Brief Report

When Patients Say They Know About Palliative Care, How Much Do They Really Understand?

Yujun Zhu, MSG, and Susan Enguídanos, PhD, MPH
University of Southern California, Los Angeles, California, USA

Abstract

Context. Lack of knowledge or misconceptions about palliative care (PC) can serve as barriers to accessing PC for seriously ill patients. Although self-reported rates of PC knowledge have been increasing, little is known about how self-reports relate to actual PC knowledge.

Objective. To determine the prevalence of PC knowledge and the portion of those reporting they are knowledgeable have actual PC knowledge of basic PC principals.

Methods. We used the Health Information National Trends Survey 5, Cycle 2, a nationally representative data set to describe the prevalence of self-reported PC knowledge. We conducted chi-squared test to compare self-rated PC knowledge level with actual knowledge. Finally, we ran a logistic regression to examine if self-reported knowledge level, age, and cancer history were associated with actual PC knowledge.

Results. About 34% of participants self-reported having at least some knowledge of PC, and 41% of those reporting familiarities with PC were able to answer all three basic PC questions correctly. Rates of correct responses for cancer patients were similar (42%) to the general sample and older adults were lower (35%). Compared with those with less than a high school education, people with a bachelor's degree and post-baccalaureate degree had higher odds ratio (21.07 and 23.07, respectively) of actual understanding of PC.

Conclusions. We found that self-reported PC knowledge may not reflect actual PC knowledge. Physicians should carefully explain PC when introducing it to patients. In addition, this PC information should be provided at a low literacy level to ensure widespread understanding of the service. J Pain Symptom Manage 2019;58:460−464. © *2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words
Palliative care, health literacy, knowledge, misconception, education

Introduction

State and national surveys consistently have demonstrated that the American public has little knowledge of palliative care (PC). In a nationally representative survey conducted in 2011, just 8% of respondents reported that they were familiar with PC,[1] with state surveys from California (2012)[2] and a more recent one from New York (2017)[3] reporting that 17%−27% of respondents, respectively, had knowledge of PC. Despite this self-reported knowledge, misconceptions and misinformation about PC are rampant; in the New York study, about half of the respondents knowledgeable about PC had a misconception about the service. There is growing concern about the public's perception that hospice and PC are more or less the same.[4] That is, PC is a "pre-hospice" program. This perception is being fueled by public communication that often pairs PC with terms such as "end of life" or "hospice".[5]

Existing surveys consist of general population and do not focus specifically on those who may need PC most or have been exposed to PC such as patients with cancer or who are older. These individuals have a greater likelihood of exposure to PC services, either through their own illness or that of a loved one. Thus,

Address correspondence to: Yujun Zhu, MSG, 3725 S Catalina St, Los Angeles, CA 90007, USA. E-mail: yujunzhu@usc.edu

Accepted for publication: May 15, 2019.

0885-3924/$ - see front matter
https://doi.org/10.1016/j.jpainsymman.2019.05.008

following research on hospice where those who have been exposed to hospice have greater knowledge of it,[6] we would expect that older populations or those with a cancer history would have greater knowledge and more accurate knowledge of PC.[7]

The purpose of this study was two-fold. First, we aimed to determine the prevalence of PC knowledge using a nationally representative data set. Next, we examined the extent to which those reporting they were knowledgeable about PC to their actual knowledge of basic PC principals. We also reviewed level of knowledge among people with a history of cancer and older adults, as both disease and age increase likelihood of exposure to PC programs and services.

Methods

Data were obtained from the National Cancer Institute's Health Information National Trends Survey (HINTS), a nationally representative data set. We used newly released HINTS 5, Cycle 2 (2018) data set containing 3504 respondents aged 18 years or older to compare self-rated PC knowledge with actual PC knowledge level.

Variables

To determine self-rated PC knowledge, participants were asked their level of knowledge about PC, with response options including: 1) never heard of it, 2) know a little bit about PC, and 3) know what PC is and could explain it to someone else. Among those who self-reported that they knew a little bit or more, respondents were next given three statements about fundamental aspects of PC and asked the extent to which they agreed with each. These questions included: 1) PC means giving up, 2) if you accept PC you must stop other treatments, and 3) PC is the same as hospice care. The Likert scale responses included strongly disagree, somewhat disagree, somewhat agree, strongly agree, and do not know. We examined self-reported and actual PC knowledge among the entire sample, and then among older adults and those with cancer to determine if there were differences by age and among illness.

Analysis

We grouped people who strongly or somewhat disagree with the statements as correct answers and grouped do not know, strongly or somewhat agree as incorrect responses. Then, we summed the number of correctly answered questions to reflect actual PC knowledge. We conducted chi-squared test to determine if actual knowledge is associated with self-reported level. Finally, we ran a logistic regression to examine if self-reported knowledge level, age, and cancer history were associated with actual PC knowledge, controlling for marital status, race, education, and income. The binary dependent variable in this model was whether participants answered all three fundamental PC questions correctly. Jackknife replicate weights were applied during the analyses for proper inference.[8]

Results

Table 1 shows demographic distribution of the data set along with self-reported PC knowledge level. The average age in this sample was 57 years (SD = 17) with more women (59%) and whites (57%). About 43% of participants had at least a bachelor's degree and about 32% had a household income over $75,000. Among the 3445 participants who reported their PC knowledge, 66% of respondents had never heard of PC, 21% knew a little, and 13% reported that they could explain PC. About 75% of the men and 75% non-whites reported that they had never heard of PC. Women (39%) and whites (40%) were significantly more likely than men (25%) and non-whites (24%) to self-report having PC knowledge. Similarly, being married, having higher education and higher income were positively associated with level of self-reported PC knowledge.

For those who had heard of PC, few agreed with the statements that PC means giving up (20%) or stopping other treatments (30%). However, almost half of the respondents (49%) agreed with the statement that PC is the same as hospice care. Although there was a significant association between self-reported and actual PC knowledge ($P = 0.007$), among those stating they are very knowledgeable, only about half (51%) correctly answered all three PC knowledge questions. Rates of correct responses for patient with a history of cancer were similar (50%) to the overall sample, however, among older adults, only 44% responded correctly to all three knowledge questions. In fact, there was no statistically significant relationship between self-reported PC knowledge with actual PC knowledge among adults who were older than 65 years and those with a history of cancer (Table 2).

In the multivariate analysis (Table 3), self-reported PC knowledge level and education were significantly associated with actual PC knowledge. For people who self-reported knowing what PC is and can explain to others, the odds of answering all the statements correctly were two times higher than for those who knew a little. Compared with those with less than a high school education, people with a bachelor's degree and post-baccalaureate degree had higher odds ratio (21.07 and 23.07, respectively) of actual PC understanding.

Table 1
Distribution of Self-Reported PC Knowledge

	Sample Distribution $n = 3504$	Never Heard PC, $n = 2283$	Know a Little PC, $n = 712$	Know and Can Explain PC, $n = 450$	*P*-value
Age (Mean, SD), yrs	57 (17)	56 (17)	57 (15)	56 (15)	0.256
Gender (Frequency, %)					<0.001
Female	2054 (59)	1205 (53)	473 (66)	333 (74)	
Male	1394 (40)	1032 (45)	232 (33)	116 (26)	
Missing	56 (2)	46 (2)	7 (1)	1 (0)	
Race (Frequency, %)					<0.001
White	1983 (57)	1165 (51)	505 (71)	291 (65)	
Non-white	1168 (33)	862 (38)	166 (23)	117 (26)	
African-American	444 (13)	328 (14)	64 (9)	40 (9)	
Hispanic	461 (13)	356 (16)	58 (8)	39 (9)	
Asian	138 (4)	95 (4)	27 (4)	15 (3)	
Other	125 (4)	83 (4)	17 (2)	23 (5)	
Missing	353 (10)	256 (11)	41 (6)	42 (9)	
Education (Frequency, %)					<0.001
<High school	275 (8)	240 (11)	16 (2)	7 (2)	
High school	631 (18)	505 (22)	85 (12)	27 (6)	
Some college	1039 (30)	710 (31)	195 (27)	117 (26)	
Bachelor's degree	910 (26)	554 (24)	206 (29)	143 (32)	
Post-baccalaureate	598 (17)	240 (11)	201 (28)	152 (34)	
Missing	51 (2)	34 (1)	9 (1)	4 (1)	
Marital status (Frequency, %)					0.019
Married	1651 (47)	1035 (45)	373 (52)	223 (50)	
Living as married	96 (3)	66 (3)	19 (3)	10 (2)	
Divorced	588 (17)	372 (16)	127 (18)	81 (18)	
Widowed	429 (12)	286 (13)	71 (10)	59 (13)	
Separated	80 (2)	59 (3)	11 (2)	6 (1)	
Single, never married	605 (17)	430 (19)	100 (14)	65 (14)	
Missing/Error	55 (2)	35 (2)	11 (2)	6 (1)	
Income (Frequency, %)					<0.001
Less than $20,000	579 (17)	460 (20)	66 (9)	39 (8)	
$20,000 to <$35,000	428 (12)	294 (13)	78 (11)	48 (11)	
$35,000 to <$50,000	404 (12)	283 (12)	70 (10)	45 (10)	
$50,000 to <$75,000	567 (16)	380 (17)	117 (16)	67 (15)	
$75,000 or more	1109 (32)	583 (26)	307 (43)	206 (46)	
Missing	417 (12)	283 (12)	74 (10)	45 (10)	

PC = palliative care.

Discussion

This manuscript is the first to compare self-reported PC knowledge with actual PC knowledge among a nationally representative sample in the U.S. The rates of self-reported PC knowledge in this very recent, nationally representative sample are higher than found in previous studies. In the present study, we found that 33% of respondents reported having knowledge of PC, compared with earlier studies citing knowledge rates of 8%, 17%, and 27%, respectively.[1–3] Our findings demonstrate that PC awareness is improving nationally, perhaps in response to the increase in prevalence of PC programs and services.[9]

However, despite this higher level of self-reported PC knowledge, most lacked actual PC knowledge; overall, 65% of respondents never heard of PC. In addition, higher rates of no PC knowledge were found among non-whites (74%) and those with high school education or less (82%). Among those reporting PC knowledge, this knowledge is accompanied by

Table 2
Association Between Self-Reported PC Knowledge With Actual PC Knowledge Level Among Subgroups

	Entire Sample[a] ($n = 1112$); Frequency (%)		Age 65 yrs and older ($n = 356$); Frequency (%)		Cancer ($n = 196$); Frequency (%)	
	Know a Little	Know and Can Explain	Know a Little	Know and Can Explain	Know a Little	Know and Can Explain
0 correct	82 (12)	25 (6)	33 (14)	11 (9)	11 (10)	6 (7)
1 correct	128 (19)	55 (13)	49 (21)	17 (13)	23 (22)	14 (15)
2 correct	234 (35)	136 (31)	77 (33)	43 (34)	33 (31)	26 (29)
All correct	231 (34)	221 (51)	71 (30)	55 (44)	38 (36)	45 (50)

[a]$P = 0.007$.

Table 3
Multivariate Logistic Regression Model for Factors Associated With Being Fully Understanding PC

	All Self-Report Knows Frequency (%; $n = 925$)	Odds Ratio
Variable		
Self-report known PC		
Little	566 (61)	
More	359 (39)	2.06[a]
Gender		
Female	642 (69)	
Male	283 (31)	1.13
Age, yrs		
<65	640 (69)	0.99
≥65	285 (31)	
Marital status		
Married	498 (54)	
Living as married	24 (3)	0.87
Divorced	172 (19)	0.96
Widowed	87 (9)	0.42
Separated	16 (2)	0.35
Single, never been married	128 (14)	0.79
Race		
Non-white	236 (26)	
White	689 (74)	1.66
Education		
Less than high school	14 (2)	
High school graduate	86 (9)	8.71
Some college	236 (26)	15.35
Bachelor's degree	290 (31)	21.07[a]
Post-baccalaureate degree	299 (32)	23.07[a]
Income		
Less than $20,000	86 (9)	
$20,000 to <$35,000	102 (11)	1.45
$35,000 to <$50,000	103 (11)	1.06
$50,000 to <$75,000	163 (18)	1.16
$75,000 or more	471 (51)	1.24
Ever had cancer		
No	773 (84)	
Yes	152 (16)	0.79

PC = palliative care.
[a]$P < 0.05$.

substantial misconceptions about PC. Findings show that although there was a significant relationship between self-reported and actual knowledge, only half of those claiming to know what PC is correctly responded to all three fundamental PC statements, and 19% of those claiming knowledge answered only one or fewer questions correctly. Surprisingly, this rate was not improved among older respondents and those with a history of cancer; in fact, while not statistically significant, there was a trend ($P = 0.08$) toward older respondents having lower actual knowledge of PC.

The most frequently missed knowledge statement for all groups was "PC is the same as hospice care." Perhaps one of the greatest barriers to PC faced by the U.S. health care system is the widespread confusion between PC and hospice, namely that PC is similar to hospice.[10] Given the negative perceptions of hospice and the well documented associations between "hospice" and negative terms such as "death" and "giving up,"[11,12] documentation of confusion between hospice and PC is concerning and can contribute to additional barriers to PC.[13]

The confusion between hospice and PC stems from the fact that PC is a component of hospice care, thus PC is provided by both hospices and PC programs. To avoid the arising consumer confusion around PC programs, some organizations are finding success in using alternate terms for their PC program, such as "supportive" or "comfort" care.[14,15]

Finally, in the regression analysis, we found that higher education attainment (bachelor's degree or more) was positively associated with actual PC knowledge. This finding may be due to issues of health literacy. A previous study found that online PC and oncology patient educational articles are written beyond the national health literacy guidelines.[16] Thus, although people may be more exposed to the term "PC," only those with higher education levels may have the advantage of understanding what the term actually means. Health literacy also has been found to be predictive of end-of-life care decisions.[17]

Limitations

The measurement tool used in the HINTS to measure actual PC knowledge was based on just three fundamental questions. To better understand the full range of PC knowledge and possible misconceptions, a more comprehensive PC knowledge questionnaire would be needed. Validated tools, such as the Palliative Care Knowledge Scale,[18] a 13-question scale that focuses on areas including the team approach, psychosocial support, and populations served,[19] may elicit a clearer understanding of the PC knowledge level among the general public.

Implications

This study provides initial insight into a comparison of stated knowledge and actual PC knowledge and demonstrates that many who claim to know about PC lacked specific knowledge of it. This finding holds tremendous implications for physicians and other clinicians. When discussing PC or initiating referrals to PC services, it is important for health care providers to present a description of the services or care, regardless of patient-stated knowledge or familiarity, to address potential misconceptions and erroneous beliefs about PC. In addition, this PC information should be provided at a low literacy level to ensure widespread understanding of the service. Finally, by asking patients and family members to describe what they know of PC, health care professionals will have the opportunity to directly address patient and family PC misconceptions and lack of knowledge.

Disclosures and Acknowledgments

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors. The authors declare no conflicts of interest.

References

1. Harrington E, McInturff B. 2011 public opinion research on palliative care. Cent to Adv Palliat Care. Am Cancer Soc Am Cancer Soc Action Netw 2011.

2. California HealthCare Foundation. Snapshot Final Chapter: Californians' Attitudes and Experiences with Death and Dying. Calif Healthc Found. 2012 (February). Available from https://www.chcf.org/wp-content/uploads/2017/12/PDF-FinalChapterDeathDying.pdf. Accessed April 2, 2019.

3. Shalev A, Phongtankuel V, Kozlov E, Shen MJ, Adelman RD, Reid MC. Awareness and misperceptions of hospice and palliative care: a population-based survey study. Am J Hosp Palliat Med 2018;35:431–439, https://doi.org/10.1177/1049909117715215.

4. Meier D, Morgan L. Messaging Palliative Care. Center to Advance Palliative Care, American Cancer Society, American Cancer Society Action Network. 2016. Available from https://www.capc.org/blog/palliative-pulse-palliative-pulse-november-2016-messaging-palliative-care/. Accessed April 3, 2019.

5. Gorman A. 'Pre-Hospice' Saves Money By Keeping People At Home Near The End Of Life. Kaiser Health News. 2017. Available from https://khn.org/news/pre-hospice-saves-money-by-keeping-people-at-home-near-the-end-of-life/. Accessed April 3, 2019.

6. Cagle JG, Van Dussen DJ, Culler KL, et al. Knowledge about hospice. Am J Hosp Palliat Med 2014;33:27–33.

7. McIlfatrick S, Noble H, McCorry NK, et al. Exploring public awareness and perceptions of palliative care: a qualitative study. Palliat Med 2014;28:273–280.

8. HINTS. Analytics Recommendations for HINTS4 – Cycle 3 Data 2014.

9. Dumanovsky T, Augustin R, Rogers M, Lettang K, Meier DE, Morrison RS. The growth of palliative care in U.S. Hospitals: a status report. J Palliat Med 2016;19:8–15.

10. Currie E, Bakitas M, Perna S, Christian B, Meneses K. "When I Heard Palliative Care, I Heard Hospice": Parents' experiences W\with pediatric Palliative Care consultation in the neonatal intensive care unit (S748). J Pain Symptom Manage 2016;51:433.

11. van Dussen D, Culler KL, Cagle JG. Perceptions about hospice from a community-based pilot study: lessons and findings. Am J Hosp Palliat Med 2011;28:418–423.

12. Ford DW, Nietert PJ, Zapka J, Zoller JS, Silvestri GA. Barriers to hospice enrollment among lung cancer patients: a survey of family members and physicians. Palliat Support Care 2008;6:357–362.

13. Zimmermann C, Swami N, Krzyzanowska M, Al E. Perceptions of palliative care among patients with advanced cancer and their caregivers. CMAJ 2016;188:711–712.

14. Dalal S, Palla S, Hui D, et al. Association between a name change from palliative to supportive care and the timing of patient referrals at a comprehensive cancer center. Oncologist 2011;16:105–111.

15. Fadul N, Elsayem A, Palmer JL, et al. Supportive versus palliative care: what's in a name? Cancer 2009;115:2013–2021.

16. Prabhu AV, Crihalmeanu T, Hansberry DR, et al. (S041) online palliative care patient education resources: do they meet national health literacy recommendations? Int J Radiat Oncol 2017;98:E12–E13.

17. Volandes AE, Paasche-Orlow M, Gillick MR, et al. Health literacy not race predicts end-of-life care preferences. J Palliat Med 2008;11:754–762.

18. Kozlov E, Carpenter BD, Rodebaugh TL. Development and validation of the Palliative Care Knowledge Scale (PaCKS). Palliat Support Care 2017;15:524–534.

19. Kozlov E, McDarby M, Reid MC, Carpenter BD. Knowledge of palliative care among community-dwelling adults. Am J Hosp Palliat Med 2018;35:647–651.