0.72 (0.51, 1.02)
\$0 to \$19,999	0.23 (0.14, 0.36)	0.59 (0.33, 1.07)
<b>Health insurance</b>		
Yes	Reference	Reference
No	0.29 (0.15, 0.56)	0.68 (0.33, 1.38)
<b>Regular provider</b>		
Yes	Reference	Reference
No	0.42 (0.33, 0.56)	0.71 (0.52, 0.97)
<b>General health</b>		
Excellent/very good	Reference	Reference
Good	0.61 (0.47, 0.78)	0.79 (0.56, 1.12)
Fair/poor	0.47 (0.32, 0.69)	0.72 (0.45, 1.14)
<b>Use internet</b>		
Yes	Reference	Reference

(Continued)

**Table 2.** (Continued.)

	Odds ratio (95% CI)	
	Crude	Adjusted
No	0.22 (0.16, 0.32)	0.31 (0.20, 0.48)
<b>History of cancer</b>		
Yes	Reference	Reference
No	0.75 (0.57, 0.99)	0.93 (0.69, 1.26)

HINTS, Health Information National Trends Study.

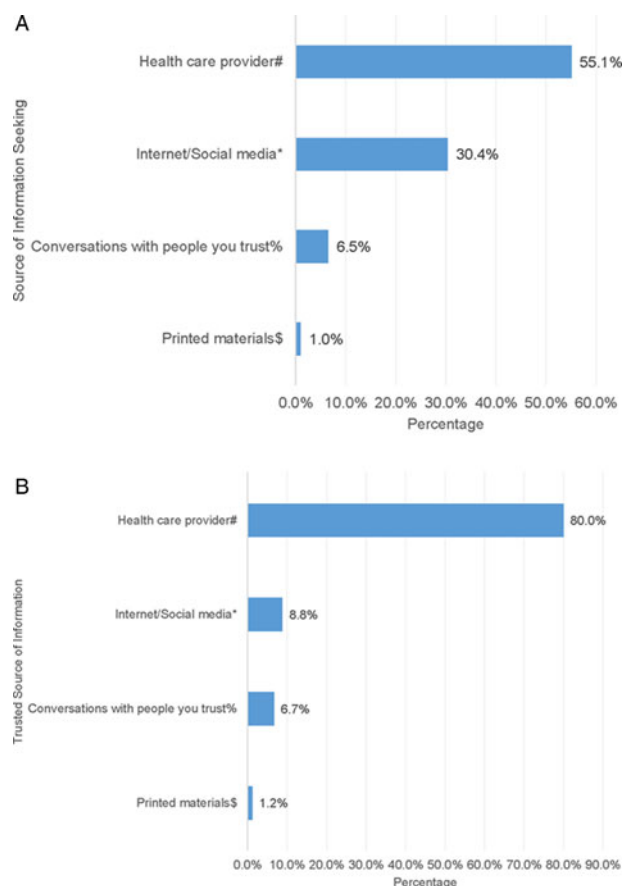
35–49 years old (aOR = 0.57; 0.41, 0.79) compared with those over 65 years old. Similarly, compared to females, males (aOR = 0.45; 0.34, 0.59) were less likely to have any knowledge about PC, as well as non-internet users (aOR = 0.31; 0.20, 0.48) compared with internet users. Additionally, respondents who held college degrees were more likely to have knowledge of PC than those with less than a high school diploma (aOR = 0.23; 0.08, 0.64), those who had only graduated from high school (aOR = 0.26; 0.17, 0.40), and those who had some college education (aOR = 0.58; 0.42, 0.81).

Among respondents who had any knowledge about PC (1,162), the majority reported going first to a healthcare provider (55.1%), followed by going to the internet/social media (30.4%), with printed materials being the least popular information source (Figure 1A). Respondents' rating of trust in healthcare providers as a source of PC information exceeded that of any other information channel. We found healthcare providers (80.0%) to be the most trusted source of PC information among those who had any knowledge about PC, followed by the internet (8.8%), and printed materials (1.2%) were again the least trusted (Figure 1B).

Table 3 presents beliefs about PC among respondents who had knowledge about PC. Most of these participants strongly/somewhat agreed that the goal of PC is to help friends and family to cope with a patient's illness (90.6%), offer social and emotional support (93.4%), manage pain and other physical symptoms (95.1%), and give patients more time at the end of life (59.2%). The majority strongly/somewhat agreed that it is a doctor's obligation to inform all patients with cancer about the option of PC (83.3%). But most strongly/somewhat disagreed that accepting PC meant giving up (81.2%) and that accepting PC meant one must stop other treatments (70.4%).

## Discussion

The findings of this study were fourfold. **First**, we found that PC knowledge in the USA was low, with only one in three individuals having any knowledge about PC. **Second**, there were socio-demographic differences between those who had heard about PC. We found that younger respondents, males, and those with lower levels of education had less knowledge about PC. **Third**, among respondents who had any knowledge about PC, most went to healthcare providers first for more information and they also endorsed healthcare providers as the most trusted source of information. **Finally**, most respondents agreed that it is a doctor's obligation to inform all patients with cancer about the option of PC. In order to expand the use of PC services, we need to better understand PC knowledge among the general population. It should be noted that PC reflects the USA model since



**Fig. 1.** (A) Sources of PC information, (B) Information sources trusted by PC knowledgeable respondents, HINTS 5 Cycle 2 (January 2018 to May 2018). # includes doctor, nurse, or social worker. \$ includes newspapers or magazines. % includes friends, relatives, or coworkers. \* includes Google or another search engine, WebMD or another medical website, Facebook, or Instagram. HINTS, Health Information National Trends Study.

PC definitions differ widely globally. In addition, it is possible that the US population may be different than the global population due to the differences in access to care and the availability of resources.

The low level of knowledge found in this study may be due to multiple reasons. First, it may be associated with hospitals not being equipped to provide PC to patients (and therefore less likely to discuss or promote PC). Although the number of US hospitals offering PC services has increased over the past decade, a previous study reported that nearly one-third of US hospitals with more than 50 beds do not provide any PC services (Dumanovsky et al., 2016). Another reason may be due to healthcare providers' low awareness/knowledge about PC. Studies have shown that providers' PC knowledge is low, possibly due to a lack of training (Osta et al., 2008; Kavalieratos et al., 2014; Haines et al., 2018). The low PC knowledge highlights the need to develop strategies to enhance awareness of the potential role that PC can play in caring for patients and their families among the general population and also healthcare providers. Increasing PC knowledge among healthcare providers would be expected to increase the frequency with which the topic is discussed. Improving patient's awareness of PC may help improve PC services utilization by increasing their request for that service. In addition, when physicians refer their patients for PC, they may be more likely to accept

if they have a better/correct understanding of what PC actually entails. For instance, because hospice is mistakenly and frequently equated with PC (we found that 32% of respondents agree that PC was the same as hospice care), patients and their families may be unwilling to accept a referral for PC early in the disease trajectory if curative treatments are still pursued (Maciasz et al., 2013). Prior research on PC knowledge and education has primarily focused on healthcare providers especially nurses, but this education should be expanded to include patients and their families.

This study found that males and those with lower education levels have the least knowledge about PC. Women, in general, seek more health information and usually have higher knowledge about health-related information than men (Mansfield et al., 2003; Rice, 2006). Furthermore, respondents who lack a high school diploma and those with only a high school degree are less likely to have knowledge about PC than those with at least some college education. These findings are consistent with previous literature on health-related information seeking (Nagler et al., 2010; Adjei Boakye et al., 2018). This may be due to low health literacy among this subgroup.

Among respondents who had any knowledge about PC, a little over half reported using healthcare providers first to seek information about PC, even though almost a third also used the internet. This finding is consistent with previous studies, which found that people usually seek health information from healthcare providers first before consulting other sources (Rains, 2007; Nguyen et al., 2017; Adjei Boakye et al., 2018). In addition, a little over three quarters of respondents expressed a high level of trust in PC information provided by healthcare providers, in contrast to all the other sources. Even though the internet has become a frequent resource for health-related information for patients, it seems people still prefer to hear about PC from their healthcare providers and place the greatest trust in information from providers. This is despite the fact that most of the respondents in our study indicated using the internet (83%) but chose to solicit PC information first from a healthcare provider. Other studies have found that patients traditionally trust their doctor or healthcare provider as a source of information compared to other communication channels (Hesse et al., 2005; Nguyen et al., 2017). As healthcare providers still represent a very viable source of information for patients on this topic, they should take every opportunity to discuss PC with patients and their families as appropriate. This complements the finding that 83% of respondents agree it is a doctor's obligation to inform all patients with cancer about the option of PC.

### Implications

The National Comprehensive Cancer Network (NCCN) asserts that PC should begin at the diagnosis of a serious illness and should be provided throughout life-prolonging treatment, including end-of-life care (National Comprehensive Cancer Network, 2017). Early integration of PC services has been shown to improve a wide range of patient-reported outcomes, including symptom burden, quality of life, depression, coping, and illness understanding (Temel et al., 2011; Zimmermann et al., 2014; Bakitas et al., 2015; El-Jawahri et al., 2017). In addition, PC programs help health systems to achieve lower costs of care (Morrison et al., 2008). Consumers need to understand a service both exists and may influence their care and personal health outcome before they will seek it out or accept it. Our study provides current estimates of PC awareness in a nationally representative sample (overall quite low) and the source of PC information most

**Table 3.** Beliefs about PC among respondents who had knowledge about PC, HINTS 5 Cycle 5 (N=1,162)

	N	Weighted %	95% CI
First question			
Palliative care goal is to help friends and family to cope with a patient's illness			
Strongly agree or somewhat agree	1,005	90.6	88.3–93.0
Strongly disagree or somewhat disagree	68	6.2	4.1–8.2
Don't know	49	3.2	1.9–4.5
Palliative care goal is to offer social and emotional support			
Strongly agree or somewhat agree	1,027	93.4	91.3–95.6
Strongly disagree or somewhat disagree	42	3.3	2.0–4.8
Don't know	46	3.2	1.8–4.5
PC goal is to manage pain and other physical symptoms			
Strongly agree or somewhat agree	1,057	95.1	93.6–96.7
Strongly disagree or somewhat disagree	30	1.8	1.0–2.6
Don't know	42	3.1	1.6–4.6
Palliative care goal is to give patients more time at the end of life			
Strongly agree or somewhat agree	645	59.2	54.0–64.4
Strongly disagree or somewhat disagree	368	32.2	28.1–36.4
Don't know	97	8.5	5.8–11.3
Second question			
Accepting palliative care means giving up			
Strongly agree or somewhat agree	169	15.1	12.2–18.0
Strongly disagree or somewhat disagree	912	81.2	78.0–84.5
Don't know	48	3.7	2.2–5.1
It is a doctor's obligation to inform all patients with cancer about the option of palliative care			
Strongly agree or somewhat agree	950	83.3	80.2–86.5
Strongly disagree or somewhat disagree	105	9.6	7.1–12.1
Don't know	81	7.1	4.9–9.3
If you accept palliative care, you must stop other treatments			
Strongly agree or somewhat agree	163	14.5	11.5–17.6
Strongly disagree or somewhat disagree	803	70.4	65.5–75.2
Don't know	167	15.1	11.0–19.2
Palliative care is the same as hospice care			
Strongly agree or somewhat agree	365	31.7	27.3–36.1
Strongly disagree or somewhat disagree	590	53.0	47.6–58.3
Don't know	175	15.3	11.3–19.4
When I think of palliative care, I automatically think of death			
Strongly agree or somewhat agree	463	42.5	38.0–47.1
Strongly disagree or somewhat disagree	619	53.7	49.3–58.0
Don't know	53	3.8	2.4–5.3

HINTS, Health Information National Trends Study.  
Totals may not add to sample size because of missing data.

frequently sought with the greatest trust (healthcare providers). With the aging population (Vespa *et al.*, 2018), it is imperative to increase knowledge about PC to improve utilization. There should be policies to educate healthcare providers about the

principles and benefits of PC, who should, in turn, initiate conversations with patients and families to educate them about PC. Due to the overwhelming responsibilities of healthcare providers, healthcare systems should incorporate PC in workforce planning

and staffing models. Because PC involves a multidisciplinary team, healthcare systems should create a dedicated PC team and, if not possible, should make sure providers are giving time to provide PC care when needed. Communication among the team will be critical, especially if PC team is not a dedicated team.

### Limitations and strengths

This study has limitations. First, PC knowledge and sources of information were self-reported, which could lead to self-report and recall bias. Second, variables such as receipt of PC and actual information sought were not assessed because they were unavailable in the HINTS. If measured, such variables could have influenced the magnitude and direction of the associations we found. Data were collected at one point in time, and different results may have been found if data were collected over different time periods. Third, the majority of the respondents did not have any knowledge about PC and, therefore, were not asked about the sources of information. Those respondents may have different sources of information. Despite these limitations, the main strength of the study is that it is one of the first of its kind to use a nationally representative population to access PC knowledge, sources of PC information, and beliefs about PC.

### Conclusion

Our study demonstrates that the majority of people in the USA are not knowledgeable about PC. Men and individuals with lower levels of education have less knowledge of PC than women and individuals with higher levels of education. We found that people use healthcare providers for sources of PC information, and they also trust information from healthcare providers the most. Future efforts to provide PC education and increase the number of conversations with patients and caregivers about PC are warranted.

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