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Improving patient knowledge of palliative care: A randomized controlled intervention study

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Abstract

Objectives—To determine if laypersons' knowledge about palliative care can improve with a brief education intervention.

Methods—152 adults were recruited to participate in a web-based randomized intervention trial that followed a 2 (content) $\times$ 2 (format) between-subjects design. Groups received either a video intervention, an information page intervention, a video control, or an information page control. An ANCOVA with contrast coding of two factors was utilized to assess if knowledge, as measured by the Palliative Care Knowledge Scale (PaCKS), increased post intervention.

Results—There was a significant difference between intervention group means and control group means on PaCKS scores from T1 to T2 $F(1, 139) = 11.10, p = 0.00, \eta_p^2 = 0.074$. There was no significant difference in PaCKS change scores between the video intervention and information page intervention.

Conclusions—This study demonstrates that an information page and a brief video can improve knowledge of palliative care in laypersons.

Practice implications—Self-administered educational interventions could be made available in diverse settings in order to reach patients and their families who may benefit from but are unaware of palliative care. Interventions more intensive than the one tested in this study might result in even more significant improvements in knowledge.

Keywords

Palliative care; Education; Palliative care knowledge; Education intervention

1. Introduction

Palliative care is team-based care that improves the quality of life for individuals with serious illness and their families and is associated with improved patient (e.g., decreased symptom burden) and system (e.g., reduced costs) outcomes [1–4]. Palliative care is

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intended to be complementary to curative treatment and can be offered throughout the course of a serious illness [1–4], in contrast to hospice, a subtype of palliative care that is reserved for the last six months of life, when only comfort care is indicated. Although palliative care programs are increasingly prevalent in America's health care systems [5,6], many patients who would benefit from palliative care and have access to it never receive palliative care or receive it too late in their illness trajectory to be maximally beneficial [7–9]. As America's population continues to age, there will be an increased need for palliative care services. It is imperative that we understand the barriers to accessing palliative care and develop interventions to improve palliative care utilization. One likely barrier is public knowledge and awareness of the service.

Grossman & Kaestner [10] proposed that patient knowledge of health services drives utilization and that consumers need to know what a service is and how it is relevant to their situation before they will seek it out or accept it. Previous research, sparse as it is, has confirmed that patients have little knowledge about palliative care. Multiple studies reported that the vast majority of layperson and patient participants have not heard of palliative care [11–13]. If patients and family members are unaware of palliative care, they are unable to ask physicians for a referral, and if physicians refer their patients to palliative care, patients may refuse if they are unfamiliar with the service or misunderstand key aspects of this type of care. Patients are not able to make fully informed treatment decisions when they are unaware of all the care options available. Furthermore, because hospice is mistakenly and frequently equated with palliative care, patients may be unwilling to accept a referral for palliative care early in their disease trajectory if they are still interested in curative treatments [14]. Indeed, palliative care tends to be introduced late in the illness trajectory [7–9,15] despite recommendations to initiate it at the time of a life-limiting illness diagnosis.

Prior research on palliative care knowledge and education has primarily focused on healthcare providers and has not explored patient knowledge and education initiatives. Physician knowledge about palliative care appears to be low [15–17], and physicians are generally unaware of their knowledge deficits [18,19]. Interestingly, physicians do not identify themselves as a prominent barrier to palliative care services. In one study, 70% of physicians reported that the most common barrier to having patients accept a palliative care referral was their unrealistic goals and expectations about their illness trajectory (Snow et al., 2009). Although physicians identify patients as the most common barrier to palliative and hospice care, little research has focused on patient factors related to palliative care utilization.

One mechanism to help patients gain knowledge about their health and available services is to address their level of health literacy (HL). The American Medical Association defines HL as “a constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health-care environment” [20]. HL is necessary for patients to obtain knowledge about their illness and be active participants in their own health care. Older age and the presence of chronic health conditions are both associated with lower levels of HL [21,22]. Because palliative care is intended for individuals with chronic health conditions, many of whom are older adults, poor HL may serve as an additional barrier for patient and family utilization of palliative care. Previous research has found that among

patients with low health literacy, education via video can be a successful medium for educating patients about end-of-life care [23]. Though written information pages are more feasible for use in hospitals and medical center waiting rooms, video may have potential benefits, including increased engagement, which can facilitate learning [23,24].

Preliminary evidence suggests that patients' lack of knowledge is a key barrier to accessing palliative care [16,25]. It is imperative that we begin to close the knowledge gap through educational interventions so that consumers can make informed decisions about how best to manage their health. Providing information in a medium that is sensitive to patients with low HL is one way of bridging knowledge gaps [26]. To our knowledge, there have been no empirical evaluations of attempts to educate the public about palliative care despite calls for researchers to focus on reducing knowledge gaps regarding palliative care utilization [27]. Accordingly, this study sought to determine if laypersons' knowledge about palliative care can improve with a brief, self-administered educational intervention. Furthermore, this study aimed to determine if a brief educational video is a more effective method of improving knowledge about palliative care than a written information page about palliative care.

2. Methods

A community sample of adults aged 18–89 ($N = 152$) was recruited from multiple sources, including two existing research registries maintained by the host university and host academic hospital, as well as through Amazon's Mechanical Turk (mTurk) workforce, an online marketplace for tasks including survey work that has been a useful and valid source of subjects for behavioral and cognitive science research [28]. To ensure age representation, recruitment goals were set for each age decade. The control group and the intervention group were not significantly different in regards to age ($t = .183$, $p = .25$). For participants' demographic characteristics and breakdown of age stratification, see Table 1.

2.1. Measures

2.1.1. Demographics—Gender, age, race, ethnicity, marital status, and education were collected for each participant.

2.1.2. Palliative Care Knowledge Scale (PaCKS) [29]—This 13-item true/false scale is used to assess general knowledge of palliative care. Although the PaCKS as a whole is a unidimensional scale of overall knowledge about palliative care, scale items cover a broad variety of topics within palliative care identified as important by palliative care professionals during scale development [30]. Two sample items from the scale include, “Palliative care is specifically for people with cancer” (false) and “Palliative care helps the whole family cope with a serious illness” (true). The PaCKS is internally consistent, valid, and brief. Scores can range from 0 to 13, with higher scores reflecting greater knowledge. Coefficient alpha in the current sample was 0.71.

Participants also rated their confidence in their answer choices (for all 13 items) on a Likert-type scale ranging from 1 (*not at all confident*) to 5 (*extremely confident*). Mean confidence scores were calculated for each participant.

2.2. Procedures

This study was reviewed and approved by the Washington University Human Research Protection Office. An advertisement was emailed to registry-recruited participants along with a link to the study. Similarly, a request for workers was posted on Amazon's Mechanical Turk site informing potential participants about the study and inviting them to a web page for more information and access to the study. The study was hosted on the Qualtrics online platform.

Sample size was determined from a G*Power analysis for an ANCOVA with contrast coding (G*Power with effect size = 0.5, α = 0.05, desired power = 0.80, $n > 74$). The initial recruitment goal was $n = 120$, but due to a website error that randomized participants only into the intervention groups, an additional 32 participants were recruited to ensure adequate power across all conditions. A random number generator (www.random.org) was used to generate a set of 122 (the error was discovered after the first 30 participants were not properly randomized) equally represented numbers ranging from one to four to establish which participants were assigned to each group in this 2 (content – intervention vs. control) $\times$ 2 (format – video vs. information page) between-subjects design. Group 1 received the video intervention, Group 2 the information page intervention, Group 3 the video control, and Group 4 the information page control.

2.3. Materials

The intervention video was a three-minute video from About.com about palliative care (<http://video.about.com/healthcareers/What-Is-Palliative-Care.htm>). In this video, a doctor discusses what palliative care is, who provides and receives it, and where patients can receive palliative care. The physician is shown interacting with a diverse range of patients in the hospital including older and younger patients and patients with varying levels of frailty. The physician speaks directly to the camera, and written information appears simultaneously on the screen to complement the message the physician is discussing. A written palliative care information page from Vanderbilt Health (<http://www.vanderbilthealth.com/palliativecare/21568>) was adapted to have the same information as the video (see Appendix A). The control video consisted of a three-minute educational video about the Mediterranean Diet and health (<http://video.about.com/nutrition/What-Is-the-Mediterranean-Diet-.htm>), while the control information page provided participants with information about the Mediterranean Diet and health (<http://cholesterol.about.com/od/cholesteroldiets/a/mediterranean.htm>).

2.4. Analyses

An ANCOVA with contrast coding of two factors was utilized to assess if knowledge, as measured by the PaCKS, increased after participants were exposed to a brief educational intervention. Ten participants had missing data on the PaCKS and were not included in final analyses. The contrast coding accounted for two factors: intervention vs. control (intervention $n = 77$, control $n = 75$) and information page intervention vs. video intervention (information page $n = 43$, video $n = 34$).

A second ANCOVA with contrast coding of two factors was utilized to assess if confidence in answer choices changed after participants were exposed to a brief educational intervention. Mean confidence scores were used as the outcome measure, and the factors remained the same as described above.

3. Results

Mean scores on the PaCKS and mean confidence ratings appear in Table 2. At post-test, scores on the PaCKS were significantly higher for both intervention groups compared to the control groups, $F(1, 139) = 11.10, p = 0.00, \eta_p^2 = 0.074$. This was a small but statistically significant improvement in knowledge. There was no significant difference between the video intervention and the intervention page, $F(1, 67) = 0.011, p = 0.92$.

At post-test, ratings of confidence in knowledge were higher in the intervention group compared to the control group, $F(1, 136) = 113.11, p = 0.00, \eta_p^2 = 0.45$. The effect size was much larger for this change. There was no significant difference between the confidence ratings in the video intervention and the intervention page, $F(1, 68) = 0.001, p = 0.97$.

4. Discussion and conclusion

4.1. Discussion and practice implications

This study demonstrated that a simple information page or a brief educational video can improve knowledge of palliative care as well as confidence in knowledge of palliative care. If patients are unaware of or are misinformed about palliative care, brief educational interventions can help to address these gaps by providing accurate and comprehensive information. Both video and information page interventions performed equally well in this study and could be made available in inpatient settings or outpatient waiting rooms of diverse subspecialists (e.g., pulmonologists, cardiologists, oncologists, and geriatricians) to reach patients and their families who may be eligible for but are unaware of palliative care. Brief, self-administered interventions can help professionals maximize their limited time with patients by focusing on issues that cannot be addressed with brochures and videos. When physicians make referrals for palliative care, priming patients with educational interventions could also expedite and enhance the process. Furthermore, because prior research elucidates that patient knowledge about a health care service is key to enhancing utilization of the service, educating patients about palliative care may be essential in reducing barriers to palliative care uptake.

Notably, participants' confidence in their knowledge about palliative care increased. This study did not include an "I don't know" response option on the PaCKS, so it unclear when participants were guessing, and with a true/false scale respondents could randomly guess correctly 50% of the time. The increased PaCKS and confidence scores post intervention suggest, however, that participants not only acquired new knowledge about palliative care, but also became more certain in their response choices. The full impact of the educational intervention is difficult to assess given the possibility that participants could have guessed correctly during both administrations of the PaCKS. Future research could consider adding an "I don't know" option to the PaCKS to limit guessing and better document knowledge

gains made after intervention. Furthermore, because this is the first study to assess the effects of educational interventions on palliative care knowledge, what constitutes a clinically significant increase in knowledge has yet to be determined. Ideally, increased knowledge about palliative care would lead to other, subsequent behavioral outcomes, such as seeking further information about palliative care and accepting it when it is offered, both of which could be measured in patients. Future research should explore how much knowledge about palliative care individuals require in order to be amenable to a referral for the service.

4.2. Limitations

This study had several limitations. Data were collected over a short period of time, and though scores on the PaCKS improved, it is not yet known whether these knowledge gains persist over the long term. Future research should investigate if knowledge gains are stable over longer time intervals. Another limitation is that while knowledge deficits of palliative care may be related to poor utilization, their relationship remains untested. Future research should elucidate the relationship between knowledge of palliative care and increased service utilization.

Finally, this study utilized a community sample rather than a sample of patients with serious or life-limiting illnesses for whom palliative care would be most relevant. It is possible that video and the information page interventions might have a differential impact, particularly for people who are older and more. Future research should investigate educational interventions in a patient population to elucidate best practices for improving knowledge about palliative care.

4.3. Conclusions

To our knowledge, this is the first randomized controlled study demonstrating that laypersons' knowledge of palliative care can be improved with brief educational interventions. This study constitutes a critical first step in developing interventions to reduce barriers, such as knowledge deficits, to palliative care access and utilization.

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Appendix A

• What is Palliative Care?

Palliative Care is specialized care that focuses on patients who are facing life-threatening illness or injury. The primary goal of palliative care is to provide expertise and treatment plans for symptom management, as well as practical and emotional support while

considering the whole patient and their situation. It is not just for the patient who is at the end of life. The Palliative Care team is interdisciplinary and offers services such as:

- Providing relief from pain and other physical symptoms
- Improving quality of life
- Providing support to the seriously ill and the family and friends who love and care for them
- Assisting the patient, family and staff with difficult medical decision-making

With palliative care, patients partner with an experienced team to determine the best options for managing their specific symptoms. Specialists meet with each patient to discuss their expectations and goals for treatment as well as their personal values and priorities. Palliative care works as a complimentary supplement to a patient's usual medical treatment; and is available to patients at any stage of illness to help manage symptoms of their treatment. The majority of palliative care in this country is delivered in the hospital but palliative care can also be seen in the outpatient clinic or in the doctor's office. Palliative care can also be in the Nursing Homes and there are some places that will also do Palliative care at home by sending clinicians to the house to do palliative care home visits.

• When is the Right Time for Palliative Care?

Patients who are coping with a serious illness can benefit from palliative care any time during their treatment. These patients may still be receiving treatment aimed at a cure. Palliative care is provided by a team of trained healthcare professionals with clinical expertise in:

- disease process
- treatment options
- pain and symptom management.

The Palliative Care Team typically sees patients:

- at the time of a new diagnosis
- at the end of life
- when a serious illness/injury is impacting their quality of life

The team is skilled in helping patients and families cope with illness.

Comfort and quality of life are important aspects of palliative care, which is why the team works with the patient's attending physician, the family, and the patient himself to achieve the patient's goals.

The Goals of Palliative Care

The goal of palliative care is to relieve pain, symptoms and stress during the course of a life threatening illness. The desired outcome and primary focus of palliative care is to increase a patient's quality of life.

Palliative care can be delivered from the first diagnosis of a disease to the end stages of a disease. It can also be delivered in conjunction with a patient's active treatment such as chemotherapy.

The Difference Between Palliative Care and Hospice

Palliative care is not the same as hospice care. Palliative Care is for anyone with a serious illness or injury and is available for patients at any time in their treatment process.

The Roles of Your Care Providers

Palliative Care Doctors and Nurse Practitioners

The palliative care team is led by highly trained expert doctors and nurse practitioners who will evaluate and treat symptoms, assist with coping with complicated conversations and situations that occur at the end of life, and will help establish goals of care that are consistent with personal beliefs, values and faith.

<http://www.vanderbilthealth.com/palliativecare/26391>

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Table 1

Demographics.

	Control		Intervention	
	<i>n/M</i>	% of total/ <i>SD</i>	<i>n/M</i>	%/ <i>SD</i>
Age	53.74	20.03	53.17	17.44
18–29	14	9.2	10	6.5
30–39	8	7.6	10	6.5
40–49	10	6.5	14	9.1
50–59	5	3.3	10	6.5
60–69	16	10.5	16	10.5
70–70	17	11.1	10	6.5
80–89	6	4.0	7	4.6
Gender				
Male	36	23.53	27	17.64
Female	40	26.14	50	32.68
Education	15.84	3.59	15.43	3.02
Race				
White	62	40.52	63	41.18
Non-white	14	9.15	14	9.15
Marital Status				
Single	21	13.73	19	12.42
Cohabiting	5	3.27	3	1.96
Married	35	22.88	39	25.49
Separated/ Divorced	8	5.23	13	8.50
Widowed	7	4.58	3	1.96

Table 2

Pre and post PaCKS and confidence scores.

	Pre PaCKS Mean (SD)	Post PaCKS Mean (SD)	Pre Confidence Mean (SD)	Post Confidence Mean (SD)
Intervention Video	10.71 (2.22)	12.00* (1.97)	2.84 (1.13)	4.08* (.88)
Intervention Information Page	11.10 (2.27)	12.33* (1.58)	2.78 (1.09)	4.07* (.77)
Control video	11.61 (1.75)	11.89 (1.39)	2.94 (.93)	3.12 (.93)
Control Information Page	10.20 (2.48)	10.70 (2.66)	2.57 (1.06)	2.62 (1.00)

Intervention and control comparison PaCKS: $F(1, 139) = 11.10, p = 0.00, \eta_p^2 = 0.074$.

Intervention and control comparison Confidence: $F(1, 136) = 113.11, p = 0.00, \eta_p^2 = 0.45$.