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

Elissa Kozlov[b,*], M. Carrington Reid[b], Brian D. Carpenter[a]

[a] *Washington University in St. Louis, Department of Psychological & Brain Sciences, St. Louis, MO, United States*
[b] *Weill Cornell Medical College, Department of Medicine, New York, NY, United States*

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) × 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.

© 2016 Published by Elsevier Ireland Ltd.

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 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

* Corresponding author at: Weil Cornell Medicine, Division of Geriatric and Palliative Medicine, 525 East 68th Street, Box 39, 1404 Baker Pavilion, New York Presbyterian Hospital, New York City, NY 10065, United States.
  E-mail address: elk2020@med.cornell.edu (E. Kozlov).

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.

Table 1
Demographics.

	Control		Intervention	
	n/M	% of total/*SD*	*n/M*	%/*SD*
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
Cohabitating	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

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