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Knowledge of Palliative Care Among Community-Dwelling Adults

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Abstract

Objective—To identify what laypersons know about palliative care using the Palliative Care Knowledge Scale (PaCKS). A secondary aim was to establish preliminary normative data for the PaCKS.

Methods—A sample of 301 adults were recruited via Amazon’s Mechanical Turk database. Participants were administered the PaCKS along with a demographic questionnaire.

Results—The mean score on the 13-item PaCKS was 5.25 (standard deviation = 4.77, range: 0–13), the median was 5, and the mode was 0, with a significant proportion of participants selecting “I don’t know” for every item. Women scored significantly higher than men, and 45- to 54- and 55- to 64-year-olds scoring highest. The PaCKS was also significantly positively correlated with education.

Conclusion—Broadly, laypersons lack knowledge about some key aspects of palliative care, though palliative care knowledge is highly variable across individuals and some groups. Targeted educational interventions are essential to improve knowledge of palliative care in order to increase access to this type of life-enhancing, supportive service.

Keywords

palliative care knowledge; patient education; palliative care misinformation; palliative care information; palliative care education; patient knowledge

Introduction

Palliative care is becoming increasingly available nationwide.^{1,2} Despite its ability to enhance quality of life for patients with life-limiting illness and their families,^{3–5} palliative care remains underutilized. In 2015, fewer than 5% of hospitalized patients were seen by a

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palliative care team.⁶ Given that the number of Americans living with serious illness is expected to double in the near future,⁷ it is essential that researchers and clinicians understand the barriers to accessing palliative care.

One potential barrier is lack of patient and layperson knowledge. Grossman and Kaestner⁸ hypothesize that knowledge of a service drives utilization, given that consumers must understand the benefits of a health service before accepting it. Indeed, greater knowledge of palliative care is associated with improved receptivity for this service.^{9,10} Preliminary research suggests that laypersons are mostly unaware of or misinformed about palliative care.^{11–14} This lack of awareness is shared by both patients and providers alike^{15–17}. In order to develop effective public education resources, more information is needed to elucidate what specific aspects of palliative care remain poorly understood.

The Palliative Care Knowledge Scale (PaCKS)¹⁵ is a 13-item true/false measure developed to ascertain laypersons knowledge of palliative care. The validity and reliability of the measure have been established.¹⁵ Given the ease of guessing on true/false format scales (people can guess correctly 50% of the time), the purpose of this study was to measure palliative care knowledge in laypersons allowing for an “I don’t know” response option (not present in the original version of the scale) to dissuade guessing.¹⁶ When used properly, an “I don’t know” option allows respondents to indicate knowledge they truly lack, which is obscured by forced guessing. A secondary aim was to establish preliminary information about how different sociodemographic groups perform on the PaCKS.

Methods

This study was approved by the host university’s Human Research Protection Office. A request for participants was posted on Amazon’s Mechanical Turk (mTURK) site informing potential participants about the study and inviting them to a web page for more information and access to the study. The mTURK is an online marketplace for tasks, including survey work, that has been a useful and valid source of subjects for behavioral and cognitive science research.¹⁷ A community-based sample of N = 301 adults aged 18 to 98 was recruited (see Table 1). Recruitment goals for age were set to ensure diverse age representation. The study was posted on mTURK for roughly 1 month until recruitment goals were satisfied.

Measures

Demographics—The following demographic information was collected: age, gender, race, ethnicity, education level, marital status, and household income.

Palliative care knowledge and familiarity—The 13 true/false PaCKS items ask about various domains of palliative care knowledge (Appendix A). The number of correct responses is tallied, and scores range from 0 (lowest knowledge) to 13 (highest knowledge). “I don’t know” responses were scored as incorrect when calculating total PaCKS scores. The Cronbach α for this sample was .94.

Participants were also asked if they had heard of palliative care (yes/no). If participants had heard of palliative care, they were also asked if they knew someone who had used palliative care.

Analysis

Descriptive analyses were utilized to characterize the sample and establish preliminary data on how different demographic groups respond to the PaCKS. *t* Tests were conducted to compare PaCKS scores across gender and familiarity with palliative care. An analysis of variance (ANOVA) with Tukey's post hoc comparisons was conducted to analyze how different age groups perform on the PaCKS. Pearson correlations were calculated to assess the relationship between education and PaCKS total scores.

Results

The mean PaCKS score was 5.25 (standard deviation [SD] = 4.77, range: 0–13), with a median of 5.00, a skew of .19, and a kurtosis of –1.50. Individual items were answered correctly from between 25% and 47% of the time (see Table 2). Participants responded incorrectly most frequently to items 5 (75% responded incorrectly) and 11 (66% responded incorrectly). They responded correctly most often to items 3, 6, 7, and 13 (46%–47%). Participants responded “I don't know” a mean of 6.5 times (SD = 5.49).

There was a significant difference in PaCKS scores between men, mean = 4.30, SD = 4.62, and women, mean = 6.13, SD = 4.76, $t(298) = -3.37$, $P < .001$, and education was significantly correlated with performance on the PaCKS ($r = .18$, $P = .002$). An ANOVA revealed a significant difference between age groups ($F_{5, 295} = 7.15$, $P < .01$), with post hoc Tukey's Honest Significant Difference comparisons revealing that people in age groups 45 to 54 and 55 to 64 scored significantly higher than those in age groups 18 to 24 and 25 to 34. Table 3 presents mean PaCKS scores by age, gender, race/ethnicity, and education status.

Fewer than half the sample had heard of palliative care (46.8%). Participants who had not heard of palliative care had lower PaCKS scores, mean = 2.23, SD = 3.60, than those who had, mean = 8.68, SD = 3.44, $t(297) = 15.91$, $P < .001$. Those who had not heard of palliative care were also more likely to answer “I don't know,” mean = 9.88, SD = 4.79, than those who had, mean = 2.70, SD = 3.29, $t(283) = -15.326$, $P < .001$.

Participants who knew someone who used palliative care scored significantly higher, $n = 76$, mean = 9.49, SD = 2.85, than those who did not know someone who used palliative care, $n = 65$, mean = 7.74, SD = 3.83, $t(116) = 3.03$, $P = .003$.

Discussion and Conclusions

These results suggest that adults in the United States lack basic knowledge about palliative care, consistent with previous studies.^{11–14} All measures of central tendency indicated low knowledge of palliative care, and tellingly, only 46% of participants had even heard of palliative care.

Palliative care knowledge is also highly variable across groups. Women and adults between the ages of 45 and 64 had higher PaCKS scores. Women (versus men) may have greater knowledge of palliative care because they are more likely to be caregivers for aging parents who have had some experience with end-of-life care.¹⁸ Individuals aged 45 to 64 may have higher PaCKS scores than other age groups, as a result of adults in this age range being more likely to experience the deteriorating health of their friends and family members.¹⁹ Although certain demographic groups may benefit from more intensive educational efforts about palliative care, the range of knowledge was very broad within every group, and education should be ideally broad in reach and scope.

Certain PaCKS items were less likely to be answered correctly than others. For example, the item, “Palliative care is exclusively for people who are in the last 6 months of life” was least likely to be answered correctly. If a person believes that palliative care can only be accessed during the last 6 months of life (which is incorrect), this misinformation poses a likely barrier to accessing care early in the illness trajectory, when palliative care can be most beneficial.^{4,20} Hospice, a subset of palliative care, is restricted to patients in the last 6 months of life, thus this item likely represents laypersons tendency to conflate hospice with palliative care. Educational interventions can be highly effective at correcting misinformation, and several educational interventions about palliative care are being developed and piloted in diverse settings.^{21–23} In order to be effective, these interventions should target the most common types of misinformation and missing information. Our results suggest that confusion between hospice and palliative care, specifically the timing of hospice versus palliative care, constitutes a particularly appropriate target for educational interventions.

Another frequently missed item states, “Palliative care encourages people to stop treatments aimed at curing their illness.” If laypersons believe that palliative care urges patients to refrain from seeking curative treatments, they would understandably be less likely to accept palliative care services early in the illness trajectory when patients may still be actively seeking curative treatment. This type of misinformation also likely constitutes a barrier to timely access to palliative care and represents another worthwhile target for future educational initiatives.

Perhaps the most striking finding was the rate at which participants answered “I don’t know.” Previous research suggests that including an “I don’t know” option on knowledge scales reduces guessing and yields more accurate data.²⁴ Given the substantial percentage of participants who selected “I don’t know” on multiple PaCKS items, health educators and providers should assume that most laypersons are unfamiliar with the characteristics of palliative care. Health literacy best practices include assuming that patients may not understand the message being conveyed by the provider.²⁵ Providing a broad overview of palliative care for all individuals, regardless of self-reported prior knowledge, can reinforce information for people with a preexisting understanding of palliative care and simultaneously create an opportunity to educate and correct misinformation for everyone else.

One limitation of this research was that it was conducted using mTURK participants. Although mTURK has been shown to be a valid and reliable source for social science data,²⁶ participants were skewed toward a more educated, white, and young sample compared to the general population. This study would benefit from replication in an in vivo format, with more racial, ethnic, and age diversity. Furthermore, this population was not a patient population; thus, the relevance of the topic of palliative care is likely greatly reduced than if we had surveyed a population of adults currently being treated for advanced illness. This study would benefit from being replicated in a patient and caregiver population for whom the topic was more immediately relevant.

In conclusion, this study found that misinformation and lack of knowledge regarding palliative care are highly prevalent in the general public. Our findings emphasize the need for public health initiatives to raise awareness and improve knowledge of palliative care.^{10,20} For example, health-care providers and systems could engage in educational campaigns and marketing strategies to inform the public on how palliative care can improve quality of life of individuals with life-limiting illness and their families. Kozlov and Carpenter published guidelines on how to develop educational materials to inform the general public about palliative care²⁶ after finding that educational materials lacked consistency and often failed to address many key core concepts in palliative care. The results from this study can further guide future educational initiatives to target key demographics, as the study identified key subgroups with limited knowledge as well as specific domains of palliative care knowledge where education is needed.

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Appendix A

Below are some questions about a type of care called palliative care. Please answer the questions below by circling True, False, or I don't know. If you do not know the answer, do not guess. Instead, respond with "I don't know."

-
1.	A goal of palliative care is to address any psychological issues brought up by serious illness.	True	False	I don't know
2.	Stress from serious illness can be addressed by palliative care.	True	False	I don't know
3.	Palliative care can help people manage the side effects of their medical treatments.	True	False	I don't know
4.	When people receive palliative care, they must give up their other doctors.	True	False	I don't know
5.	Palliative care is exclusively for people who are in the last 6 months of life.	True	False	I don't know
6.	Palliative care is specifically for people with cancer.	True	False	I don't know
7.	People must be in the hospital to receive palliative care.	True	False	I don't know
8.	Palliative care is designed specifically for older adults.	True	False	I don't know
9.	Palliative care is a team-based approach to care.	True	False	I don't know
10.	A goal of palliative care is to help people better understand their treatment options.	True	False	I don't know
11.	Palliative care encourages people to stop treatments aimed at curing their illness.	True	False	I don't know
12.	A goal of palliative care is to improve a person's ability to participate in daily activities.	True	False	I don't know
13.	Palliative care helps the whole family cope with a serious illness.	True	False	I don't know
-

Table 1Demographic Characteristics of Study Participants.^a

Measure	Mean (SD)	n (%)
Age, years		
18–24	22.5 (1.9)	32 (10.6)
25–34	29.4 (2.8)	55 (18.2)
35–44	38.1 (2.7)	59 (19.6)
45–54	49.7 (3.0)	60 (19.9)
55–64	58.9 (2.6)	61 (20.2)
65+	70.2 (6.1)	34 (11.2)
Gender (female)		156 (51.8)
Race/ethnicity		
Asian		14 (4.7)
Black		28 (9.3)
Hispanic/Latino		10 (3.3)
White		241 (80.1)
Multiracial		8 (2.6)
Education		
Some high school		2 (<1)
High school graduate/GED		42 (14.0)
Some college		84 (28.0)
Associate's degree		41 (13.7)
Bachelor's degree		103 (34.3)
Graduate degree		28 (9.3)
Missing		1 (<1)
Marital status		
Single or not married/cohabitating		154 (51.2)
Married/partnered		98 (32.6)
Separated or divorced		38 (12.7)
Widowed		11 (3.7)
Household income		
\$0–\$19 999		59 (19.6)
\$20 000–\$39 999		98 (32.6)
\$40 000–\$59 999		66 (21.9)
\$60 000–\$79 999		38 (12.6)
\$80 000–\$99 999		13 (4.3)
\$100 000+		27 (9.0)

Abbreviation: SD, standard deviation.

^aN = 301. \$ signifies US\$.

Table 2True, False, and Don't Know (DK) Responses for Each PaCKS Item.^{a,b}

Item	% True	% False	% DK
1. A goal of palliative care is to address any psychological issues brought up by serious illness.	38	11	51
2. Stress from serious illness can be addressed by palliative care.	44	7	49
3. Palliative care can help people manage the side effects of their medical treatments.	46	4	50
4. When people receive palliative care, they must give up their other doctors.	7	43	50
5. Palliative care is exclusively for people who are in the last 6 months of life.	18	25	57
6. Palliative care is specifically for people with cancer.	5	47	48
7. People must be in the hospital to receive palliative care.	5	46	49
8. Palliative care is designed specifically for older adults.	9	41	50
9. Palliative care is a team-based approach to care.	42	8	50
10. A goal of palliative care is to help people better understand their treatment options.	34	15	51
11. Palliative care encourages people to stop treatments aimed at curing their illness.	16	34	50
12. A goal of palliative care is to improve a person's ability to participate in daily activities.	39	12	49
13. Palliative care helps the whole family cope with a serious illness.	46	6	48

Abbreviation: PaCKS, Palliative Care Knowledge Scale.

^aN = 301.^bBolded text represents the correct answer.

Table 3

Overall Score on PaCKS Based on Demographic Characteristics.

Measure	n	Mean (SD)
Total	301	5.25 (4.77)
Age, years		
18–24	32	3.22 (4.02)
25–34	55	4.40 (4.36)
35–44	59	3.49 (4.23)
45–54	60	7.03 (4.87)
55–64	61	7.03 (4.75)
65+	34	5.24 (4.87)
Gender		
Male	145	4.30 (4.62)
Female	156	6.13 (4.76)
Race/ethnicity		
Asian	14	4.57 (4.31)
Black	28	3.86 (4.04)
Hispanic/Latino	10	3.80 (3.01)
White	241	5.57 (4.91)
Multiracial	8	3.38 (4.69)
Education		
Some high school	2	3.50 (4.95)
High school graduate/GED	42	4.48 (4.77)
Some college	84	4.57 (4.60)
Associate's degree	41	4.32 (4.99)
Bachelor's degree	103	6.09 (4.68)
Graduate degree	28	6.89 (4.86)
Missing	1	NA (NA)
Marital status		
Single or not married/cohabitating	154	4.95 (4.37)
Married/partnered	98	5.04 (5.11)
Separated or divorced	38	6.24 (5.53)
Widowed	11	7.91 (3.41)
Income		
\$0–\$19 999	59	5.32 (4.79)
\$20 000–\$39 999	98	5.29 (4.56)
\$40 000–\$59 999	66	4.89 (4.75)
\$60 000–\$79 999	38	5.92 (4.97)
\$80 000–\$99 999	13	3.62 (4.87)
\$100 000+	27	5.67 (5.41)

Abbreviations: PaCKS, Palliative Care Knowledge Scale, SD, standard deviation, NA, Not Available. \$ signifies US\$.