Brief Report

Patterns of Palliative Care Beliefs Among Adults in the U.S.: Analysis of a National Cancer Database

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Abstract

Background. Palliative care (PC) is associated with increased quality of life for individuals with life-limiting illnesses. Despite growing recognition of the need for public advocacy and involvement, data on public perception of PC are limited. We sought to examine patterns of beliefs, sociodemographic differences, and the impact of information source on perceptions of PC.

Measures and Intervention. Data were analyzed from the 2018 Health Information National Trends Survey, a representative sample of public knowledge on cancer-related information. Prevalence of perceptions was estimated among adults who self-identified as knowledgeable about PC; multivariable logistic regression invoking stepwise variable selection was used to determine associations with perceptions.

Outcomes. Overall, 42.5% automatically thought of death when thinking about PC, and 31.7% equate PC with hospice care. Lower proportions perceived PC as incompatible with curative medical therapy: 15.1% believed PC means giving up, and 14.5% believed PC requires the discontinuation of other treatments. Perceptions varied by age, race, education attainment, income, and marital status. In adjusted models, source of PC information was not related to differences in PC perception: PC is giving up ($P \geq 0.28$), requirement to stop curative therapy ($P \geq 0.07$), and equation with hospice care ($P \geq 0.29$).

Conclusions. Six in every 10 American adults knowledgeable about PC have at least one documented misperception, with differential beliefs by sociodemographic groups. Source of information had little impact on PC beliefs. These findings may help focus future measures to educate the public about the role of PC in health care and address gaps in knowledge. J Pain Symptom Manage 2019;58:1056–1067. © *2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words
Palliative care, perceptions, beliefs, knowledge, epidemiology, information sharing

Introduction

As a growing field, palliative care (PC) has benefitted in the U.S. from public advocacy by organizations such as the Center to Advance Palliative Care, American Academy of Hospice and Palliative Medicine, and the National Hospice and Palliative Care Organization.[1–3] Although 65% of U.S. hospitals have palliative care programs as of 2015,[4] few Americans have heard of PC and among those knowledgeable about PC, there are limited data about their perceptions and beliefs.[5,6] International advocacy organizations have information about availability of palliative care, but limited data about global prevalence of programs.[7] From its origins, palliative care has had its roots in the advocacy of patients and families, so the issue of public understanding of PC has relevance as it continues to grow as a specialty.[8–10]

The Health Information National Trends Survey (HINTS) is a nationally representative survey designed to routinely collect data about the American public's knowledge of cancer-related information. Data from

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HINTS have been used to examine public knowledge and attitudes about tobacco and human papilloma virus.[11–13] In 2018, for the first time, there were questions about knowledge of palliative care, allowing us to assess public understanding of PC.

Patterns and predictors of public PC knowledge are not well understood. We hypothesized there are prevalent misbeliefs as to what constitutes PC. To better understand the current public perception, this study aims to 1) estimate the prevalence of common misperceptions regarding PC in the U.S., 2) identify sociodemographic disparities in PC knowledge, and 3) determine which information sources are associated with PC misbeliefs. We believe that understanding variations in perceptions will help to focus educational outreach concerning PC to the public.

Methods

We analyzed data from the 2018 administration of the National Cancer Institute's HINTS data set. Data were collected from January 26 to May 2, 2018 by mailing the questionnaire to a stratified probability sample of the noninstitutionalized adult, civilian population. The sampling design and methodology have been described previously.[14] There have been 12 iterations of HINTS; this study analyzes HINTS 5, Cycle 2, the most recent administration and the first version to include questions on palliative care knowledge and information sourcing. Respondents were asked about their knowledge of PC, and those who indicated they were knowledgeable about it were asked additional follow-up questions to assess their beliefs on the meaning of palliative care, as well as their primary sources of information on the topic. A total of 3504 adults were surveyed in the 2018 HINTS data, of which 1192 adults (study cohort) indicated they were knowledgeable about PC and answered at least one question about their perceptions of PC.

Variables Analyzed

The HINTS questionnaire consists of ≥400 variables or questions. It contains a set of core items asked in every administration, as well as questions on a feature topic unique to that survey administration. This study used the following variables for our analysis:

A) Demographic and Disease Characteristics. Demographic characteristics included sex, race, age, partnership status, employment status, education, income, and nation of birth. Comorbidity burden was also included because diagnosis with a chronic illness may affect exposure to PC. History of cancer, diabetes, hypertension, heart condition, lung disease, arthritis, and depression were examined. Noncancer conditions were combined into a single chronic comorbidity category for analysis.

B) Beliefs and Knowledge About PC. Respondents who indicated they were knowledgeable about PC were asked follow-up questions to indicate on a Likert-scale (i.e., strongly agree/somewhat agree/somewhat disagree/strongly disagree/don't know) their agreement to each of four beliefs on the meaning of PC: "How much do you agree or disagree with the following statements about palliative care: 1) Accepting palliative care means giving up, 2) If you accept palliative care, you must stop other treatments, 3) Palliative care is the same as hospice care, and 4) When I think of palliative care, I automatically think of death." Each belief was dichotomized to compare those who agreed with each belief statement (somewhat or strongly agree) and those who disagreed (somewhat or strongly disagree) or did not know. Respondents who were not knowledgeable about PC were not asked the follow-up questions about their beliefs and thus were excluded from this analysis.

C) Sources of Information About PC. Two questions were used to determine sources of information about PC: "Imagine you had a strong need to get information about palliative care. 1) Where would you go first to get information, and 2) Which of the following would you most trust as a source of information about palliative care?" For each question, respondents were able to choose printed materials (newspapers or magazines), health care provider (doctor, nurse, social worker), Internet (search engine or medical web site), or interpersonal sources (conversations with trusted people or social media).

Data and Statistical Analysis

Weighted frequencies and prevalence with 95% CI were calculated to describe the demographic composition of the cohort by agreement or disagreement with each PC belief. Bivariable and multivariable logistic regression models invoking stepwise variable selection were constructed to examine associations of demographic and clinical characteristics with each PC perception. Variable selection was used to remove collinearity owing to redundant predictors.[15] Crude and adjusted odds ratios (ORs) were generated. For each surveyed PC belief, three models were created to examine associations. Model 1 analyzed associations of the belief with demographic and clinical characteristics (i.e., age, gender, race, occupation status, marital status, previous education, income, location of birth, and cancer and noncancer diagnosis). Models 2 and 3 examined associations with first and most trusted information source, respectively, adjusted for the significant predictors from Model 1.

Complete case analysis was performed, and a two-sided $P \leq 0.05$ threshold was considered significant for all tests. Jack-knife replicate method was used to

Table 1

Associations of Sociodemographics, Clinical Characteristics, and Information Source With Belief That PC Means Giving up (N = 1173)

	Disagree/Don't Know	Moderate or Strongly Agree	Univariable Model		Multivariable Model[a]	
Variable	Wtd. Freq. (Prev. [95% CI])	Wtd. Freq. (Prev. [95% CI])	Crude OR [95% CI]	*P*-value	Adjusted OR [95% CI]	*P*-value
Total	60,715,084	10,740,671	—	—	Model 1	
Age, yrs						
≤34	9,820,228 (88.1 [79.0–97.3])	1,322,820 (11.9 [2.7–21.0])	REF [1.00]	—	REF [1.00]	—
35–49	15,795,330 (87.9 [81.6–94.3])	2,164,304 (12.1 [5.7–18.4])	1.02 [0.34–3.07]	0.98	1.31 [0.44–3.91]	0.62
50–64	19,934,148 (85.0 [79.8–90.2])	3,510,908 (15.0 [9.8–20.2])	1.31 [0.48–3.59]	0.60	1.94 [0.69–5.49]	0.20
≥65	12,179,797 (80.1 [74.5–85.7])	3,021,970 (19.9 [14.3–25.5])	1.84 [0.71–4.76]	0.20	2.85 [1.13–7.20]	0.03
Gender						
Male	20,752,149 (84.9 [78.1–89.7])	3,989,502 (16.1 [10.3–21.9])	REF [1.00]	—		
Female	36,963,581 (86.0 [82.4–89.5])	6,030,500 (14.0 [10.5–17.6])	0.85 [0.50–1.45]	0.54		
Race/ethnicity						
White	46,447,674 (86.6 [83.3–89.9])	7,196,355 (13.4 [10.1–16.7])	REF [1.00]	—	REF [1.00]	—
Black	6,279,899 (89.2 [81.4–96.9])	762,117 (10.8 [3.1–18.6])	0.78 [0.31–1.99]	0.60	0.94 [0.37–2.39]	0.89
Asian	1,711,623 (58.7 [36.8–80.7])	1,203,050 (41.3 [19.3–63.2])	4.54 [1.75–11.77]	0.003	5.89 [1.86–18.63]	0.003
Other	4,551,434 (83.1 [69.3–96.8])	927,516 (16.9 [3.2–30.7])	1.32 [0.43–4.05]	0.63	1.10 [0.35–3.48]	0.87
Occupation status						
Employed	37,807,037 (87.3 [83.9–90.7])	5,487,937 (12.7 [9.3–16.1])	REF [1.00]	—		
Unemployed	1,687,434 (87.9 [75.7–100.0])	231,614 (12.1 [0.0–24.3])	0.95 [0.28–3.16]	0.93		
Other	19,761,275 (81.5 [75.7–87.3])	4,471,839 (18.5 [12.7–24.3])	1.56 [0.95–2.57]	0.08		
Marital status						
Married/living as married	36,676,863 (86.2 [81.9–90.5])	5,872,890 (13.8 [9.5–18.1])	0.72 [0.38–1.38]	0.32		
Previously married	10,752,316 (85.9 [81.1–90.7])	1,771,012 (14.1 [9.3–18.9])	0.74 [0.38–1.46]	0.38		
Never married	12,080,991 (81.8 [74.0–89.6])	2,687,095 (18.2 [10.4–26.0])	REF [1.00]	—		
Education						
Less than high school	1,656,128 (66.0 [36.2–95.9])	851,300 (34.0 [4.1–63.8])	REF [1.00]	—		
High school diploma	29,555,819 (83.4 [78.5–88.3])	5,888,970 (16.6 [11.7–21.5])	0.39 [0.10–1.55]	0.18		
College degree	28,357,547 (88.8 [85.4–92.1])	3,590,727 (11.2 [7.9–14.6])	0.25 [0.06–1.04]	0.06		
Income range, $						
≤34,999	10,166,864 (80.5 [71.8–89.3])	2,457,249 (19.5 [10.7–28.2])	REF [1.00]	—		
35,000–74,999	13,881,043 (84.5 [76.5–92.4])	2,552,946 (15.5 [7.6–23.5])	0.76 [0.31–1.90]	0.55		
≥75,000	30,626,557 (86.9 [83.1–90.7])	4,631,881 (13.1 [9.3–16.9])	0.63 [0.32–1.24]	0.17		
Born in the U.S.						
Yes	53,271,421 (85.8 [82.6–89.0])	8,837,084 (14.2 [11.0–17.4])	REF [1.00]	—		
No	6,646,433 (77.7 [67.4–88.0])	1,903,587 (22.3 [12.0–32.6])	1.73 [0.87–3.43]	0.12		
Ever had cancer						
No	54,002,250 (85.0 [81.9–88.2])	9,488,534 (14.9 [11.8–18.1])	REF [1.00]	—		
Yes	6,712,835 (84.3 [76.9–91.7])	1,252,137 (15.7 [8.3–23.1])	1.06 [0.55–2.04]	0.86		
Noncancer comorbidities						
None	23,135,564 (84.0 [78.7–89.3])	4,412,890 (16.0 [10.7–21.3])	REF [1.00]	—		
≥1	37,579,520 (85.6 [82.3–88.9])	6,327,781 (14.4 [11.1–17.7])	0.88 [0.54–1.44]	0.61		

First source of information on PC					Model 2	
Print media	649,370 (73.7 [45.1−100.0])	231,564 (26.3 [0.0−54.9])	2.03 [0.34−12.21]	0.43	0.44 [0.03−6.83]	0.55
Health care provider	32,778,826 (85.1 [81.2−88.9])	5,759,901 (14.9 [11.1−18.8])	REF [1.00]	—	REF [1.00]	—
Internet search	18,504,170 (85.5 [79.3−91.7])	3,137,432 (14.5 [8.3−20.7])	0.97 [0.53−1.76]	0.91	1.15 [0.56−2.34]	0.70
Interpersonal source	4,008,760 (84.8 [76.2−93.5])	715,915 (15.2 [6.5−23.8])	1.02 [0.49−2.12]	0.96	1.06 [0.42−2.69]	0.90
Trusted source of information on PC					Model 3	
Print media	715,747 (72.5 [43.8−100.0])	271,499 (27.5 [0.0−56.2])	2.16 [0.45−10.29]	0.33	1.56 [0.28−8.67]	0.60
Health care provider	47,690,240 (85.0 [81.9−88.2])	8,396,267 (15.0 [11.8−18.1])	REF [1.00]	—	REF [1.00]	—
Internet search	5,238,426 (84.4 [75.0−93.8])	968,511 (15.6 [6.2−25.0])	1.05 [0.52−2.13]	0.89	1.26 [0.55−2.91]	0.58
Interpersonal source	4,252,357 (85.4 [76.8−94.0])	725,291 (14.6 [6.0−23.2])	0.97 [0.47−2.02]	0.93	0.63 [0.26−1.49]	0.28

PC = palliative care; OR = odds ratio.

[a] Model 1 examined sociodemographic and clinical predictors. Models 2 and 3 evaluated associations with first and most trusted source of information, respectively. Gray cells indicate that the variable was not included in the final selection models.

calculate accurate national estimates and standard errors using the final and replicate weights provided in the HINTS data set. All analyses were conducted in SAS version 9.4 (SAS Institute, Cary, NC). This study complies with the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guidelines.[16]

Results

Sample Characteristics

Data were included from 1192 (weighted frequency: 72,584,607) American adults who answered at least one question about their perceptions of PC. Mean age was 50.6 (95% CI: 49.3−51.9) years. Demographic breakdown included 63.5% female, 77.1% Caucasian and 11.0% Black, 60.8% married and 18.0% previously married, 51.1% high school graduates and 45.4% college graduates, and 88.1% born in the U.S.

Knowledge and Beliefs About PC

Overall, 28.7% of American adults self-reported as knowledgeable about palliative care. Of these, 42.5% [95% CI: 38.0%−47.1%] indicated they automatically thought of death when thinking about PC, and 31.7% [27.3−36.2] equate PC with hospice care. A lower proportion of the population perceived PC as incompatible with curative medical therapy: 15.1% [12.2%−18.0%] believed PC means giving up, and 14.5% [11.5%−17.6%] believed PC requires the patient to stop any other treatment. Overall, of adults knowledgeable about PC, 59.2% (weighted frequency: 42,964,800) agreed with at least one of the four misperceptions.

Older age (multivariable stepwise logistic regression, adjusted OR [95% CI], ≥65 years: 2.85 [1.13−7.20]) and Asian race (5.89 [1.86−18.63]) predicted belief that PC means giving up (Table 1). High school diploma (0.23 [0.05−0.99]) and higher income (≥\$75,000: 0.35 [0.18−0.68]) were protective against belief that PC requires patients to stop curative treatment (Table 2). Equation of PC and hospice care was associated with race (black: 1.84 [1.04−3.24]) and marital status (married: 2.21 [1.06−4.62], previously married: 2.34 [1.02−5.39]), but inversely associated with higher income ((\$35,000−74,999: 0.56 [0.35−0.91], ≥\$75,000: 0.49 [0.28−0.86]) (Table 3). There were no significant predictors of belief that PC is associated with death ($P > 0.05$) (Table 4).

Source of PC Information

Health care providers were the first source from whom American adults most frequently sought information on PC (prevalence [95% CI]: 59.3% [54.4%−64.1%]), followed by Internet search (32.6% [28.2%−37.0%]), conversations with trusted people

Table 2

Associations of Sociodemographics, Clinical Characteristics, and Information Source With Belief That PC Requires Patients to Stop Curative Treatments ($N = 1177$)

	Disagree/Don't Know	Moderate or Strongly Agree	Univariable Model		Multivariable Model[a]	
Variable	Wtd. Freq. (Prev. [95% CI])	Wtd. Freq. (Prev. [95% CI])	Crude OR [95% CI]	*P*-value	Adjusted OR [95% CI]	*P*-value
Total	61,114,959	10,259,833	—	—	Model 1	
Age, yrs						
≤34	9,379,135 (84.2 [74.6–93.8])	1,763,913 (15.8 [6.2–25.4])	REF [1.00]	—		
35–49	16,822,938 (93.7 [89.9–97.4])	1,136,696 (6.3 [2.6–10.1])	0.34 [0.14–0.93]	0.03		
50–64	19,347,584 (83.2 [77.0–89.5])	3,896,119 (16.8 [10.5–23.0])	1.07 [0.47–2.46]	0.87		
≥65	12,612,187 (82.3 [77.6–86.9])	2,718,754 (17.7 [13.1–22.4])	1.15 [0.50–2.61]	0.74		
Gender						
Male	21,193,846 (86.3 [80.9–91.7])	3,376,926 (13.7 [8.3–19.1])	REF [1.00]	—		
Female	37,116,441 (86.1 [82.4–89.9])	5,976,340 (13.9 [10.1–17.6])	1.01 [0.57–1.79]	0.97		
Race/ethnicity						
White	46,539,974 (86.7 [83.4–90.0])	7,118,029 (13.3 [10.0–16.6])	REF [1.00]	—		
Black	5,997,469 (86.6 [78.1–95.1])	927,602 (13.4 [4.9–21.9])	1.01 [0.43–2.36]	0.98		
Asian	2,331,139 (80.0 [62.3–97.7])	583,534 (20.0 [2.3–37.7])	1.64 [0.49–5.44]	0.41		
Other	4,406,457 (80.3 [60.3–100.0])	1,082,187 (19.7 [0.0–39.7])	1.61 [0.37–7.06]	0.52		
Occupation status						
Employed	37,653,485 (87.4 [83.5–91.4])	5,425,976 (12.6 [8.6–16.5])	REF [1.00]	—		
Unemployed	1,345,785 (70.1 [14.1–100.0])	573,262 (29.9 [0.0–85.9])	2.96 [0.02–480.04]	0.67		
Other	20,405,289 (83.9 [79.4–88.4])	3,906,026 (16.1 [11.6–20.6])	1.33 [0.79–2.24]	0.28		
Marital status						
Married/living as married	37,227,873 (87.3 [83.7–91.0])	5,406,629 (12.7 [9.0–16.3])	0.88 [0.42–1.82]	0.72		
Previously married	10,396,789 (82.2 [73.5–90.9])	2,251,408 (17.8 [9.1–26.5])	1.31 [0.54–3.19]	0.55		
Never married	12,419,485 (85.8 [78.4–93.1])	2,058,018 (14.2 [6.9–21.6])	REF [1.00]	—		
Education						
Less than high school	1,407,380 (56.1 [20.9–91.3])	1,100,047 (43.9 [8.7–79.1])	REF [1.00]	—	REF [1.00]	—
High school diploma	30,463,678 (86.6 [82.3–91.0])	4,696,132 (13.4 [9.0–17.7])	0.20 [0.04–0.91]	0.04	0.23 [0.05–0.99]	<0.05
College degree	28,232,414 (87.8 [84.4–91.3])	3,919,876 (12.2 [8.7–15.6])	0.18 [0.04–0.80]	0.03	0.27 [0.06–1.13]	0.07
Income range, $						
≤34,999	9,205,151 (74.9 [64.8–84.9])	3,092,817 (25.1 [15.1–35.2])	REF [1.00]	—	REF [1.00]	—
35,000–74,999	13,782,210 (83.6 [77.2–90.0])	2,705,155 (16.4 [10.0–22.8])	0.58 [0.27–1.25]	0.16	0.61 [0.28–1.32]	0.20
≥75,000	31,540,097 (89.1 [85.5–92.8])	3,848,188 (10.9 [7.2–14.5])	0.36 [0.18–0.75]	0.007	0.35 [0.18–0.68]	0.003
Born in the U.S.						
Yes	53,398,153 (86.1 [83.1–89.0])	8,624,647 (13.9 [11.0–16.9])	REF [1.00]	—		
No	6,942,085 (81.2 [70.1 92.2])	1,610,456 (18.8 [7.8–29.9])	1.44 [0.67–3.09]	0.35		
Ever had cancer						
No	54,186,990 (85.6 [82.4–88.7])	9,134,588 (14.4 [11.3–17.6])	REF [1.00]	—		
Yes	6,927,968 (86.0 [79.2–92.8])	1,125,245 (14.0 [7.2–20.8])	0.96 [0.52–1.80]	0.91		
Noncancer comorbidities						
None	23,671,350 (86.8 [81.5–92.1])	3,595,418 (13.2 [7.9–18.5])	REF [1.00]	—		
≥1	37,443,609 (84.9 [81.1–88.7])	6,664,415 (15.1 [11.3–18.9])	1.17 [0.65–2.10]	0.59		

First source of information on PC					Model 2	
Print media	710,788 (89.0 [71.4−100.0])	87,749 (11.0 [0.0−28.6])	0.70 [0.06−8.20]	0.77	0.51 [<.001−999+]	0.96
Health care provider	32,930,258 (85.0 [81.7−88.4])	5,792,174 (15.0 [11.6−18.3])	REF [1.00]	—	REF [1.00]	—
Internet search	18,591,659 (85.9 [78.9−92.8])	3,060,031 (14.1 [7.2− 21.1])	0.94 [0.49−1.79]	0.84	0.96 [0.52−1.78]	0.89
Interpersonal source	4,040,849 (85.4 [74.8−95.9])	692,136 (14.6 [4.1−25.2])	0.97 [0.36−2.66]	0.96	1.20 [0.43−3.31]	0.73
Trusted source of information on PC					Model 3	
Print media	720,143 (81.0 [56.9−100.0])	169,332 (19.0 [0.0−43.1])	1.67 [0.29−9.62]	0.56	1.05 [0.18−6.15]	0.96
Health care provider	49,452,657 (87.7 [84.5−90.8])	6,961,902 (12.3 [9.1−15.5])	REF [1.00]	—	REF [1.00]	—
Internet search	4,716,386 (76.0 [60.3−91.6])	1,490,551 (24.0 [8.4−39.7])	2.25 [0.86−5.89]	0.10	1.73 [0.80−3.73]	0.16
Interpersonal source	3,630,502 (73.0 [58.1−88.0])	1,341,842 (27.0 [12.0−41.9])	2.63 [1.09−6.33]	0.03	2.56 [0.93−7.08]	0.07

PC = palliative care; OR = odds ratio.

[a] Model 1 examined sociodemographic and clinical predictors. Models 2 and 3 evaluated associations with first and most trusted source of information, respectively. Gray cells indicate that the variable was not included in the final selection models.

(6.9% [4.6%−9.2%]), printed materials (1.1% [0.4%−1.7%]), and social media (0.1% [0.0%−0.3%]). Providers were even more so the most trusted source of PC information (82.8% [79.5%−86.1%]), compared to 8.8% [6.0%−11.7%] for Internet search, 6.9% [5.2%−8.7%] conversations with trusted individuals, 1.2% [0.5%−1.9%] printed materials, and 0.3% [0.0%−0.6%] social media.

People who relied on interpersonal sources as their first source tended to believe PC is associated with death (adjusted OR [95% CI]: 2.03 [1.08−3.80]) (Table 4). Primary and most trusted source of PC information did not significantly influence other PC beliefs: giving up ($P \geq 0.28$), stop curative therapy ($P \geq 0.07$), and equate with hospice care ($P \geq 0.29$).

Discussion

This population-based study found low prevalence of public knowledge of palliative care in the U.S. Approximately six in every 10, representing an estimated 43 million adults, agreed with at least one of the four misperceptions evaluated in this study. In particular, many of those who identified as knowledgeable about PC associate it with death and equate it to hospice. This parallels findings in smaller studies: for example, a survey of New York adults found 53.2% of those who knew about PC had a significant misbelief such as association with end of life.[6]

Our study also found PC perceptions vary by sociodemographic groups. In particular, accurate PC beliefs were more prevalent among adults with higher income and more education, suggesting health care disparities and socioeconomic differences may contribute to comparatively lower understanding of PC. Importantly, misunderstanding has been associated with lower receptivity toward PC services.[17] A pilot study in Japan evaluated PC attitudes before and after an educational intervention and found increased knowledge of PC led to improved receptivity to PC.[18] Moreover, high frequency of misperceptions could dissuade people from considering PC.[18] One in three adults in our study equated PC and hospice, and even more automatically thought of death with PC. Taken together, these findings suggest underutilization of PC is partly amenable to education of patients and the broader public. Improving patient understanding of PC should be a priority objective to better engage patients in advance care planning and remove barriers to utilization.[19]

Association of favorable attitudes toward PC with higher income and education suggests low health literacy may contribute to misperceptions. Indeed, the average reading level of end-of-life and PC patient education materials available on the Internet is equivalent to 11−12 grade level.[20,21] Guidelines recommend health materials

Table 3

Associations of Sociodemographics, Clinical Characteristics, and Information Source With Belief That PC Equates to Hospice Care ($N = 1173$)

	Disagree/Don't Know	Moderate or Strongly Agree	Univariable Model		Multivariable Model[a]	
Variable	Wtd. Freq. (Prev. [95% CI])	Wtd. Freq. (Prev. [95% CI])	Crude OR [95% CI]	*P*-value	Adjusted OR [95% CI]	*P*-value
Total	49,248,783	22,649,892	—	—	Model 1	
Age, yrs						
≤34	8,025,633 (72.0 [60.1–84.0])	3,117,415 (28.0 [16.0–39.9])	REF [1.00]	—		
35–49	12,861,721 (71.6 [61.3–81.9])	5,097,912 (28.4 [18.1–38.7])	1.02 [0.43–2.45]	0.96		
50–64	15,842,980 (65.8 [57.8–73.8])	8,230,758 (34.2 [26.2–42.2])	1.34 [0.69–2.58]	0.38		
≥65	10,011,616 (66.2 [59.4–73.0])	5,107,119 (33.8 [27.0–40.6])	1.31 [0.65–2.67]	0.44		
Gender						
Male	18,408,974 (74.0 [66.4–81.6])	6,467,418 (26.0 [18.4–33.6])	REF [1.00]	—		
Female	28,306,756 (65.2 [59.5–70.9])	15,098,234 (34.8 [29.1–40.5])	1.52 [0.95–2.44]	0.08		
Race/ethnicity						
White	37,859,884 (70.3 [65.5–75.1])	15,999,130 (29.7 [24.9–34.5])	REF [1.00]	—	REF [1.00]	—
Black	4,361,028 (59.8 [47.1–72.5])	2,927,367 (40.2 [27.5–52.9])	1.59 [0.92–2.74]	0.09	1.84 [1.04–3.24]	0.04
Asian	1784,241 (61.2 [39.1–83.4])	1,130,432 (38.8 [16.6–60.9)	1.50 [0.57–3.95]	0.40	1.89 [0.67–5.34]	0.22
Other	3,607,413 (65.7 [49.0–82.5])	1,881,231 (34.3 [17.5–51.0])	1.23 [0.55–2.75]	0.60	1.68 [0.66–4.24]	0.27
Occupation status						
Employed	31,279,358 (71.6 [66.3–76.8])	12,423,157 (28.4 [23.2–33.7])	REF [1.00]	—		
Unemployed	1,251,240 (59.5 [20.1–98.9])	851,843 (40.5 [1.1–79.9])	1.71 [0.34–8.70]	0.51		
Other	15,895,833 (66.1 [59.6–72.6])	8,143,526 (33.9 [27.4–40.4])	1.29 [0.90–1.85]	0.16		
Marital status						
Married/living as married	29,350,099 (68.3 [62.6–74.0])	13,614,964 (31.7 [26.0– 37.4])	1.50 [0.78–2.90]	0.22	2.21 [1.06–4.62]	0.04
Previously married	7679,383 (61.9 [54.5–69.3])	4,723,388 (38.1 [30.7–45.5])	1.99 [1.05–3.80]	0.04	2.34 [1.02–5.39]	0.05
Never married	11,400,434 (76.4 [66.1–86.8])	3,515,819 (23.6 [13.2–33.9])	REF [1.00]	—	REF [1.00]	—
Education						
Less than high school	1,666,476 (71.3 [45.8–96.8])	671,948 (28.7 [3.2–54.2])	REF [1.00]	—		
High school diploma	21,639,867 (60.3 [52.8–67.8])	14,257,581 (39.7 [32.2–47.2])	1.63 [0.50–5.39]	0.41		
College degree	25,110,547 (78.2 [73.9–82.5])	6,996,991 (21.8 [17.5–26.1])	0.69 [0.20–2.38]	0.55		
Income range, $						
≤34,999	7,515,793 (58.0 [48.4–67.5])	5,450,793 (42.0 [32.5–51.6])	REF [1.00]	—	REF [1.00]	—
35,000–74,999	11,555,776 (69.3 [59.4–79.2])	5,123,863 (30.7 [20.8–40.6])	0.61 [0.38–0.97]	0.04	0.56 [0.35–0.91]	0.02
≥75,000	25,263,211 (71.5 [65.4–77.5])	10,070,967 (28.5 [22.5–34.6])	0.55 [0.34–0.89]	0.01	0.49 [0.28–0.86]	0.01
Born in the U.S.						
Yes	42,933,703 (68.6 [64.0–73.2])	19,624,023 (31.4 [26.8–36.0])	REF [1.00]	—		
No	5,572,804 (65.1 [52.9–77.4])	2,982,166 (34.9 [22.6–47.1])	1.17 [0.68–2.03]	0.57		
Ever had cancer						
No	4,4156,498 (69.1 [64.7–73.5])	19,733,583 (30.9 [26.5–35.3])	REF [1.00]	—		
Yes	5,092,286 (63.6 [53.9–73.3])	2,916,309 (36.4 [26.7–46.1])	1.28 [0.85–1.94]	0.23		
Noncancer comorbidities						
None	19,022,057 (67.7 [60.6–74.7])	9,081,114 (32.3 [25.3–39.4])	REF [1.00]	—		
≥1	30,226,726 (69.0 [63.4–74.6])	13,568,778 (31.0 [25.4–36.6])	0.94 [0.62–1.43]	0.77		

					Model 2	
First source of information on PC						
Print media	565,350 (76.3 [46.6–100.0])	17,565 (23.7 [0.0–53.4])	0.65 [0.10–4.42]	0.65	0.84 [0.06–12.11]	0.90
Health care provider	26,420,796 (67.7 [62.2–73.2])	12,604,231 (32.3 [26.8–37.8])	REF [1.00]	—	REF [1.00]	—
Internet search	15,392,436 (70.9 [62.1–79.6])	6,323,504 (29.1 [20.4–37.9])	0.86 [0.53–1.40]	0.54	0.74 [0.42–1.31]	0.29
Interpersonal source	3,246,555 (68.8 [58.8–78.8]	1,473,265 (31.2 [21.2–41.2])	0.95 [0.57–1.58]	0.84	0.82 [0.45–1.47]	0.49
Trusted source of information on PC					Model 3	
Print media	587,739 (65.0 [35.9–94.0])	317,111 (35.0 [6.0–64.1])	1.25 [0.35–4.41]	0.73	1.73 [0.28–10.93]	0.55
Health care provider	39,580,917 (69.8 [65.1–74.5])	17,102,395 (30.1 [25.5–34.8])	REF [1.00]	—	REF [1.00]	—
Internet search	4,155,630 (67.2 [50.6–83.8])	2,028,362 (32.8 [16.2–49.4])	1.13 [0.51–2.49]	0.76	0.95 [0.39–2.28]	0.90
Interpersonal source	3,091,256 (62.4 [46.9–77.9])	1,860,004 (37.6 [22.1–53.1])	1.39 [0.70–2.76]	0.34	0.91 [0.36–2.25]	0.83

PC = palliative care; OR = odds ratio.

[a]Model 1 examined sociodemographic and clinical predictors. Models 2 and 3 evaluated associations with first and most trusted source of information, respectively. Gray cells indicate that the variable was not included in the final selection models.

are written at a Grade 6–7 reading level.[22–24] Previous research on health literacy and PC information have focused on online materials.[20,21,25] Additional research is needed to examine patient understanding after PC education by providers and to determine the reading accessibility of nononline (e.g., print) materials. Our findings suggest education initiatives should develop informative materials understandable to individuals with lower health literacy.

There are many clinical implications of PC misperceptions in the context of low health literacy. Clinicians should use materials with simple language and visual images, when possible. During the patient encounter, providers ideally can spend extra time to explain unfamiliar concepts as patients may struggle to understand clinical jargon and disease concepts. Finally, investigators have theorized patients in PC may benefit from teaching back what they heard to ensure understanding.[26] Future studies will determine optimal strategies to effectively disseminate accurate PC information to the public.

There were also racial disparities in perceptions such that minority groups were more likely to associate PC with giving up and hospice. Importantly, our finding that African-American adults tended to equate PC and hospice aligns with previous findings that African-Americans are less likely to complete advance care planning or engage in hospice.[27,28] Racial minorities opt against hospice care because of cultural issues and knowledge deficits.[29,30] Moreover, a study of deceased African-Americans found fewer than one in three received hospice and more than half were never informed about hospice. Negative perception in these communities may contribute to the underutilization of these services.[29,31] Demographic differences outlined in this study identify specific populations most vulnerable to underutilization of PC and emphasize the need for approaches tailored to specific cultural needs.

This study found 59.3% of patients primarily rely on health care providers for PC information and 82.8% considered them their most trusted source of information. Given the persistent rate of misbeliefs among patients who rely on their providers for information, this may highlight the need for broader dissemination of PC information to health care providers. Previous research reported U.S. physicians tend to equate PC with hospice and end-of-life care. A survey of 61 nurses found certificate training in PC was associated with better PC knowledge and increased knowledge was significantly correlated with more positive attitudes toward PC.[32] Thus, improving PC awareness among health care providers may represent a high-yield opportunity to improve public knowledge.

Source of information did not moderate associations with giving up, conclusion of curative therapy, or equation with hospice. This suggests these misbeliefs are pervasive across Internet, print media,

Table 4

Associations of Sociodemographics, Clinical Characteristics, and Information Source With Belief That PC Is Associated With Death ($N = 1182$)

	Disagree/Don't Know	Moderate or Strongly Agree	Univariable Model		Multivariable Model[a]	
Variable	Wtd. Freq. (Prev. [95% CI])	Wtd. Freq. (Prev. [95% CI])	Crude OR [95% CI]	*P*-value	Adjusted OR [95% CI]	*P*-value
Total	41,845,861	30,076,609	—	—	Model 1	
Age, yrs						
≤34	6,885,005 (61.8 [46.6–76.9])	4,258,043 (38.2 [23.1–53.4])	REF [1.00]	—		
35–49	10,010,116 (55.7 [46.7–64.8])	7,949,518 (44.3 [35.2–53.3])	1.28 [0.60–2.77]	0.52		
50–64	14,274,743 (59.6 [53.0–66.1])	9,693,471 (40.4 [33.9–47.0])	1.10 [0.57–2.11]	0.78		
≥65	8,871,385 (58.5 [51.4–65.7])	6,282,724 (41.5 [34.3–48.6])	1.15 [0.56–2.33]	0.70		
Gender						
Male	13,939,073 (56.4 [47.8–65.1])	10,763,483 (43.6 [34.9–52.2])	REF [1.00]	—		
Female	25,995,716 (59.7 [54.8–64.7])	17,512,960 (40.3 [35.3–45.2])	0.87 [0.59–1.30]	0.50		
Race/ethnicity						
White	30,510,037 (56.5 [51.5–61.5])	23,476,147 (43.5 [38.5–48.5])	REF [1.00]	—		
Black	4,670,893 (65.4 [52.4–78.4])	2,473,677 (34.6 [21.6–47.6])	0.69 [0.38–1.23]	0.20		
Asian	1,480,844 (50.8 [30.3–71.4])	1,433,830 (49.2 [28.6–69.7])	1.26 [0.52–3.05]	0.60		
Other	3,349,638 (61.0 [43.0–79.0])	2,139,006 (39.0 [21.0–57.0])	0.83 [0.38–1.81]	0.63		
Occupation status						
Employed	26,737,859 (61.0 [55.1–66.9])	17,066,112 (39.0 [33.1–44.9])	REF [1.00]	—		
Unemployed	669,646 (34.9 [0.0–73.7])	1,249,401 (65.1 [26.3–100.0])	2.92 [0.53–16.11]	0.21		
Other	13,456,808 (55.8 [49.2–62.3])	10,677,675 (44.2 [37.7–50.8])	1.24 [0.88–1.75]	0.21		
Marital status						
Married/living as married	24,249,812 (56.2 [50.5–62.0])	18,867,636 (43.8 [38.0–49.5])	1.53 [0.85–2.74]	0.16		
Previously married	7,206,987 (57.8 [48.9–66.8])	5,251,231 (42.2 [33.2–51.1])	1.43 [0.84–2.42]	0.18		
Never married	9,755,065 (66.2 [54.5–77.9])	4,977,151 (33.8 [22.1–45.5])	REF [1.00]	—		
Education						
Less than high school	1,145,586 (48.4 [13.0–83.9])	1,219,818 (51.6 [16.1–87.0])	REF [1.00]	—		
High school diploma	20,898,694 (58.4 [51.1–65.7])	14,882,902 (51.6 [16.1–87.0])	0.67 [0.15–2.91]	0.59		
College degree	19,256,487 (59.8 [54.7–64.9])	12,963,717 (40.2 [35.1–45.3])	0.63 [0.16–2.56]	0.51		
Income range, $						
≤34,999	7,120,609 (54.7 [46.5–63.0])	5,889,828 (45.3 [37.0–53.5])	REF [1.00]	—		
35,000–74,999	9,815,356 (59.5 [50.9–68.0])	6,693,412 (40.5 [32.0–49.1])	0.82 [0.51–1.32]	0.42		
≥75,000	21,204,250 (59.8 [53.3–66.4])	14,230,547 (40.2 [33.6–46.7])	0.81 [0.53–1.25]	0.34		
Born in the U.S.						
Yes	36,452,601 (58.3 [53.3–63.2])	26,117,877 (41.7 [36.8–46.7])	REF [1.00]	—		
No	4,739,943 (55.4 [42.8–68.1])	3,812,599 (44.6 [31.9–57.2])	1.12 [0.64–1.98]	0.68		
Ever had cancer						
No	37,484,480 (58.7 [53.8–63.6])	26,408,957 (41.3 [36.4–46.2])	REF [1.00]	—		
Yes	4,361,381 (54.3 [43.7–64.9])	3,667,652 (45.7 [35.1–56.3])	1.19 [0.74–1.92]	0.46		
Noncancer comorbidities						
None	16,298,886 (58.3 [50.8–65.7])	11,659,028 (41.7 [34.3–49.2])	REF [1.00]	—		
≥1	25,546,975 (58.1 [53.1–63.2])	18,417,581 (41.9 [36.8–46.9])	1.01 [0.71–1.43]	0.96		

First source of information on PC					Model 2	
Print media	626,036 (78.4 [55.6−100.0])	172,502 (21.6 [0.0−44.4])	0.42 [0.10−1.79]	0.23	0.42 [0.10−1.79]	0.23
Health care provider	23,442,604 (60.3 [53.9−66.8])	15,425,849 (39.7 [33.2−46.1])	REF [1.00]	—	REF [1.00]	—
Internet search	12,418,002 (57.1 [47.5−66.6])	9,347,269 (42.9 [33.4−52.5])	1.14 [0.71−1.85]	0.58	1.14 [0.71−1.85]	0.58
Interpersonal source	2,028,159 (42.9 [30.8−54.9])	2,704,826 (57.1 [45.1−69.2])	2.03 [1.08−3.80]	0.03	2.03 [1.08−3.80]	0.03
Trusted source of information on PC					Model 3	
Print media	657,711 (72.7 [47.4−97.9])	247,138 (27.3 [2.06−52.6])	0.52 [0.14−1.91]	0.32	0.52 [0.14−1.91]	0.32
Health care provider	32,703,284 (57.8 [52.4−63.3])	23,836,617 (42.2 [36.7−47.6])	REF [1.00]	—	REF [1.00]	—
Internet search	3,017,143 (48.6 [33.5−63.7])	3,189,793 (51.4 [36.3−66.5])	1.45 [0.76−2.78]	0.26	1.45 [0.76−2.78]	0.26
Interpersonal source	3,438,496 (69.1 [56.7−81.4])	1,539,152 (30.9 [18.6−43.3])	0.61 [0.32−1.18]	0.14	0.61 [0.32−1.18]	0.14

PC = palliative care; OR = odds ratio.

[a] Model 1 examined sociodemographic and clinical predictors. Models 2 and 3 evaluated associations with first and most trusted source of information, respectively. Gray cells indicate that the variable was not included in the final selection models.

provider settings, and community. This research provides nationally representative estimates of where adults primarily obtain information about PC. However, qualitative studies are needed to elucidate the underlying motivations for why adults prefer particular information sources. In this study, adults who relied on interpersonal sources for PC information associated PC with death. It is likely that individuals who discuss PC or post about it on social media are sharing personal accounts that may often involve death. Thus, adults who rely primarily on these accounts will associate PC with death. However, it may be adults who associate PC with death are more likely to read personal accounts of PC experiences from others. The cross-sectional nature of this study precluded conclusions about the directionality of association between information source and perception of PC as death.

Limitations

Strengths of this study include the large sample size and complex weighting allowing for representative estimates of awareness and beliefs across the U.S. adult population. Smaller-scale surveys may underrepresent demographic minorities; owing to the sampling methodology, the HINTS is able to reflect nationwide diversity. However, there are limitations. Analysis was constrained by the questions asked in the survey. Respondents were forced to select a primary information source from a list of choices and were unable to designate an "other" choice. In addition, respondents' individual experiences with PC are unknown. Previous research has found the majority of adults knowledgeable about PC had personal experience with hospice.[28] These experiences may drive PC beliefs, and future qualitative and quantitative studies are warranted to better understand the effects of life events on PC awareness and beliefs. Two final limitations merit mention: 1) all variables in HINTS are self-reported, and 2) respondents comprise American adults and as such cannot be generalized to other countries. In international settings where overall prevalence of palliative care is likely lower than in the U.S., there might be a higher prevalence of some misperceptions. Qualitative studies in other countries have reported similarly low awareness and prevalent misperceptions about PC.[33] More international studies are needed to fully understand the global misperceptions of PC.

Conclusion

Overall, six out of every 10 adults knowledgeable about PC had misperceptions of what it constitutes. Importantly, there are significant sociodemographic differences in beliefs about PC that suggest low health literacy may contribute to misperceptions. Continued research will elucidate the impact of misperceptions on PC access and utilization. Future interventions and public measures are needed to educate the public about the role of PC in health care using communication effective for populations with limited health literacy.

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