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Development and Validation of the Palliative Care Knowledge Scale (PaCKS)

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Development and Validation of the Palliative Care Knowledge Scale (PaCKS)
by
Elissa Kozlov

A dissertation presented to the
Graduate School of Arts and Sciences
of Washington University in
partial fulfillment of the
requirements for the degree
of Doctor of Philosophy

August 2016
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<div align="right">Elissa Kozlov</div>

Washington University in St. Louis

August 2016

ABSTRACT OF THE DISSERTATION

Development and Validation of the Palliative Care Knowledge Scale (PaCKS)

By

Elissa Kozlov

Doctor of Philosophy in Psychology

Washington University in St. Louis, 2016

Professor Brian D. Carpenter, Chair

Professor Thomas L Rodebaugh, Co-Chair

Palliative care is a team-based, specialty service that improves the quality of life for individuals with serious illness and their families. However, current research suggests that this life-improving service is drastically underutilized. Patient knowledge of a healthcare service is theorized to drive utilization. If people do not know what palliative care is, they cannot be expected to seek out or accept a referral for the service. Currently, there are no psychometrically evaluated scales to assess knowledge of palliative care. The purpose of this study is to develop a reliable and valid scale that broadly measures knowledge about palliative care. An initial item pool of 38 true/false questions was developed based on extensive pilot data. The preliminary items were administered to a community sample of 614 adults aged 18-89 as well as 30 palliative care professionals. Using Exploratory and Confirmatory Factor Analysis (EFA & CFA, respectively), correlational analyses, ICC and KR-20, I assessed the reliability, stability, internal consistency, and validity of a 13-item Palliative Care Knowledge Scale (PaCKS). I investigated

how scores on the PaCKS change after a brief, online educative intervention on palliative care. Results of this study indicate that the PaCKS meets or exceeds psychometric standards of scale development. This scale will be useful for clinicians and researchers interested in improving palliative care access and utilization through increasing knowledge.

Introduction

Palliative care provides relief to people with serious illness and their family members through symptom management, psychosocial support, and care team coordination (Higginson et al., 2003). By reducing unnecessary financial, psychological, and physical burdens for patients and families (Manfredi et al., 2000), palliative care enhances quality of life while reducing overall healthcare costs (Hanson, Usher, Spragens, & Bernard, 2008). Although the number of interdisciplinary palliative care teams is rising in hospitals throughout the United States (Morrison, Maroney-Galin, Kralovec, & Meier, 2005; Veterans Health Administration, 2008), palliative care services are still underutilized. According to a 2011 survey from the National Hospice and Palliative Care Organization, of all the individuals who died in 2011 in the United States, only 44.6% received hospice care, a subtype of palliative care for patients in the last six months of life. No data are available on how many patients receive palliative care throughout the course of their illness, but the Center for Advancement of Palliative Care estimates that at least 6 million people in the United States could benefit from palliative care they are not receiving ("Palliative Care Facts and Stats," n.d.). In order to expand the use of palliative care services, we must better understand barriers to access and utilization in order to develop interventions to address them. Barriers can be grouped into two broad categories: 1) supply-side barriers, which are institutional or provider obstacles that prevent access to a service, and 2) demand-side barriers, which are patient factors that limit utilization of a service.

Supply-Side Barriers

Prior research has largely focused on barriers on the supply side of palliative care utilization, such as institutional or provider variables that delay or constrain access to palliative care. For example, one potential barrier is limited availability. In 2011, the state-by-state report

card on access to palliative care revealed that only 63% of the nation's hospitals with at least a 50-bed capacity had palliative care teams (Morrison, Augustin, & Meier, 2011), though only 10% of Mississippi hospitals had palliative care services compared to 100% of Vermont hospitals (Goldsmith et al., 2008). Another barrier is an insufficient number of healthcare professionals trained to provide palliative care. According to a 2008 Hospice and Palliative Medicine Workforce Taskforce, there are not enough palliative medicine specialists to meet the growing need of palliative and hospice programs, and the gap in supply does not show signs of improving. The Taskforce estimated that between 279 and 472 new specialists would need to enter the workforce annually, but training programs in the United States only produce 180 new palliative care specialists per year (Lupu & American Academy of Hospice and Palliative Medicine Workforce Task Force, 2010).

Another barrier lies within non-palliative medicine physicians' knowledge of palliative care. Because these physicians are the ones who can refer people to palliative care, lack of knowledge among them about palliative care can limit their referrals. Research on this question has largely focused on referral to hospice, which is a better-utilized subtype of palliative care. Ogle and colleagues (2002) surveyed 190 physicians whose mean score of 3.5 on an eight-point knowledge test about hospice referrals demonstrated that physicians lack basic knowledge about when referrals are appropriate. Furthermore, physicians may be unaware of their knowledge deficits. In a study of 125 physicians, only 28% acknowledged lacking sufficient knowledge about hospice eligibility requirements, yet 84% were unable to identify diagnoses that are appropriate for hospice (Brickner et al., 2004). A qualitative study conducted in the United Kingdom using focus groups revealed that physicians from various specialties grasped the general concept of holistic palliative care but lacked clarity in the details of what palliative

medicine specifically contributes to the care of seriously ill patients (Hanratty et al., 2006).

Finally, gaps in knowledge are also apparent in students, as in one study of 70 medical residents that found that the average score on a true/false test about palliative medicine was only 58% (Fischer et al., 2003).

Lacking awareness and knowledge of palliative care interferes with physicians referring their patients to the service. Physicians are gatekeepers to consultation-based services such as palliative care and thereby facilitate or limit access. Snow et al. (2009) surveyed two groups of physicians at an academic hospital: those who had referred at least one patient to palliative care and those who had never referred a patient to palliative care. Forty-two percent of the non-referrers were unaware that the consultation service existed. Referrals to palliative care are also less likely if clinicians have unfavorable attitudes about palliative care. Indeed, some physicians have endorsed skepticism regarding palliative care's ability to improve life for patients with illnesses other than cancer (Hanratty et al., 2006). Furthermore, the physicians in the study by Snow et al. (2009) who referred a patient to palliative care were significantly more likely than physicians who never referred patients to palliative care to agree with the statement, "Palliative care specialists are the best persons to coordinate the palliative care of patients with advanced disease" (29% versus 8%, $p < .05$). Notably, fewer than one third of the referring physicians overall agreed with the statement, which suggests that to maximize referrals to palliative care, physicians have to be aware of, knowledgeable about, and realistic about how palliative care can improve quality of life above and beyond what nonspecialist physicians are capable of doing alone.

Interestingly, physicians do not identify themselves as the largest barrier to palliative care services. Seventy percent of physicians reported that the most common barrier to making a

palliative care referral was that patients have unrealistic goals and expectations about their illness trajectory (Snow et al., 2009), and 69% of physicians reported that patients are unwilling to accept hospice referrals (Ogle et al., 2002). 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.

Demand-Side Barriers

Demand-side barriers are patient factors that limit utilization of a service, such as patient knowledge about the service (Ensor & Cooper, 2004). Grossman & Kaestner (1997) 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 and hospice services. For instance, in a focus group study of 26 African American and 27 Latino American adults, participants reported being unaware of what services hospice provides, how those services are paid for, and who is eligible to receive them (Born et al., 2004). Similarly, in a study of 262 cancer patients in the United Kingdom, 81.3% did not recognize the term "palliative care" (Koffman et al., 2007). If patients and family members are not aware of palliative care, they will not know to ask physicians for a referral. Furthermore, if physicians attempt to refer their patients to palliative care, patients may refuse if they are unfamiliar with the service or misunderstand its key aspects. More basic research is needed on what people know about palliative care. By identifying gaps in knowledge, programs can be designed to educate consumers and providers about palliative care, thereby increasing access and utilization. This project focused on patient knowledge of palliative care in order to begin to identify these gaps.

One mechanism to help patients gain knowledge about their health and available services is health literacy (HL). The American Medical Association refers to HL as "a constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health-care environment" (American Medical Association, 1999). HL is a reflection of current abilities and skills, and is thus necessary in order for patients to obtain knowledge about their illness and be active participants in their own health care. Older age and chronic health conditions are both associated with lower HL (Gazmararian et al., 1999; Williams et al., 1995). 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.

Pain Management as a Model of Knowledge Improvement

The clinical literature on pain demonstrates how identifying and improving knowledge deficits about health care services can lead to overall improvements in utilization and access. Similar to the palliative care literature, pain research has shown that physicians often lack knowledge in key components of pain management, which interferes with effective pain control (Elliot & Elliot, 1992; Elliott, et al., 1995; Ferrell, Virani, Grant, Vallerand, & McCaffery, 2000; Rabow, Hardie, Fair, & McPhee, 2000). Likewise, patients' negative attitudes and false beliefs about pain and its management play a key role in the under treatment of pain (Oldenmenger et al., 2009). For example, in a study of 270 cancer patients, between 37% and 85% endorsed attitudes likely to interfere with adequate pain control, such as concern about drug tolerance, fatalistic belief about pain management, and fear that complaining of pain distracts the doctor from treating the disease (Ward et al., 1993). Similarly, in a study of 42 cancer patients in Canada, nearly 25% of patients believed that pain medications are bad for their bodies (Riddell

& Fitch, 1997). If patients believe that a medication is contraindicated for their health, they may be less inclined to take the medication as indicated, and thus suffer the consequence of inadequate pain management (Pargeon & Hailey, 1999). Thus, attitudes and beliefs about pain are related to treatment willingness and adherence.

Fortunately, educational interventions about pain and its treatment improve patients' attitudes and knowledge and decrease patient-related barriers to adequate treatment. Educational interventions about pain and pain management have improved patient knowledge, attitudes, and pain outcomes such as pain intensity and use of analgesics (Allard, Maunsell, Labbe, & Dorval, 2001; Bennett, Bagnall & Closs, 2009; Oldenmenger et al., 2009). It is reasonable to believe that increasing knowledge of palliative care would analogously improve its utilization.

The Current Study

Knowledge about palliative care among clinicians and laypeople appears to be low, and knowledge may be an important factor related to palliative care service utilization. Therefore, it is imperative to clarify what people do not know about palliative care in order to close this knowledge gap. One challenge to assessing knowledge about palliative care, however, is that currently there are no psychometrically evaluated assessment instruments available to measure general knowledge about palliative care. A palliative care knowledge scale would be useful for clinicians, program administrators, policy developers, and researchers interested in improving palliative care in a broad range of populations and settings. A palliative care knowledge scale also could be used to understand knowledge gaps and thus guide important educational interventions with patients, family members, and healthcare personnel. To that end, the main goal of this study was to develop an acceptable, efficient, and valid scale that measures knowledge about palliative care. This scale was developed for laypeople rather than healthcare

professionals in order to begin to understand and characterize what potential patients and family members of patients know and don't know about palliative care.

Pilot Work for Scale Development

Preliminary work included several activities designed to identify fundamental principles and features of palliative care that could be tested in a knowledge scale. These activities included:

- a literature review of education and knowledge about palliative care;

- focus groups with laypeople with some experience with end-of-life care;

- semistructured interviews with palliative care professionals;

- a review of information sheets about palliative care available on the Internet;

- concept mapping of key concepts in palliative care with healthcare professionals; and

- preliminary scale item generation.

Literature review. In order to determine the scope of the proposed Palliative Care Knowledge Scale (PaCKS), I conducted a literature review of research in the field of palliative care knowledge and education. Google Scholar and PubMed were searched with the terms "palliative care knowledge," "palliative care education," "palliative care assessment," and "palliative services knowledge test." Additional articles were identified through reference lists of articles found through the initial search terms. The literature revealed minimal research regarding knowledge of palliative care services. The existing palliative care knowledge assessment instruments are intended for nurses, medical students, and medical residents (Fischer, Gozansky, Kutner, Chomiak, & Kramer, 2003; Meekin, Klein, Fleischman, & Fins, 2000; Ross, McDonald, & McGuinness, 1996). Though the provider assessment instruments are too technical for the general public (e.g., contain questions about appropriate morphine dosing at end of life),

qualitative analysis revealed preliminary content domains that might be useful in a more general scale, such as the clinical components of palliative care, palliative care as a continuum of care, differences between hospice and palliative care, eligibility criteria for palliative care, and palliative care as complementary to curative treatments (Meekin, Klein, Fleischman & Fins, 2000; Metzger, Norton, Quinn, & Gramling, 2013; Ross, McDonald, & McGuinness, 1996).

Focus groups. I also conducted two focus groups with 4-6 lay people in each. The purpose of the focus groups was to gain the consumer's perspective on important knowledge domains of palliative care. Participants were recruited from the Volunteers for Health database and were eligible if they had ever provided care for a family member at the end of life. Focus group participants had an average age of 67.63 ($SD = 4.57$) and were 25% male. Participants had provided care at end of life for parents, siblings, spouses, uncles, and cousins. Focus groups were semistructured, and participants were asked about their experiences with and perceptions of palliative care. The focus groups revealed a diffuse unfamiliarity with and lack of knowledge about palliative care. Participants were also encouraged to share their experience with providing care for loved ones at end of life. These experiences included varying levels of involvement and information received from the medical community regarding end-of-life care and decisions. No members of the focus group reported that they were informed of or offered palliative care. Qualitative information from the focus groups was integrated into item generation, discussed later.

Interviews with palliative care professionals. Concurrent with the lay people focus groups, I conducted semistructured interviews with two palliative care psychologists and one palliative care social worker. The purpose of these interviews was to gain the clinician perspective on key principles in palliative care. Other disciplines were not included in this

interview phase because the initial three interviews did not generate new information about palliative care knowledge that was useful to item development. The professionals were highly technical, nuanced, and skilled in their description of palliative care, and this level of expertise was deemed too advanced for a general knowledge scale.

Internet search. Next, I turned to information available to consumers on the Internet to determine how palliative care is presented and depicted in information easily and commonly accessed by the general population. Online brochures and web pages dedicated to explaining palliative care were identified by searching keywords "palliative care information," "palliative care," and "what is palliative care" using Google. I chose to search for information using Google in order to mirror the most common approach the general population uses to search for information related to palliative care. Unique web pages from the first six pages of search results from Google were selected for review. Additionally, I searched the major palliative care organizations' websites (i.e., Center to Advance Palliative Care, American Cancer Society, and American Academy of Hospice and Palliative Medicine) for web pages and included these as well. Information web pages ranged in length from one to seven pages. Web pages came from hospitals, not-for-profit organizations, online medical information sites (i.e., WebMD), and healthcare clinics. Twenty-six palliative care information pages were examined.

With the aid of a senior undergraduate research assistant, I developed a coding scheme for web page content based on a preliminary examination of all 26 palliative care information pages and previous research. The codes focused on common domains and facts presented within the information pages. Next, four coders independently coded the information pages, with at least two different coders assigned to each page. Coding discrepancies were resolved through consensus meetings. Descriptive statistics were calculated to summarize the information

portrayed in the information pages. From the information page analysis, I developed 22 domains

of palliative care knowledge that appeared most frequently throughout the online resources.

These 22 domains were utilized during the item generation phase. All domains were represented

by at least one item. When possible, multiple items were generated to reflect the domains.

Additionally, to understand further how palliative care knowledge is organized, I conducted a

concept mapping study with the 22 domains.

   Concept mapping. Concept mapping is a statistical technique designed to depict visually

the relationships among ideas and information. The purpose of the concept mapping was to

further understand how palliative care domains might be organized and clustered. This was done

to help inform scale item generation and to provide myself with an in-depth understanding of

palliative care knowledge. I recruited 20 palliative care researchers and clinicians to sort the 22

previously established domains from the information page analysis into as many groups as they

desired. The palliative care professionals all had at least two years of experience practicing or

researching palliative care. Professionals included physicians, nurses, nurse practitioners,

psychologists, social workers, and chaplains. In addition to sorting the domains, participants

ranked on a 1-5 Likert-type scale how important each was to the overall concept of knowledge

about palliative care. The ranking allowed me to consult many palliative care professionals

quickly and concisely to make sure that each domain is important to the overall construct of

palliative knowledge. All domains had a mean ranking of at least 4.0, indicating relevance to the

general construct of palliative care knowledge. In order to ensure broad content coverage,

participants were also asked to write in domains they thought were not represented. No write-in

responses were provided.

Concept mapping involves two main procedures. The first step is to conduct multidimensional scaling (MDS), which creates a map to represent visually the similarity among items, as rated by the palliative care researchers and clinicians. MDS can also assist investigators in determining the number of dimensions that underlie the items on the concept map. A two-dimensional solution was selected because Kruskal and Wish (1978) recommend two-dimensional solutions in cluster analyses combined with MDS. See Figure 1 for the results of the MDS. Items on the top of the map seemed to refer to pragmatics of palliative care (e.g., "palliative care can occur at any time during a serious illness"), whereas items on the bottom of the map referred more to the philosophy of palliative care (e.g., "a central goal of palliative care is to help patients better understand their treatment options"). Furthermore, items on the right side of the map referred to consumer information whereas items on the left side of the map referred more to system or practitioner information.

In the second step of concept mapping, I used the *xy* coordinates of the concept map as the input for a hierarchical cluster analysis. Qualitative and quantitative analyses both suggested that a six-cluster solution best fit the data. The six clusters can be categorized as goals of palliative care, finances of palliative care, the palliative care team, system-related components of palliative care, timing of palliative care, and symptoms that palliative care addresses (see Appendix A).

Preliminary item generation. Finally, I used the concept mapping analyses as well as information from preliminary activities to guide item genesis. In collaboration with Professor Carpenter and six graduate and undergraduate students in the Clinical Geropsychology laboratory, I generated 38 true/false items based on the 22 domains from the information page analyses and the six clusters that the concept mapping analyses uncovered. True/false formatting

was chosen, as opposed to multiple choice, because a multiple-choice format is no better than true/false at distinguishing false guesses from misinformation (Kline, 2005; Stanley & Hopkins, 1972), and it is more efficient to administer and score. I decided not to include an "I don't know" option because it would complicate scoring and it neglects different degrees of uncertainty. Next, items were tested for to establish reliability and validity, which comprises the dissertation project. To establish the scale's scale validity, I had the following specific aims.

Aim 1: Evaluate the factor structure of the PaCKS. I aimed to create a scale that measures one broad construct, knowledge of palliative care. Using Exploratory and Confirmatory Factor Analysis (EFA & CFA, respectively), I set out to determine if the conceptual latent factors hypothesized to make up the PaCKS actually underlie people's responses to the instrument (Joreskog, 1969). Factor analysis was used to provide support that the PaCKS validly and consistently measures the hypothesized underlying construct of knowledge of palliative care.

Aim 2: Evaluate the reliability of the PaCKS.

2a. Evaluate internal consistency. To evaluate internal consistency, I calculated Kuder-Richardson Formula 20 (KR-20). KR-20 is a measurement of internal consistency appropriate for assessments with dichotomous items. Acceptable internal consistency for this type of knowledge scale would be between .6 and .9. (Streiner & Norman, 2008).

2b. Evaluate test-retest stability. To evaluate test-retest stability, the PaCKS was administered two times over a 10-minute time period to a subsample of participants, and a two-way random Intra-class Correlation Coefficient (ICC) under the absolute agreement definition was conducted. Fair to good test-retest stability would be indicated by an ICC of .40-.75, and excellent stability would be indicated by an ICC greater than .75 (Fleiss, 2011).

Aim 3: Evaluate the validity of the PaCKS.

3a. Evaluate construct validity. Construct validity refers to whether a test is measuring what it claims to measure (Cronbach & Meehl, 1955). I used several strategies to evaluate construct validity. I hypothesized that palliative care professionals should score close to ceiling on the PaCKS, so I included 30 palliative care professionals in the sample. Additionally, I investigated how scores on the PaCKS change after a brief, online educative intervention on palliative care. If education about palliative care increases knowledge, then scores on the PaCKS should significantly increase following educational intervention.

3b. Evaluate convergent validity. Convergent validity is demonstrated when measurements of two theoretically similar constructs are positively related. I hypothesized that knowledge of palliative care would be positively correlated with general health literacy. I also hypothesized that knowledge of palliative care would be positively correlated with general intellectual functioning. Specific values to establish strong convergent validity are not generally provided in the literature; rather, conventional practices indicate that convergent validity and divergent validity must be interpreted together (Streiner & Norman, 2008). I also hypothesized that knowledge of palliative care is related to experience with palliative care. Thus, I hypothesized that palliative care knowledge in a community-based sample would be positively correlated with experience with palliative care. However, I hypothesized that knowledge of palliative care is a separate but related construct to experience with palliative care, health literacy, and general intellectual functioning, therefore the correlations should not be overly high (Streiner & Norman, 2008).

3c. Evaluate divergent validity. Divergent validity is demonstrated when measurements of two theoretically dissimilar constructs are not related to one another. I hypothesized that

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knowledge of palliative care would be relatively unrelated to knowledge of arthritis. I

hypothesized that the correlation between the PaCKS and the Arthritis Knowledge Questionnaire

would be below .3, indicating a modest association. Alternatively, if the correlation was larger

than .3, I hypothesized that the relationship would be due to the relationship with health literacy.

3d. Evaluate discriminative validity. Discriminative validity is demonstrated when two

groups that are hypothesized to have extreme and different values on a construct are compared to

one another and found to be statistically different (Streiner & Norman, 2008). I hypothesized that

palliative care professionals would have statistically significantly more knowledge about

palliative care than individuals with low health literacy and little experience with palliative care.

Methods

Sample

A community-based sample of adults aged 18-89 ($N = 614$) and a professional sample of

palliative care clinicians and researchers ($N = 30$) were recruited. See Table 1 for a summary of

subsamples recruited for each aim of the study. Subsample sizes were based on prior research

psychometrically evaluating health condition knowledge scales ($N = 116$ in Allen & Jones, 1998;

$N = 346$ in Baifour, Kowai, Cooper, et al., 2007). In order to add to the diversity of the

community sample in regards to age, health literacy, and health care experience, I recruited from

multiple sources that included Barnes Jewish Hospital Volunteers for Health (VFH), the

Washington University Department of Psychology Older Adult Subject Pool, and Amazon's

Mechanical Turk (mTurk) database.

To ensure diverse age representation, I set recruitment goals for each age decade. For a

breakdown of participants' demographic characteristics for each substudy, see Table 2. Once age

stratification goals were achieved, the remaining participants were sampled from all sources.

I recruited 30 palliative care professionals through professional contacts and the Hospice and Palliative Care Special Interest Group Listserv of the Gerontological Society of America.

Measures

Demographics. In order to characterize the sample, I collected the following demographic information for each participant: gender, age, race, ethnicity, marital status, and education (see Appendix B).

Experience with Palliative Care Questionnaire. Dow et al. (2010) assessed knowledge of hospice care by simply asking patients, "Have you heard of hospice?" I revised this item for "palliative care" and included seven other questions I wrote to address familiarity with palliative care and hospice (see Appendix C). Items had dichotomous yes/no responses or Likert-type responses ranging from 1 to 5 or 1 to 10. Responses to individual items were considered independently in analyses.

Medical Term Recognition Test (METER; Rawson et al., 2010). The METER is a brief (2 minute), self-administered measure of health literacy consisting of 40 medical words and 40 nonwords (see Appendix D). Respondents are asked to identify the words from the nonwords. Scores range from 0-40 based on a sum of correctly identified medical words. The METER has excellent internal consistency reliability ($\alpha = .93$) and strong validity as indicated by its high correlation ($r = .74$) with the Rapid Estimate of Adult Literacy in Medicine, another measure of health literacy (Davis, Crouch, Long, et al., 1991). In this study, the METER had excellent internal consistency reliability ($\alpha = .89$).

The Arthritis Knowledge Questionnaire – General Subscale, Form A (AKQ; Edworthy, Devins, & Watson, 1995). The AKQ is a 15-item multiple-choice questionnaire to assess general knowledge of arthritis (see Appendix E). Correct responses are summed for a total

score (0-15), with higher scores indicating greater knowledge about arthritis. Coefficient alpha for this measure is adequate ($\alpha = .76$; Edworthy, Devins & Watson, 1995), but in the current sample, alpha was slightly lower than the acceptable cut off of .7 ($\alpha = .67$).

Shipley Vocabulary Test (Shipley, 1940). The Shipley Vocabulary Test is a 40-item vocabulary test to measure general intellectual functioning (see Appendix F). The test presents progressively more difficult vocabulary words, and respondents are asked to select from a list of four words the one that is most similar in meaning to the target word. Correct items are summed for a final score (0-40). The test has excellent internal consistency ($\alpha = .87$, Shipley, 1940), and in this study's sample was similarly strong ($\alpha = .85$).

Palliative Care Knowledge Scale (PaCKS). This new scale aimed to assess general knowledge of palliative care (see Appendix G). In its preliminary form, it contained 38 true/false items that address a wide range of facts and basic principles about palliative care. Creating a final, reliable and valid version of the scale was the goal of this project.

Materials

Beyond the online survey, the only other materials for this study were intervention videos used in the evaluation of construct validity. The first was a three-minute video from About.com about palliative care (http://video.about.com/healthcareers/What-Is-Palliative-Care.htm). It features Dr. Nathan Goldstein from the Center for the Advancement of Palliative Medicine and Mount Sinai School of Medicine Department of Geriatrics and Palliative Care. In this video, Dr. Goldstein discusses what palliative care is, who provides and receives it, and where patients can receive palliative care. A written palliative care information page was from Vanderbilt Health (http://www.vanderbilthealth.com/palliativecare/21568), adapted to have the same information as the video. The control video was a three-minute educational video about the Mediterranean Diet

and health (http://video.about.com/nutrition/What-Is-the-Mediterranean-Diet-.htm). In this video, health coach and lifestyle blogger Maria Saracen describes the tenets and benefits of the Mediterranean Diet. The control information page was about the Mediterranean Diet and health (http://cholesterol.about.com/od/cholesteroldiets/a/mediterranean.htm) and describes what the Mediterranean Diet consists of and associated health benefits.

Procedure

This study was reviewed and approved by the Washington University Human Research Protection Office (HRPO). An advertisement for the research study was emailed to different age groups of the VFH database and included a link to the study. Similarly, a request for workers, called HITs, was posted on Amazon's Mechanical Turk site, informing potential participants about the study and inviting them to click a link to a web page for more information. The study was hosted on the Qualtrics online platform. The link guided participants to the study's informational sheet detailing the research process. They were informed that they could skip any items they wanted and that participation was fully voluntary. MTurk workers were reimbursed $1.50 for their time, which is considered standard-to-above average pay for a one-hour task. Non-mTurk participants could elect to be in a lottery to win a $30 gift certificate for every 20 participants enrolled. If participants were interested in participating in the study, they consented by clicking the "next" button at the bottom of the page. Participants then received a preliminary screening measure that determined eligibility based on age stratification needs. All participants first received the core assessment that consisted of demographic questions, Experience with Palliative Care Questionnaire, the METER, and the PaCKS. A subsample of 321 adults were also administered the Shipley in addition to the core assessment. A different subsample of 56 adults was recruited to take the AKQ in addition to the core assessment to establish divergent validity.

Another different subsample of 152 participants was recruited for a brief, randomized intervention substudy to assess construct validity and test-retest reliability. Minimum sample size was determined from a G*Power analysis for an ANCOVA with contrast coding (G*Power with effect size = .5, α = .05, desired power = .80, n = 74). I used a random number generator (www.random.org) to generate a set of 152 equally represented numbers ranging from one to four to establish which participants were assigned to each group in this 2 (content) X 2 (format) between-subjects design. Group 1 received the video intervention, Group 2 the information sheet intervention, Group 3 the video control, and Group 4 the information sheet control. The control group participants' scores on the PaCKS at Time 1 and Time 2 were used for test-retest analyses.

Data Analysis

Aim 1: Exploratory and Confirmatory Factor Analysis

First, I split my sample in half by generating a random pattern of 644 ones and twos. This process yielded a first sample of 299 participants and second of 345. I utilized the first subsample to explore factor structures and scale construction, and I utilized the second subsample to confirm the solutions achieved in the first. I conducted an Exploratory Factor Analysis (EFA) and Principal Components Analysis (PCA) on a combined random sample of the community and professional samples using the statistical software programs Mplus and SPSS. I utilized an EFA with geomin rotation and weighted least squares mean and variance adjusted (WLSMV) estimator to examine the structure of the PaCKS' 38 items. WLSMV is the estimator recommended for categorical data (Muthén, du Toit, & Spisic, 1997). A PCA was run using SPSS to help determine the appropriate number of factors to be extracted. A scree plot of eigenvalues was examined to determine the most appropriate solution. Kaiser's eigenvalue-greater-than-one rule (1960) was considered when determining the appropriate number of

factors. After determining the appropriate factor structure, I utilized Confirmatory Factor Analysis (CFA) to reduce the number of items and achieve strong indices of fit. During CFA procedures, I considered individual items for elimination based on low, nonsignificant, or negative factor loadings, r-squared values, and item thresholds. Global model fit was evaluated using the following: Tucker-Lewis Index (TLI; Tucker & Lewis, 1973), comparative fit index (CFI; Bentler, 1990), and the root mean square error of approximation (RMSEA; Steiger & Lind, 1980). The following values indicate a good fit of the model to the data: TLI and CFI ranging from .95 to 1.0; RMSEA below .06; (Hu & Bentler, 1999). Once I established the factor structure of the PaCKS, I then conducted a CFA on the second subsample ($n = 345$) to evaluate the hypothesized factor structure established through EFA, PCA, and CFA techniques. All subsequent analyses were conducted on the items chosen to remain in the PaCKS.

Comparability of subsamples. After I established the factor structure of the PaCKS, I conducted a multiple-group factor analysis between the mTurk sample and the non-mTurk sample to determine if groups were systematically responding differently on the PaCKS. Based on the results of this analysis, additional multiple-group factor analyses were run post-hoc to understand better and characterize sources of differences between groups.

Aim 2: Evaluate the Reliability of the PaCKS

Aim 2a: Evaluate internal consistency of the PaCKS. Items should be moderately correlated with each other and should correlate moderately with the total score in order to indicate that items are measuring different aspects of the same underlying construct (Streiner & Norman, 2008). The recommended range for measures of internal consistency is $\alpha = .7-.9$. To assess homogeneity of the items, I calculated KR-20, which is a test for dichotomous variables analogous to Cronbach's alpha.

Aim 2b: Evaluate test-retest stability. I calculated an ICC (2,1) to assess test-retest stability between the two administrations of the PaCKS.

Aim 3: Evaluate the validity of the PaCKS.

Aim 3a: Evaluate construct validity. To assess construct validity, I examined the qualitative data that the palliative care professionals provided on each item. If multiple professionals raised concerns about an item's relatedness to the overall construct of palliative care knowledge, I flagged the item as a first candidate for deletion. I calculated the percentage of palliative care professionals who answered each item correctly. Items with less than 90% of professionals answering correctly were candidates for deletion. To provide further information regarding construct validity, I assessed whether knowledge increased after being exposed to a brief educational intervention. I conducted an ANCOVA with contrast coding on the subsample of participants in the intervention study. The ANCOVA was contrast coded with two factors: intervention vs. control (intervention $n = 77$, control $n = 75$) and reading intervention vs. video intervention (reading $n = 43$, video $n = 34$).

Aim 3b: Evaluate convergent validity. Using Mplus, I modeled the relationship between the final version of the PaCKS and the total score on the METER using structural equation modeling (SEM). I also used SEM to model the relationship between the PaCKS and the total score of the Shipley. Based on results of these analyses, I then conducted a multiple linear regression analysis with simultaneous entry to clarify the relationship among the PaCKS, Shipley, and METER. Last, I calculated a Pearson's r correlation between individual items from the Experience with Palliative Care Questionnaire with total scores on the PaCKS.

Aim 3c: Evaluate divergent validity. Using Mplus, I modeled the relationship between the PaCKS and total scores on the AKQ using SEM. I then conducted a multiple linear

regression with simultaneous entry to clarify the relationships among the METER, the PaCKS, and the AKQ.

Aim 3d: Evaluate discriminative validity. Because I hypothesized that palliative care professionals would be a group of individuals with high knowledge of palliative care, I compared them to individuals who have a hypothesized low amount of knowledge, that is, individuals with low health literacy. I hypothesized that individuals with low health literacy (as assessed by the METER) and little experience with palliative care (as assessed by the Experience with Palliative Care Questionnaire) would have low knowledge of palliative care. Thus, I selected the 30 individuals with the lowest total scores on the METER who had not heard of palliative care and compared these individuals' scores on the PaCKS to the 30 palliative care professionals' scores using an independent samples *t*-test. Because the palliative care professionals were hypothesized to have more knowledge of palliative care, they were expected to score significantly higher than the general public on the PaCKS.

Additional correlational post hoc analyses were performed to characterize the relationship among the PaCKS, Shipley, METER, Experience with Palliative Care Questionnaire, and age.

Results

Demographics

See Table 2 for the age stratification results of the study and Table 3 for demographic information on the 614 participants in the non-mTurk and mTurk community sample. The mean age of the sample was 45.34 (*SD* = 18.09), and the mean years of education was 15.49 (*SD* = 3.12). Participants were primarily women (61.2%), Caucasian (80.3%), and married (50.6%). The professionals sample had a mean age of 50.17 (*SD* = 10.31), and mean number of years of palliative care experience was 9.13 (*SD* = 5.20). Professionals came from multiple healthcare

backgrounds including medical doctor ($n = 7$), nurse ($n = 7$), nurse practitioner ($n = 4$), social

worker ($n = 6$), psychologist ($n = 4$), researcher ($n = 1$), and chaplain ($n = 1$).

Initial Item Screening

PaCKS items 22, 24, 27, 34, and 36 (see Appendix G) were flagged as candidates for

deletion because fewer than 90% of the palliative care professionals answered these items

correctly. Item 26 was also flagged for deletion because of its content similarity to item 27, as

both pertain to government-based insurance covering the costs of palliative care. These items

were included in the EFA, but they were flagged as potential candidates for deletion. No items

achieved ceiling (i.e., were answered correctly by more than 95% of respondents) within the

community sample, so all were retained at this phase.

Aim 1: Exploratory And Confirmatory Factor Analysis

Initial EFA on the first subsample revealed that 11 factors had eigenvalues of greater than

1.0. The Principal Components Analysis (PCA) also revealed 11 factors with eigenvalues of

greater than 1.0. Given the lack of clinical utility of an 11-factor scale, as well as the intended

overlap of content among some items during the scale development process, this factor structure

was rejected. Instead, the one-, two-, three-, and four-factor solutions were evaluated. The two-

factor solution revealed systematic response bias in the PaCKS, as the two factors appeared to

reflect which items had correct true answers versus correct false answers. The three- and four-

factor solutions followed this pattern of bias as well and thus were rejected. Given the

demonstration of bias in the EFA, a bifactor solution with bias modeled and accounted for was

attempted in a Confirmatory Factor Analysis (CFA) with the first half of the full sample. In a

bifactor model, each item loads on two factors: a general factor as well as a specific subfactor

that can take into account additional dependencies among items (Li, Bolt, & Fu, 2006). A

bifactor model can be useful in accounting for nuisance dimensionality from response bias or method variance (Cho, Cohen & Kim, 2014). See Figure 2 for a conceptual representation of the traditional bifactor model.

In conducting a bifactor CFA for the PaCKS, each item was modeled on a primary factor labeled Knowledge of Palliative Care as well as a secondary factor labeled Bias. Unlike a traditional bifactor model, all items loaded on both the main factor and the secondary factor in my model. This was achieved by fixing factor loadings of true items at 1 and false items at -1 in order to account for the bias observed in the EFA. This new solution not only conceptually accounted for the bias, but preliminary indices of fit suggested that it also better fit the factor structure of the data. All subsequent analyses utilized the bifactor model.

Individual items were evaluated and considered for deletion based on a combination of indicators: high percentage of incorrect responses from the professionals, lowest R^2 values, lowest factor loadings, and content redundancy. Items were deleted one at a time throughout the data analysis process. A final 13-item, one factor solution with bias modeled was selected based on significant loadings for all items and excellent indices of fit: CFI = .97, TLI = .96, RMSEA = .031, 90% Confidence Interval (CI) = .00 - .049. In order to cross validate this solution, a CFA of the 13 items was conducted in the second subsample (n = 345). Results from the cross-validation CFA also revealed a similar pattern of significant loadings and excellent indices of fit: CFI = .99, TLI = .98, RMSEA = .022, 90% CI = .00 - .040. See Table 4 for the factor loadings and R^2 of each item on the final 13-item scale.

Participants from mTurk were then compared to non-mTurk participants using multiple-group CFA to determine if the PaCKS fulfills measurement invariance across these two populations and to determine if items are functioning similarly across the groups. Measurement

invariance is a statistical property that indicates that people from different populations who are identical on the underlying construct being measured score identically on a test of that theoretical construct (Meredith & Millsap, 1992). To evaluate measurement invariance, I tested a highly constrained model in which factor loadings and thresholds were constrained across groups with delta parameterization. Delta parameterization fixes residual variances at 1 in the first group and allows them to be free in the second group. This model also fixes latent factor means at 0 for the first group and frees them in the second group. Using a chi square difference test, I then compared this constrained model to a less constrained model in which all thresholds and loadings were freed. The results of this test revealed that the models were significantly different and thus not invariant between groups, χ^2 (26) = 57.32, $p < .001$. An alternate method of evaluation of group differences utilizes CFI differences (Cheung & Rensvold 2002). The invariant CFI of .93 and the noninvariant CFI of .96 also exceeded the threshold of .01 difference, thus confirming that there is a difference in how the mTurk sample responded compared to the non-mTurk sample.

I hypothesized that age was driving the difference between the mTurk and non-mTurk sample given the significant differences between mean age in the mTurk sample ($M = 38.56$, $SD = 12.85$) and the non-mTurk sample ($M = 54.39$, $SD = 20.03$); $t(418.72) = 11.21$, $p < .001$. I therefore ran a multiple-group CFA comparing the sample on age rather than data source using the same steps as above. The median of the full sample was 41 years old, so the sample was split based on participants aged 18 - 41 and participants aged 42 - 99. I hypothesized that the age group difference test would be significant parallel to the previous differences found between the mTurk and non-mTurk samples. The chi-square test was significant, $\chi^2(26) = 55.07$, $p < .001$, indicating a significant difference between how the younger and older adults responded on the

PaCKS. To test further the hypothesis that age was driving the difference between mTurk and non-mTurk respondents, the two samples were made age equivalent by deleting younger adults from the mTurk sample and older adults from the non-mTurk sample until means and quartiles were roughly equivalent. The total size of the mTurk sample after younger adults were eliminated was $n = 240$ and $n = 198$ for the non-mTurk sample with older adults removed. I hypothesized that the mTurk and non-mTurk groups would demonstrate measurement invariance once age was manipulated to be equivalent in the two groups. The chi-square test was again run between the constrained and unconstrained models resulting in a nonsignificant finding, $\chi^2(26) = 33.21$, $p = .16$, indicating that when age is equivalent in the mTurk and non-mTurk sample, the PaCKS is invariant across groups.

To understand further how age affects the PaCKS, partial factorial invariance was tested by constraining only the factor loadings but allowing the thresholds to vary. These analyses were utilized to determine if the same underlying construct was being measured in both groups. Thresholds represent the expected value on the latent variable at which an individual transitions from getting an item incorrect to correct. When factors are constrained and thresholds are allowed to vary, nonsignificant chi-square difference tests indicate that the underlying constructs are the same as measured in both groups, and one group requires different levels of the latent construct to achieve the same score on the test. I hypothesized that allowing thresholds to vary on the PaCKS while constraining the factor loadings would reveal no significant differences between groups. The results of the chi-square difference test in the partially invariant model revealed no significant differences between older and younger adults, $\chi^2(13) = 13.14$, $p = .44$, indicating that the groups are invariant when loadings are constrained but thresholds are not. Further evaluation of the thresholds revealed that, generally, older adults have larger negative

thresholds than younger adults ($M = -1.15$, $SD = .31$ versus $M = -.90$, $SD = .21$, respectively), which suggests that older adults are more likely than younger adults to answer an item correctly on the PaCKS with lower levels of the latent construct of knowledge of palliative care. Given this finding, age was modeled into analyses of convergent and divergent validity to characterize further the role of age in the validity of the PaCKS.

Aim 2: Evaluate the Reliability of the PaCKS

Aim 2a: Evaluate internal consistency of the PaCKS. KR-20 was calculated for the 13-item final version of the PaCKS. The KR-20 was .71, which indicated adequate internal consistency among the items (Streiner, 2003). No items were deleted based on this analysis.

Aim 2b: Evaluate test-retest reliability. A two-way random Intraclass Correlation Coefficient (ICC) under the absolute agreement definition was conducted on PaCKS total scores at Time 1 and Time 2 for the control participants in the intervention study who had complete PaCKS data ($n = 72$). The ICC was .70 (95% CI .56, .80), which indicated reasonable stability across the 10-minute administrations (Tweree et al., 2007).

Aim 3: Evaluate the Validity of the PaCKS

Aim 3a: Evaluate construct validity. Using Mplus, I modeled the relationship between the 13-item PaCKS and each Experience with Palliative Care Questionnaire question. Age was also modeled in the relationship between the PaCKS and Experience items in a series of post-hoc analyses. Table 5 lists all the correlations between the PaCKS total score and each Experience with Palliative Care Questionnaire question in the full sample. Table 5 also lists the correlations with each Experience with Palliative Care Questionnaire question with the General factor and the Bias factor using SEM in the partially invariant model that accounted for age differences. The

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PaCKS was significantly and positively correlated with all the Experience with Palliative Care Questionnaire items except for the item that asked about experience with hospice care.

An ANCOVA with contrast coding was conducted on a subsample of participants (n = 152) who were exposed to a brief educational intervention to assess if the scores on the PaCKS were sensitive to changes in the latent construct of palliative care knowledge. The ANCOVA was contrast coded to compare the video and reading intervention with the video and reading controls, controlling for Time 1 PaCKS. There was a significant difference between intervention group means at post-test (M = 12.15, SD = 1.77) and control group means (M = 11.18, SD = 2.34); $F(1, 139)$ = 11.10, p = .00, η_p^2 = .074. There was no significant difference between the video intervention (M = 12.00, SD = 1.97) and the intervention page (M = 12.29, SD = 1.61); $F(1, 67)$ = .011, p = .92.

Aim 3b: Evaluate convergent validity. Using Mplus, the relationship between the 13-item PaCKS was modeled with the total score on the METER. I hypothesized that the main factor on the PaCKS would significantly and positively correlate with the METER, and the Bias factor would have either a nonsignificant or negative correlation. The main factor correlated at .37 (p < .001), and the Bias factor correlated at -.18 (p < .001*)*. To further elucidate the relationship between the PaCKS and the METER, the relationship was explored in the partially invariant model that accounted for age differences. Results revealed a significantly larger correlation between the PaCKS and the METER in younger adults than older adults (r = .42, p < .00 and r = .23, p < .001, respectively). The 13-item PaCKS was also modeled with the total score on the Shipley. I hypothesized that the main factor on the PaCKS would significantly and positively correlate with the Shipley, and the Bias factor would have either a nonsignficant or negative correlation. The main factor correlated at .47 (p < .001), and the Bias factor correlated

at -.14 (p = .06). To further characterize the relationship between the PaCKS and the Shipley, the relationship was explored in the partially invariant model that accounted for age differences. Results showed similarly significant correlations between the PaCKS and the Shipley in younger and older adults (r = .46, p < .001 and r = .36, p < .001, respectively).

The same analyses were repeated with the PaCKS total scores in SPSS in order to evaluate further the relationship using non-SEM procedures. The correlation between the total score of the PaCKS and the METER was .33 (p < .001). The correlation between the PaCKS total and the Shipley was .36 (p < .001). Given the moderate correlations with the expected convergent scales, no further analyses were conducted.

Aim 3c: Evaluate divergent validity. Using Mplus, the relationship between the 13-item PaCKS was modeled with the total score on the AKQ. I hypothesized that scores on the PaCKS would be nonsignificantly correlated with the AKQ, and that if they were related, the relationship would be accounted for by health literacy. The main factor correlated at .64 (p < .001), and the Bias factor correlated at .12 (p = .52). The analysis was repeated in SPSS with the PaCKS total score to further evaluate the relationship using non-SEM procedures, and the correlation was .49 (p < .001). Because of the multicolinearity among age, METER and AKQ, these variables were centered before they were entered into a multiple linear regression analysis to predict the PaCKS score. The interaction between age and METER, and age and AKQ, were also entered as predictor variables. The linear combination of these variables was significantly related to the PaCKS, $F(5,48)$ = 3.48, p = .01, with an R^2 of .27. Only the AKQ was a significant predictor of the PaCKS in this model. See Table 6 for the model results.

Aim 3d: Evaluate discriminative validity. The professionals' total scores on the 13-item PaCKS was compared to the 30 community participants with the lowest METER scores

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who also reported they had not heard of palliative care. An independent samples *t*-test was conducted to compare PaCKS scores between these two groups with hypothesized varying levels of knowledge. There was a significant difference in PaCKS scores between professionals ($M = 12.73$, $SD = .58$) and community members with low METER scores who said they had never heard of palliative care ($M = 8.70$, $SD = 2.74$; $t(55) = 7.86$, $p < .001$, Cohen's $d = .81$), indicating a large effect size. A second independent samples *t*-test was conducted to compare PaCKS scores between the professionals and the full community sample. There was a significant difference in PaCKS scores between professionals ($M = 12.73$, $SD = .58$) and community members ($M = 10.92$, $SD = 2.2$; $t(83.87)$, $p < .001$).

Discussion

The primary aim of this study was to develop a brief scale to assess knowledge of palliative care in a community sample. Following several comprehensive steps to generate a preliminary set of items, subsequent analyses were used to create a final, 13-item self-administered scale, the Palliative Care Knowledge Scale (PaCKS), that meets or exceeds psychometric standards of scale development. The strong indices of fit in the confirmatory bifactor model support that the PaCKS has one general factor measuring knowledge of palliative care. Further analyses lend additional evidence that the PaCKS is unidimensional, reliable, and validly measuring the construct of knowledge of palliative care.

As a brief description, the final version of the PaCKS has 13 true/false items that cover a broad range of topics within the construct of palliative care. The items of the PaCKS map onto five of the six clusters established in the concept mapping pilot study, including goals of palliative care, members of the palliative care team, system-related components of palliative care, timing of palliative care, and symptoms that palliative care addresses. The sixth cluster,

finances of palliative care, is not represented in the PaCKS, in part, because of uncertainty in the veracity of the items. There is inconsistency among palliative care professionals and web-based resources on whether Medicare and Medicaid cover the costs of palliative care. Given the changing landscape of the U.S. healthcare system under the Affordable Care Act, reimbursement for palliative care is still unclear, thus the items related to palliative care financing were not included in the final version of the PaCKS. Given its broad content coverage, the PaCKS would be useful in order to gain a preliminary assessment of individuals' gaps in knowledge of palliative care.

Reliability of the PaCKS

This study established that the PaCKS is a reliable and stable measure of knowledge of palliative care. Scores are consistent, at least over a short time period, and the scale items have good internal consistency. The KR-20 of the PaCKS was .71, which suggests that items are reasonably consistent, and yet not entirely homogenous or redundant. Notably, the KR-20 and the ICC values were nearly identical. KR-20 is considered the upper limit of probable reliability (Streiner, 2003). Thus, the ICC theoretically could not have had a higher value than the KR-20. Additionally, the excellent fit indices of the CFA provide further support that the PaCKS is measuring a unidimensional latent construct consistently. CFA procedures reveal a scale's internal structure by revealing which items are consistent with one another, which is a form of internal consistency (Downing, 2004). The PaCKS exceeded psychometric standards for consistency as demonstrated by the KR-20, ICC, and CFA results.

Validity of the PaCKS

The results of this study also support that the PaCKS is validly measuring the underlying construct of palliative care knowledge. In terms of construct validity, as predicted, 1) palliative

care professionals score highly on the PaCKS, 2) individuals who have more experience with palliative care score higher on the PaCKS than individuals with less experience, and 3) education about palliative care increases scores on the PaCKS. Not only does this brief pilot study lend support to the construct validity of the PaCKS, but it also demonstrates promising results for the efficacy of educational interventions to improve individuals' knowledge of palliative care in the general population.

One detail to note is that knowledge, experience, and familiarity with *hospice care* were not related to scores on the PaCKS. Though hospice is an important component of palliative care, individuals who have experience with hospice may not have more knowledge about palliative care generally. In fact, many aspects of hospice care do not apply to palliative care. For example, hospice has stricter eligibility criteria (e.g., by traditional criteria, patients must be in the last 6 months of life, and patients must forgo all curative interventions), and experience with hospice may result in individuals having misconceptions about palliative care.

The results of this study also confirm the convergent and discriminative validity of the PaCKS. As hypothesized, the PaCKS was moderately correlated with health literacy and general intellectual functioning: people who have more health literacy and more intelligence overall, also have greater knowledge of palliative care. Because health literacy is considered a necessary set of skills for acquiring knowledge about healthcare (American Medical Association, 1999), the moderate association between the PaCKS and the METER suggests that individuals low on health literacy lack the skills to acquire knowledge about palliative care. Yet the moderate association between health literacy and knowledge of palliative care lends support for the convergent validity of the PaCKS, as it indicates that the PaCKS is not a proxy for health literacy; rather, it measures a related but unique construct. In terms of discriminative validity,

scores on the PaCKS indicate that palliative care professionals have more knowledge about palliative care than individuals in the general community, individuals with low health literacy, and individuals who have not heard of palliative care.

The PaCKS failed to meet the criteria I established *a priori* for divergent validity, though arthritis knowledge was possibly a poor construct to compare with palliative care knowledge. I hypothesized that knowledge of palliative care would be unrelated to knowledge of arthritis, or related only through the relationship with health literacy. Nonetheless, the PaCKS and the AKQ had an unexpectedly large, positive, and significant correlation. This may have occurred because individuals with arthritis have high rates of comorbid life-limiting illnesses, such as congestive heart failure, chronic pulmonary disease, dementia, and renal disease (Gabriel, Crowson & O'Fallon, 1999), and this high rate of comorbidity may drive people to learn about medical care options, including palliative care. I selected the AKQ without researching general demographics of individuals with arthritis, thus I was unaware of this high comorbidity rate at the time of study development. Health literacy, in theory, could account for some of this association, but the relationship between the two health care knowledge scales was stronger than the relationship between the METER and either scale. More research on how and why individuals becomes knowledgeable about health care in general is needed to understand better the strong association between scores on the AKQ and PaCKS.

Understanding the Bias Subfactor

The factor analyses identified a Bias subfactor that represents people's tendency to answer all items as true or all items as false, independent of their knowledge of palliative care. I argue that the Bias subfactor can be considered a "nuisance" factor that is unrelated to general knowledge of palliative care. The Bias subfactor did not routinely correlate largely or

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significantly with hypothesized similar constructs. When Bias correlated significantly with other constructs, the correlation was modest in magnitude and smaller than the correlation with the general knowledge factor. For example, Bias was negatively correlated with the METER, which suggests that individuals with low health literacy have a tendency, unrelated to knowledge of palliative care, to answer PaCKS questions as true, regardless of the correct answer. Bias was also significantly and negatively correlated with the question, "Have you heard of palliative care?" This correlation suggests that individuals who have not heard of palliative care have the tendency, unrelated to knowledge of palliative care, to answer questions as true on the PaCKS, regardless of the correct answer. Because Bias was modestly and inconsistently associated with other related constructs, it can generally be considered akin to "guessing." For the purposes of scoring the PaCKS, researchers should be aware that Bias can be modeled and accounted for in SEM, and clinicians should be aware that there may be a tendency for respondents low in experience and health literacy to guess true on the PaCKS regardless of the correct answer. Including an "I don't know" response option on the PaCKS for use in clinical settings may be a way to ensure that patients' misinformation or knowledge gaps are correctly identified by minimizing guessing.

Age Effects and the PaCKS

Results also suggest that the same underlying construct is measured by the PaCKS in older and younger groups, though older adults may require less knowledge about palliative care than younger adults in order to answer items correctly on the PaCKS. Because the PaCKS item thresholds are not invariant across age groups, the PaCKS demonstrates only partial measurement invariance. Millsap and Kwok (2004) offer suggestions for evaluating the impact of partial invariance in scales. Broadly, they argue that the intended use of the scale must be

taken into account when properties of measurement invariance are violated. The intention of the PaCKS is to characterize broadly what people know and do not know about palliative care. The scale is not intended to be a sensitive or specific measure that separates individuals into groups, so partial violation of measurement invariance does not have dire consequences. However, when using the PaCKS, researchers and clinicians should be aware that older adults' scores have the potential to be slightly inflated compared to younger adults'.

To characterize further age differences in responses to the PaCKS, I utilized structural equation modeling to evaluate how younger and older adults' scores on the PaCKS relate to similar and divergent constructs. Small differences (less than .05) in the magnitude of association were noted between younger and older adults on most constructs. One exception arose for the question, "Have you heard of hospice care?" This item was correlated .48 with the PaCKS for younger adults but only .03 for older adults. Older adults were more likely to have heard of hospice in this sample, which is unsurprising given older adults' increased likelihood of having experienced the death of a friend, relative, or partner. Because older adults are more likely to have heard of hospice, this question is a poor predictor for performance on the PaCKS for this age group. Younger adults, in contrast, are less likely to have heard of hospice. Younger adults who *have* heard of hospice likely have acquired some general knowledge about end of life care, which is reflected in their scores on the PaCKS. Though age plays a role in how people respond to the PaCKS, the age effects are mostly explained by the varying life experiences of older and younger adults. The PaCKS therefore validly assesses broad knowledge of palliative care in all adults, regardless of age.

Limitations

This study had several limitations that are important to note. First, I collected data via the Internet, and participants could have looked up information when answering the PaCKS. Though the Internet, and mTurk in particular, has been used for social sciences research and shown to be a valid and reliable way to collect data (e.g., Berinsky, Huber & Lenz, 2012; Buhrmester, Kwant & Gosling, 2011), it is possible that some participants utilized the Internet to look up information about palliative care despite receiving instructions not to. Given that the mTurk sample did not achieve ceiling on the PaCKS, and that results on the Shipley and AKQ were similar to previous studies (Edworty, Devins, & Watson, 1995; Verhaeghen, 2003), it is unlikely that the majority of the sample inflated their scores by looking up answers.

Another limitation is that in modeling Bias in the PaCKS, I utilized a bifactor model to account for guessing. Ideally, I would have utilized an Item Response Theory (IRT) model, such as the IRT Three Parameter Logistic model, as this is a more nuanced statistical procedure to model guessing in dichotomous questionnaires (Bock & Aitkin, 1981). Because this procedure requires statistical software to which I did not have access, this analysis will need to be conducted in the future.

As a scale, the PaCKS itself also has some potential limitations. Its true/false format, while efficient, forces respondents to guess on items they do not know or about which they are unsure. Some degree of guessing is expected in all knowledge-dependent tests, but it dilutes, in some way, what an individual's score on the PaCKS represents. It is possible to use a bifactor CFA to model and account for guessing and bias in how people respond on the measure, which is useful in the research realm but less practical for clinical use. Additionally, the PaCKS is a brief and diffuse measure of knowledge of palliative care. It is not intended to be a comprehensive assessment of all domains of palliative care knowledge. The PaCKS will be most useful to

determine initially who has limited knowledge of palliative care, and more extensive evaluation will be needed to determine more precisely the depth and breadth of knowledge and its gaps.

Future Research

This study provides essential groundwork to investigate several additional questions. For example, future research could establish normative data for the PaCKS, especially age-based norms. The current study established that the PaCKS is a valid, consistent measure of knowledge of palliative care, but this study did not provide the necessary conditions to establish norms for the PaCKs. Because a large 38-item battery was administered to develop the PaCKS, this study's scores are likely influenced by the context clues provided in the 25 items that were not included in the final scale. In order to establish norms, the 13-item PaCKS could be given to large samples of adults across the lifespan, without other scales or questionnaires that might unintentionally provide information about palliative care.

I would also be interested in administering the PaCKS with an "I don't know" response option to provide additional information about how and when people are likely to guess on the PaCKS. While this option would complicate modeling responses in SEM, it would be useful to know how often individuals select the "I don't know" option, as well as which items receive the most "I don't know" responses when that option is available. Though there are varying degrees of uncertainty that are not represented by an "I don't know" option, these data would provide more information about palliative care knowledge gaps. For example, for clinicians, "I don't know" responses represent a different kind of knowledge gap than an incorrect response and therefore suggest a different kind of conversation for remediation. Because guessing can be accommodated by SEM and IRT techniques, an "I don't know" option may not be necessary for

researchers. This would depend on the specific research questions asked as well as the statistical procedures utilized.

Furthermore, future research could seek to use this scale with healthcare professionals and determine its validity. Because access to palliative care depends, in part, on medical professionals making referrals to the service, it is essential that the general healthcare workforce is knowledgeable about palliative care. Future research could administer the full 38-item battery used to develop the PaCKS to medical professionals either to confirm the validity of the 13-item PaCKS in this population or to establish a complementary scale for healthcare professionals. Ideally, this scale would be used with all health professions who provide direct service to people with serious illness and their family, including physicians, nurses, occupational and physical therapists, home health aids, patient advocates, and caseworkers. With a medical professionals version of the PaCKS, researchers will be able to identify healthcare professionals that would benefit from educational interventions to enhance knowledge of palliative care.

Once the validity of the PaCKS is established with healthcare professionals, future research could focus on elucidating how knowledge of palliative care affects health care professionals' attitudes toward the service and likelihood to refer patients to the service. Previous research suggested that healthcare providers who are unaware of palliative care or hold unfavorable attitudes about palliative care are less likely to make referrals to the service (Snow et al., 2009). A provider version of the PaCKS would be useful to determine how knowledge of palliative care is related to willingness to refer to palliative care. Specifically, I would be interested in replicating and extending the Snow et al. (2009) study that investigated the differences between nonpalliative care physicians who refer patients to palliative care versus those who have never referred. I would use the PaCKS in order to assess if knowledge of

palliative care was lower in the nonreferrers. If there was a significant difference in knowledge of palliative care among physicians who refer versus those who do not, I would then investigate if the nonreferrers increased their referral rates following an educational intervention to increase knowledge of palliative care.

The provider-version of the PaCKS could also be used to develop and evaluate educational initiatives for professionals. Palliative care teams and hospital administrators offer professional development seminars to enhance knowledge of palliative care, but little is known about whether these seminars actually have their intended effect. The provider-version of the PaCKS would be a useful pre- and post-assessment measure to determine the efficacy of educational outreach seminars in healthcare settings.

Future research could also seek to establish the validity of the PaCKS with patients with serious illness and their families, as the service is most immediately relevant to this population. Once established as valid with this population, the PaCKS could characterize knowledge of palliative care in individuals who have recently been diagnosed with a life-limiting illness and their family to determine how much people who would benefit from the service know about it. In addition to characterizing knowledge of palliative care in a clinical sample, the PaCKS could also be useful in exploring the role of knowledge of palliative care in patients' willingness to accept or pursue a referral for the service. Prior theories have suggested that lack of knowledge of a healthcare service is a barrier to patient utilization of the service (Ensor & Cooper, 2004; Grossman & Kaestner, 1997). If knowledge is, in fact, a barrier to patients accessing palliative care, then the PaCKS could be used to identify key areas for individualized educational interventions.

Though this scale was developed with a community sample of adults aged 18-88, to my knowledge, the PaCKS is the only psychometrically evaluated, reliable and valid assessment of knowledge of palliative care currently available. With the successful development of this scale, new research exploring how knowledge of palliative care influences access and utilization of the service is possible. Prior research in palliative care has not assessed knowledge of palliative care, though many studies suggest that knowledge deficits contribute to the underutilization of the service (e.g., Brickner et al., 2004; Ensor & Cooper, 2004; Grossman & Kaestner, 1997; Ogle et al., 2002). Future research can now identify key populations who might be low in palliative care knowledge.

Clinical Implications

The PaCKS has not only expansive research possibilities, but also the potential to be a useful clinical tool. The PaCKS can be used in a variety of settings to identify knowledge deficits that might inhibit patients from seeking or accepting referrals for palliative services. Use of the PaCKS could extend from doctors' private offices, to medical waiting rooms, to media publications and brochures mailed to residences in order to identify knowledge gaps in palliative care. The PaCKS can be used to identify patients who are eligible for, yet unaware of, palliative care by incorporating the self-assessment in written materials available in medical settings. If patients are unaware of palliative care or have misinformation or knowledge gaps about palliative care, the PaCKS will identify these gaps and could lead patients to accurate information sources. For example, combined with an informational brochure, such as the one used in this study, the PaCKS could be an integral part of a self-administered educational intervention to improve knowledge of palliative care. These brochures could be disseminated in waiting rooms of hospitals, pulmonologists, cardiologists, oncologists, and geriatricians, for

example, in order to reach patients and their families who may be eligible for but unaware of palliative care.

The inpatient hospital environment is another location where the PaCKS could be clinically relevant. Hospitals can be hectic environments, and medical professionals often have limited time to spend with each patient. Brief assessments help professionals maximize their limited time with patients by focusing on the issues that are most relevant to the client as identified by a self-assessment. The brevity of the PaCKS is an asset to clinicians in fast-paced medical environments, as the scale can quickly identify knowledge gaps that might inhibit acceptance of a referral to palliative care. When physicians make referrals for palliative care, giving patients the PaCKS to see what they know about palliative care could expedite the process by allowing nonpalliative care clinicians to target misinformation and knowledge gaps identified by the PaCKS. Specifically, patients or family members who incorrectly answer items on the PaCKS could meet with a healthcare provider to receive education explaining the correct answers. Furthermore, if a patient is referred to palliative care having never received the PaCKS, the palliative care team can use the brief assessment to facilitate their first contact by determining sources of misinformation about palliative care that may interfere with willingness to utilize the service. For instance, patients may think that palliative care and hospice care are synonymous, which could result in resistance to palliative care team involvement in patient care if the patient is pursuing curative treatments.

Furthermore, the PaCKS could be used to inform public health initiatives to target broad knowledge gaps in palliative care. This study revealed that 25% of our sample believed that palliative care is exclusively for people in the last six months of life. If people are unaware of their eligibility for palliative care, or if they mistake palliative care as being synonymous with

hospice care, they may be unlikely to accept or pursue a referral for the service. Once normative data for the PaCKS are established, a targeted advertisement campaign could be developed based on the items on the PaCKS that the general population is most likely to answer incorrectly in order to combat the most common domains of misinformation about palliative care in a broad, public setting. For example, creating billboards or television commercials that explain what palliative care is and who it is for could encourage people to seek palliative care if they develop a serious illness or if they have family members with serious illness.

Conclusion

Creating a scale to measure knowledge of palliative care was a critical step to understanding and combating potential barriers to access and utilization of this life-improving service. Previous theories and research about healthcare barriers hypothesized that lack of knowledge of a health service may contribute to underutilization. The PaCKS can facilitate future research that will determine not only how lack of knowledge affects palliative care utilization, but also how to remedy knowledge deficits in palliative care by evaluating the efficacy of educational interventions. The PaCKS has the potential to be an integral and useful tool in clinical, research, and public health contexts in order to identify knowledge deficits in palliative care that may be contributing to the systemic underutilization of this life-improving service.

References

Allard P., Maunsell E., Labbe J., & Dorval, M. (2001). Educational interventions to improve cancer pain control: A systematic review. *Journal of Palliative Medicine, 4*, 191–203.

Allen, R., & Jones, M. (1998). The validity and reliability of an Asthma Knowledge Questionnaire used in the evaluation of a group asthma education self-management program for adults with asthma. *Journal of Asthma, 35*, 537–545.

American Medical Association, Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs (1999). Health literacy: Report of the Council of Scientific Affairs. *Journal of the American Medical Association*, *281*, 552–557.

Baifour, D, Kowai, G., Tasca, G. A., Cooper, C., Angel, J. B., Macpherson, P. A…Cameron, D.W. (2007). Development and psychometric validation of the HIV Treatment Knowledge Scale. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV, 19*, 1141–1148.

Bennett M., Bagnall A., & Closs S. (2009). How effective are patient-based educational interventions in the management of cancer pain? Systematic review and meta-analysis. *Pain*, *143*, 192–199.

Berinsky, A. J., Huber, G. A., & Lenz, G. S. (2012). Evaluating online labor markets for experimental research: Amazon.com's Mechanical Turk. *Political Analysis*, *20*, 351–368.

Born, W., Greiner, A., Sylvia, E., Butler, J., & Ahluwalia, J. (2004). Knowledge, attitudes and beliefs about end-of-life care among inner-city African Americans and Latinos. *Journal of Palliative Medicine, 7*, 247–256.

Bock, R.D., & Aitkin, M. (1981). Marginal maximum likelihood estimation of item

  parameters: application of an EM algorithm. *Psychometrika 46*, 443–459.

Brickner, L., Scannell, K., Marquet, S., & Ackerson, L. (2004). Barriers to hospice care

  and referrals: Survey of physicians' knowledge, attitudes, and perceptions in a

  health maintenance organization. *Journal of Palliative Medicine, 7*, 411–417.

Buhrmester, M., Kwang, T., & Gosling, S. D. (2011). Amazon's Mechanical Turk: A new source

  of inexpensive, yet high-quality, data?. *Perspectives on Psychological Science*, *6*, 3–5.

Center to Advance Palliative Care (no date). *Palliative care facts and stats.* Retrieved

  from www.capc.org/news-and-events/press.../press-kit-palliative-care-

  facts.pdf

Cheung, G. W., & Rensvold, R. B. (2002). Evaluating goodness-of-fit indexes for testing

  measurement invariance. *Structural Equation Modeling*, *9*, 233–255.

Cho, S. J., Cohen, A. S., & Kim, S. H. (2014). A mixture group bifactor model for binary

  responses. *Structural Equation Modeling: A Multidisciplinary Journal*, *21*, 375–395.

Cronbach, L.J., & Meehl, P. E. (1955). Construct validity in psychological tests.

  Psychological Bulletin, 52, 281–302.

Davis, T. C., Crouch, M. A., Long, S. W., Jackson, R. H., Bates, P., George, R. B., &

  Bairnsfather, L. E. (1991). Rapid assessment of literacy levels of adult primary care patients.

  Family Medicine, *23*, 433-435.

Department of Veterans Affairs, Veterans Health Administration. (2008). *Palliative*

  Care Consultation Teams (VHA Directive 2008-066). Retrieved from

  http://www1.va.gov/vhapublications/ViewPublication.asp?pub_ID=1784

Downing, S.M. (2004). Reliability: On the reproducibility of assessment data. *Medical*

Education, 38, 1006 – 2012.

Edworthy, S., Devins, G., & Watson, M. (1995). The Arthritis Knowledge Questionnaire: A test

    for measuring patient knowledge of arthritis and its self management. *Arthritis &*

    Rheumatism, 38, 590–600.

Elliott T. E. & Elliott B. A. (1992). Physician attitudes and beliefs about use of

    morphine for cancer pain. *Journal of Pain and Symptom Management, 7*, 141–

    148.

Elliott, T. E., Murray, D. M., Elliott, B.A., Braum, B., Oken, M. N., Johnson, K.,

    …Lichtblau, L. (1995). Physician knowledge and attitudes about cancer pain

    management: A survey from the Minnesota cancer pain project. *Journal of Pain*

    and Symptom Management, 10, 494–504.

Ensor, T., & Cooper, S. (2004). Overcoming barriers to health service access:

    Influencing the demand side. *Health Policy and Planning, 19*, 69–79.

Exline, J. J., Pargament, K. I., Grubbs, J. B., & Yali, A. M. (2014). The Religious and Spiritual

    Struggles Scale: Development and initial validation. *Psychology of Religion and*

    Spirituality, *6*, 208–217.

Ferrell, B., Virani, R., Grant, M., Vallerand, A., & McCaffery, M. (2000) Analysis of pain

    content in nursing textbooks. *Journal of Pain and Symptom Management, 19*,

    216–228.

Fischer, S., Gozansky, W., Kutner, J., Chomiak, A., & Kramer, A. (2003). Palliative care

    education: An intervention to improve medical residents' knowledge and

    attitudes. *Journal of Palliative Medicine, 6*, 391–399.

Fleiss, J. L. (2011). *Design and analysis of clinical experiments* (Vol. 73). New York: John

    Wiley & Sons.

Gabriel, S.E., Crowson, C.S., & O'Fallon, W.M. (1999). Comorbidity in arthritis. *The Journal of*

    Rheumatology, 26, 2475–2479.

Gardner, R. M., Brown, D. L., & Boice, R. (2012). Using Amazon's Mechanical Turk website to

    measure accuracy of body size estimation and body dissatisfaction. *Body Image*, *9*,

    532-534.

Gazmararian, J., Baker, D., Williams, M., Parker, R., Scott, T., Green, D…Koplan, J.

    (1999). Health literacy among Medicare enrollees in a managed care

    organization. *Journal of the American Medical Association, 281*, 545-551.

Goldsmith, B., Dietrich, J., Du, Q., & Morrison, S. (2008). Variability in access to

    hospital palliative care in the United States. *Journal of Palliative Medicine, 11*,

    1094–1102.

Grossman, M., & Kaestner, R. (1997). Effects of education on health. In: J.R. Behrman & N.

    Stacey (Eds.), *The social benefits of education* (pp. 69-123). Anne Arbor, MI: University of

    Michigan Press.

Hanratty, B., Hibbert, D., Mair, F., May, C., Ward, C., Corcoran, G…Litva, A. (2006).

    Doctors' understanding of palliative care. *Palliative Medicine, 20,* 493–497.

Hanson, L., Usher, B., Spragens, L., & Bernard, S. (2008). Clinical and economic

    impact of palliative care consultation. *Journal of Pain and Symptom Management,*

    35, 340–346.

Higginson, I., Finlay, I., Goodwin, D., Hood, K., Edwards, A., Cook, A…Normand, C.

    (2003). Is there evidence that palliative care teams alter end-of-life experiences

of patients and their caregivers? *Journal of Pain and Symptom Management, 25*, 150–168.

Joreskog, K.G., (1969). A general approach to confirmatory maximum likelihood factor analysis. *Psychometrika*, *34*, 183–202.

Kaiser, H.F. (1960). The application of electronic computers to factor analysis. *Educational and Psychological Measurement, 20*, 141–151.

Kline, T.J.B. (2005). *Psychological testing: A practical approach to design and evaluation.* Thousand Oaks, CA: Sage.

Koffman, J., Burke, G., Dias, A., Raval, B., Byrne, J., & Daniels, C. (2007). Demographic factors and awareness of palliative care and related services. *Palliative Medicine, 2*, 145–153.

Kruskal, J. & Wish, M. (1978). *Multidimensional scaling.* Newbury Park, California: Sage Publications, Inc.

Li, Y., Bolt, D. M., & Fu, J. (2006). A comparison of alternative models for testlets. *Applied Psychological Measurement*, *30*, 3–21.

Lupu, D., & American Academy of Hospice and Palliative Medicine Workforce Task Force. (2010). Estimate of current hospice and palliative medicine physician workforce shortage. *Journal of Pain and Symptom Management, 40*, 899–911.

Manfredi, P., Morrison, S., Morris, J., Goldhirsch, S., Carter, J, & Meier, D. (2000). Palliative care consultations: How do they impact the care of hospitalized patients? *Journal of Pain and Symptom Management, 20*, 166–173.

Mason, W., & Suri, S. (2012). Conducting behavioral research on Amazon's Mechanical Turk. *Behavior Research Methods, 44*, 1–23.

Meekin, S., Klein, J., Fleischman, A., & Fins, J. (2000). Development of a palliative

    education assessment tool for medical student education. *Academic Medicine,*

    75, 986–992.

Meredith, W., & Millsap, R. E. (1992). On the misuse of manifest variables in the detection of

    measurement bias. *Psychometrika*, *57*, 289–311.

Metzger, M., Norton, S., Quinn, J., & Gramling, R. (2013). Patient and family

    members' perceptions of palliative care in heart failure. *Heart & Lung: The Journal*

    of Acute and Critical Care, 42, 112–119.

Millsap, R. E., & Kwok, O. M. (2004). Evaluating the impact of partial factorial invariance on

    selection in two populations. *Psychological Methods*, *9*, 93–115.

Morrison, S., Augustin, R., & Meier, D. (2011). America's care of serious illness: A

    state-by-state report card on access to palliative care in our nation's hospitals.

    Journal of Palliative Medicine, *14*, 1094–1096.

Morrison, S., Maroney-Galin, C., Kralovec, P., & Meier, D. (2005). The growth of

    palliative care programs in United States hospitals. *Journal of Palliative Medicine,*

    8, 1127–1134.

Muthén, B., Du Toit, S. H., & Spisic, D. (1997). Robust inference using weighted least squares

    and quadratic estimating equations in latent variable modeling with categorical and

    continuous outcomes. *Psychometrika*, *75*, 1–45.

Oldenmenger, W., Sillevis Smitt, P., van Dooran, S., Stoter, G., & van der Rijt, C. (2009).

    A systematic review on barriers hindering adequate cancer pain management and

    interventions to reduce them: A critical appraisal. *European Journal of Cancer,* 45,

    1370–1380.

Pargeon, K., & Hailey, B. J. (1999). Barriers to effective cancer pain management: A

    review of the literature. *Journal of Pain and Symptom Management, 18*, 358–368.

Rabow, M. W., Hardie, G. E., Fair, J. M., & McPhee, S. J. (2000) End-of-life care content

    in 50 textbooks from multiple specialties. *Journal of the American Medical*

    Association, *283*, 771–778.

Ramsey, P., Carline, J., Inui, T., Larson, E., LoGerfo, J., & Weinrich, M. (1989).

    Predictive validity of certification by the American Board of Internal Medicine.

    Annals of Internal Medicine, 110, 719–726.

Rawson, K., Gunstad, J., Hughes, J., Spitznagel, M., Potter, V., Waechter, D., & Rosneck,

    J. (2010). The METER: A brief, self-administered measure of health literacy.

    Society of General Internal Medicine, *15,* 67–71.

Riddell, A. & Fitch, MI. (1997). Patient's knowledge of and attitudes toward the

    management of cancer pain. *Oncological Nursing, 24*, 1775–1784.

Ross, M., McDonald, B., & McGuinness, J. (1996). The Palliative Care Quiz for Nursing

    (PCQN): The development of an instrument to measure nurses' knowledge of

    palliative care. *Journal of Advanced Nursing, 23*, 126–137.

Shipley, W.C. (1940). A self-administering scale for measured intellectual impairment and

    deterioration. *Journal of Psychology: Interdisciplinary and Applied*, *9,* 6–14.

Snow, C. E., Varela, B. R., Pardi, D. A., Adelman, R. D., Said, S., & Reid, M. C. (2009).

    Identifying factors affecting utilization of an inpatient palliative care service: A

    physician survey. *Journal of Palliative Medicine*, *12*, 231–237.

Sprouse, J. (2011). A validation of Amazon Mechanical Turk for the collection of

    acceptability judgments in linguistic theory. *Behavior Research Methods*, *43*, 155–167.

Stanley, J. C., & Hopkins, K. D. (1972). *Educational and psychological measurement and evaluation*. Englewood Cliffs, NJ: Prentice Hall.

Streiner, D. L. (2003). Starting at the beginning: An introduction to coefficient alpha and internal consistency. *Journal of Personality Assessment*, *80*, 99–103.

Streiner, D. L., & Norman, G. R. (2008). *Health measurement scales: A practical guide to their development and use*. Oxford, UK: Oxford University Press.

Terwee, C. B., Bot, S. D., de Boer, M. R., van der Windt, D. A., Knol, D. L., Dekker, J., ... & de Vet, H. C. (2007). Quality criteria were proposed for measurement properties of health status questionnaires. *Journal of Clinical Epidemiology*, *60*, 34–42.

Verhaeghen, P. (2003). Aging and vocabulary score: A meta-analysis. *Psychology and Aging*, *18*, 332–339.

Ward, S., Goldberg, N., Miller-McCauley, V., Mueler, C., Nolan, A., Pawlik-Plank, D…Weissman, D. (1993). Patient-related barriers to management of cancer pain. *Pain*, *52*, 319–324.

Williams, M. V., Parker, R. M., Baker, D. W., Parikh, N. S., Pitkin, K., Coates, W. C., & Nurss, J. R. (1995). Inadequate functional health literacy among patients at two public hospitals. *Journal of the American Medical Association*, *274*, 1677–1682.

Zachary, RA. (1991). *Shipley Institute of Living Scale Revised Manual*. Los Angeles: Western Psychological Services.

Table 1

Subsamples Recruited for the Substudies

Sub-study	Sample Source	Total Sample	Assessments	Analyses
Intervention Study	mTurk & Community	$n = 154$	- Core Assessment - Intervention - PaCKS Time 1 & 2	convergent and construct validity, test-retest reliability, Exploratory Factor Analysis (EFA), Confirmatory Factor Analysis (CFA)
AKQ Study	mTurk & Community	$n = 56$	- Core Assessment - AKQ - Shipley	divergent validity, EFA, CFA
Core Study (includes above two studies)	mTurk & Community	$n = 404$	- Core Assessment - Shipley	convergent validity, construct validity, EFA, CFA
Professionals Study	Palliative Care Professionals	$n = 30$	- Core Assessment	Construct validity, discriminative validity, EFA, CFA

Note. Core Assessment consists of the demographics, METER, Experience with Palliative Care Questionnaire, and PaCKS.

Table 2

Age Stratification for Substudies

	Age							
Sub-study	18-29	30-39	40-49	50-59	60-69	70-79	80+	Total
Intervention Study	**≥16** 26 (r1[1]) 8 (vid[2])	**≥16** 26 (r1) 6 (vid)	**≥20** 25 (r1) 9 (vid)	**≥20** 23 (r1) 10 (vid)	**≥20** 7 (r1) *22 (r1)* *2 (vid)* *9 (vid)*	**≥16** 2 (r1) *23 (r1)* *1 (vid)* *12 (vid)*	**≥16** *11(r1)* *8 (vid)*	*170 (r1)* *67(vid)*
AKQ Study	**5** 5	**5** 5	**10** 10	**10** 10	**10** *8* 6	**5** *6*	**5** *6*	*n = 56* *all stratified*
Core Study + Shipley (goals reflect totals goals of above two studies)	**≥ 21** 76 *44*	**≥ 21** 46 *49*	**≥ 30** 24 *13*	**≥ 30** 15 *19*	**≥ 30** 4 *24*	**≥ 21** *7*	**≥ 21** *25*	*321*
Professionals Study	1	3	9	14	1	2	0	*n = 30*
Total	**160**	**135**	**91**	**101**	**79**	**53**	**25**	*N = 644*

Bold = goal, <u>Underlined</u> = actual mTurk, *Italicized* = actual non-mTurk, <u>*Underlined and Italicized*</u> = Total Recruited
[1]r1 = Randomized control study sample 1. Only information page and control page data were used in the r1 sample as a result of a Qualtrics malfunction with the video play-back. The video participants' data were added to the Core Study data, as all core scales were administered before the video malfunction.
[2]vid = Only the video control and video intervention were offered in a second round of sampling to account for the video play-back malfunction that occurred in the r1 sample.

Table 3
Demographic Information

	Community		mTurk		Professionals	
	N/M	*%/SD*	*N/M*	*%/SD*	*N/M*	*%/SD*
Age	54.39	20.03	38.56	12.85	50.16	10.30
Sex						
Male	65	24.7	178	50.7	6	20
Female	198	75.3	172	49	24	80
Transgender	0	0	1	.3	0	0
Education	15.79	3.27	15.26	2.98		
Race						
White	232	88.2	261	74.4	29	97
Black	20	7.6	25	7.1	0	0
Asian	5	1.9	46	13.1	0	0
Hispanic	4	1.5	18	5.1	0	0
Alaskan/Native American	8	3.0	15	4.3	1	3.33
Hawaiian/Pacific Islander	1	.4	2	.6	0	0
Other	3	1.1	2	.6	0	0
Marital Status						
Single	55	20.9	133	37.9	1	3.33
Cohabitating	13	4.9	34	9.7	0	
Married	133	50.6	144	41.0	20	66.67
Separated/ Divorced	45	17.1	38	10.8	4	13.33
Widowed	17	6.5	2	.6	1	3.33

Table 4

Factor Loadings and R-squared for Final 13 Item PaCKS

Item #	PaCKS Content	Loading	R-Squared
1	A goal of palliative care is to addresses any psychological issues brought up by serious illness. (T)	.64**	.57**
3	Stress from serious illness can be addressed by palliative care. (T)	.58**	.50**
5	Palliative care can help people manage the side effects of their medical treatments. (T)	.71**	.66**
11	When people receive palliative care, they must give up their other doctors. (F)	.61**	.54**
14	Palliative care is exclusively for people who are in the last six months of life. (F)	.59**	.51**
15	Palliative care is specifically for people with cancer. (F)	.58**	.49**
18	People must be in the hospital to receive palliative care. (F)	.68**	.62**
19	Palliative care is designed specifically for older adults. (F)	.50**	.41**
21	Palliative care is a team-based approach to care. (T)	.62**	.54**
23	A goal of palliative care is to help people better understand their treatment options. (T)	.47**	.39**
25	Palliative care encourages people to stop treatments aimed at curing their illness. (F)	.57**	.49**
28	A goal of palliative care is to improve a person's ability to participate in daily activities. (T)	.59**	.51**
33	Palliative care helps the whole family cope with a serious illness. (T)	.53**	.44**

** $p < .01$

Table 5

PaCKS Validity Correlations

Scale/Question	*Mean/n*	*SD/%*	*Pearson r* with PaCKS Total	SEM *Corr.* PaCKS	*SEM Corr.* with Bias
Exp. 1 – Have you heard of PC? (y = 1/n = 2)	376 – Y 268 - N	58.4% 41.6%	-.26**	-.43**	.23**
Exp. 2 – How familiar are you with PC? (1-5)	2.78	1.57	.12**	.31**	-.07
Exp. 3 – How experienced with PC are you? (1-5)	2.13	1.33	.13**	.19**	-.05
Exp. 4 – How knowledgeable about PC are you? (1-10)	3.97	2.94	.21**	.31**	-.13*
Exp. 5 – Have you heard of hospice? (y = 1/n = 2)	610 – y 34 - n	94.7% 5.3%	-.29**	-.42**	-.22**
Exp. 6 - How familiar are you with hospice? (1-5)	4	.94	.17**	.23**	-.07
Exp. 7 - How experienced with hospice are you? (1-5)	2.96	1.43	.06	.09	.01
Exp. 8 - How knowledgeable about hospice are you? (1-7)	6.16	2.31	.15**	.18**	-.03
Shipley	31.66	5.05	.34**	.47**	-.14*
METER	37.12	5.11	.33**	.37**	-.18**
AKQ	9.79	2.82	.49**	.64**	.12
Age	45.56	17.83	.15**	.2**	-.01

* *p* < .05, ** *p* < .01

Table 6

Linear Regression Predicting PaCKS from Age, METER, AKQ, and Interactions (n = 56)

Variable	*B*	*SE B*	*beta*
AKQ	.32	.1	.44**
METER	.17	.15	.46
Age	.32	.02	-.06
AKQ*Age	.00	.00	.08
METER*Age	.00	.00	.32

** *p* < .01

R^2 = .27

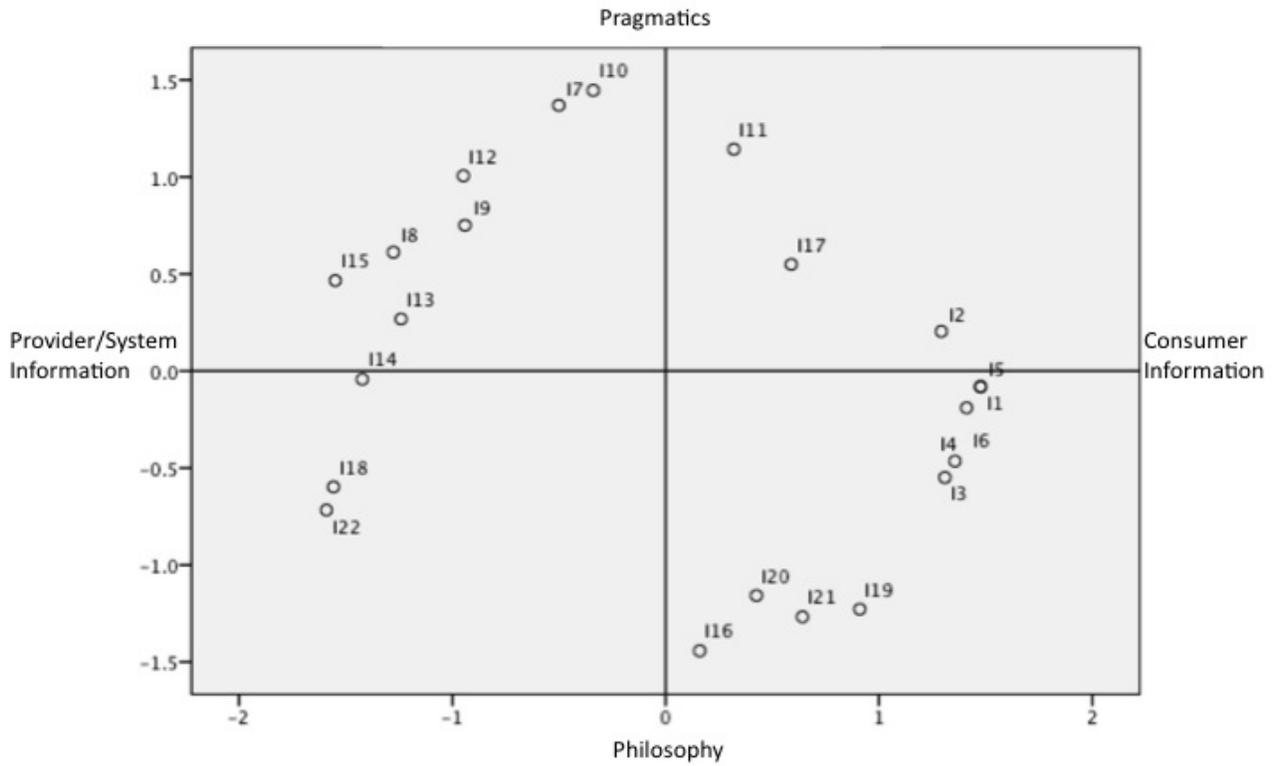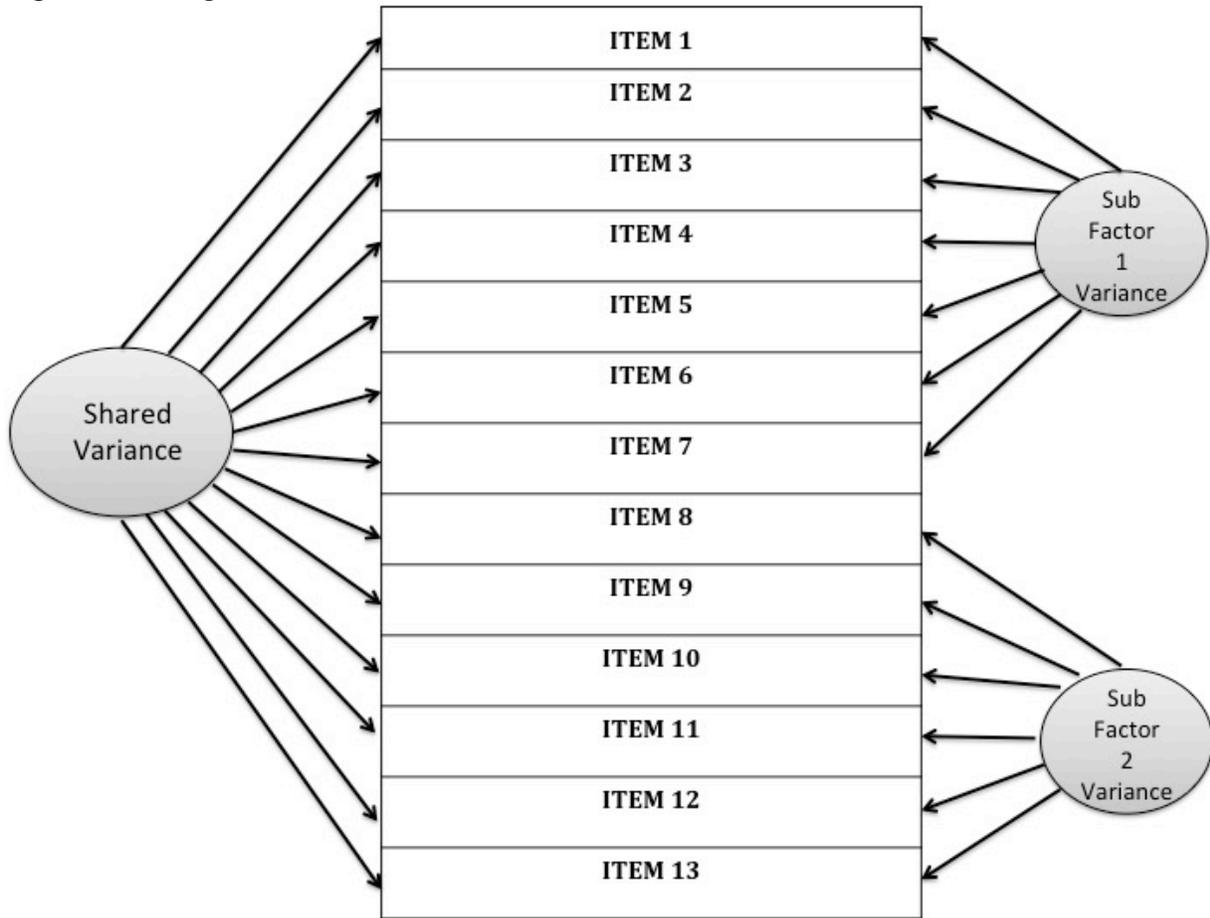*Figure 1*. Nonmetric multidimensional scale with two dimensional solution concept map.

Figure 2. Example of a bifactor model

.

Results of Cluster Analysis and Concept Mapping Item Key

Cluster 1
1. Palliative care addresses the psychological symptoms associated with serious illness **(T)**
2. Palliative care addresses the side effects of the treatment of serious illness **(T)**
3. Palliative care addresses the physical symptoms associated with serious illness **(T)**
4. Palliative care addresses the spiritual issues associated with serious illness **(T)**
5. Palliative care addresses the social issues associated with serious illness **(T)**
6. Palliative care addresses the practical issues associated with serious illness **(T)**

Cluster 2
7. When patients begin palliative care, they can continue to receive treatments aimed at curing their illness **(T)**
9. Hospice and palliative care are different **(T)**
10. Patients can receive palliative care at any time during a serious illness **(T)**
11. Palliative care can have the largest impact when it starts at the time of diagnosis of a serious illness **(T)**
12. Palliative care can be given in a variety of settings **(T)**
13. Palliative care can be provided for patients of any age **(T)**

Cluster 3
8. Patients in palliative care can keep their other doctors **(T)**
14. Different types of health care providers work together to form a palliative care team **(T)**
15. Medical doctors have to pass a specific test to be called a palliative care specialist **(T)**

Cluster 4
16. A central goal of palliative care is to can help patients better understand their treatment options **(T)**
19. A central goal of palliative care is to improve a patient's ability to participate in daily activities **(T)**
20. A central goal of palliative care is to improve communication among patients and their family and healthcare team **(T)**
21. A central goal of palliative care is to help patients better understand their illness **(T)**

Cluster 5
17. Palliative care helps patients decide if and when to stop treatments aimed at curing their illness **(T)**

Cluster 6
18. Medicare and Medicaid cover some of the costs associated with palliative care **(T)**
22. Patients with serious illness who receive palliative care generally have lower hospital costs than patients with serious illness who do not receive palliative care. **(T)**

Appendix B
Demographic Questions

Demographics (community sample)

1. How old are you? _____

2. What is your gender?
    _____male
    _____female
    _____transgender

3. What is your ethnicity and race (check all that apply)?
    _____American Indian or Alaskan Native
    _____Asian
    _____Black or African American
    _____Caucasian
    _____Hispanic/Latino
    _____Native Hawaiian or other Pacific Islander

4. How many years of education do you have? _____

5. What is your primary occupation? _____

6. Is English your native language?
    _____Yes
    _____No

Demographics (palliative care professionals)

1. How old are you? _____

2. What is your gender?
    ____Male
    ____Female
    ____Transgender

3. What is your ethnicity and race (check all that apply)?
    _____American Indian or Alaskan Native
    _____Asian
    _____Black or African American
    _____Caucasian
    _____Hispanic/Latino
    _____Native Hawaiian or other Pacific Islander

4. How long have you been working in palliative care (in years)? _____

5. What is your professional background?
   ____Medical Doctor
   ____Nurse
   ____Nurse Practitioner
   ____Social Worker
   ____Psychologist
   ____Chaplain/Spiritual Advisor
   ____Pharmacist
   ____Massage Therapist
   ____Physical Therapist
   ____Occupational Therapist
   ____Nutritionist/Dietician
   ____Other (please specify)_____

6. Are you primarily a researcher, clinician or both?
   ____Researcher
   ____Clinician
   ____Both

Appendix C
Experience & Familiarity with Palliative Care Questionnaire

1. Have you heard of palliative care?

   Yes   **No**

2. How much do you agree with this statement: "I am familiar with palliative care."
   1 – Strongly Disagree
   2 – Disagree
   3 – Neutral
   4 – Agree
   5 – Strongly Agree

3. How much do you agree with this statement: "I have experience with palliative care."
   1 – Strongly Disagree
   2 – Disagree
   3 – Neutral
   4 – Agree
   5 – Strongly Agree

4. Select any number between 1 and 10 to indicate how much knowledge you think you have about palliative care.
   1 – I know nothing at all
   2
   3
   4
   5 – I have some knowledge
   6
   7
   8
   9
   10 – I am very knowledgeable

5. Have you heard of hospice care?

   Yes   **No**

6. How much do you agree with this statement: "I am familiar with hospice care."
   1 – Strongly Disagree
   2 – Disagree
   3 – Neutral
   4 – Agree
   5 – Strongly Agree

7. How much do you agree with this statement: "I have experience with hospice care."

1 – Strongly Disagree
2 – Disagree
3 – Neutral
4 – Agree
5 – Strongly Agree

8. Select any number between 1 and 10 to indicate how much knowledge you think you
have about hospice care.
1 – I know nothing at all
2
3
4
5 – I have some knowledge
6
7
8
9
10 – I am very knowledgeable

Appendix D
METER Instructions and Items

The following list contains some real medical words. For example, some of the words have to do with body parts or body functions, kinds of diseases, or things that can make your health better or worse. The list also contains some items that may look or sound like medical words but that are not actually real words. As you read through the list, put an "X" next to the items that you know are real words. You should not guess. Only put an "X" next to an item if you're sure it's a real word.

_____	Irrity	_____	Inlest
_____	Arthritis	_____	Pollent
_____	Obesity	_____	Malories
_____	Flu	_____	Cancer
_____	Behaviose	_____	Alcoheliose
_____	Syphilis	_____	Antibiotics
_____	Potassium	_____	Antiregressant
_____	Hormones	_____	Colitis
_____	Nerves	_____	Diabetes
_____	Pilk	_____	Occipitent
_____	Rection	_____	Nausion
_____	Blout	_____	Impetigo
_____	Boweling	_____	Menstrual
_____	Exercise	_____	Abghorral
_____	Pustule	_____	Seizure
_____	Cerpes	_____	Appendix
_____	Kidney	_____	Fam
_____	Emergency	_____	Infarth
_____	Potient	_____	Dose
_____	Menopause	_____	Hemorrhoids
_____	Diagnosis	_____	Testicle
_____	Depretion	_____	Eye
_____	Jaundice	_____	Midlocation
_____	Gallbladder	_____	Insomniate
_____	Miscarriage	_____	Bloodgatten
_____	Hepatitis	_____	Sexually
_____	Astiringe	_____	Pelvince
_____	Nutral	_____	Vaccilly
_____	Asthma	_____	Prescription
_____	Inflammatory	_____	Germs
_____	Anemia	_____	Gonorrhea
_____	Allagren	_____	Tumic
_____	Prognincy	_____	Fatigue
_____	Stress	_____	Osteoporosis
_____	Ellargic	_____	Constipation

Arthritis Knowledge Questionnaire (AKQ; Edworthy, Devins, & Watson, 1995)

1. Tendons are:
    a. Fibrous cords that attach muscles to bone
    b. The cover at the end of bones
    c. Fibrous cords that attach bone to bone
    d. Bone chips
    e. Don't know
2. The most important goal of the physician caring for people with arthritis is:
    a. To keep or improve the present level of functioning
    b. To do everything they can to cure the person
    c. To give patients enough medication to stand the pain
    d. To keep patients quiet and uncomplaining
    e. Don't know
3. The most realistic treatment for arthritis is:
    a. One which gives immediate relief
    b. One which helps you keep up a near normal life
    c. One with no unpleasant side-effects
    d. One which cures the diseases
    e. Don't know
4. Two to four tablets of aspirin a day can:
    a. Only reduce mild pain
    b. Reduce inflammation
    c. Fight infection
    d. Help both pain and inflammation
    e. Don't know
5. To a physician "diagnostic certainty" means:
    a. Your guess is as good as mine
    b. I am certain you have this diagnosis
    c. How certain I am that you have this disease
    d. How certain I am that I can diagnose a disease
    e. Don't know
6. Which of the following is known to be true:
    a. Some foods are bad for people with arthritis
    b. Food allergies can make people with arthritis feel worse
    c. The timing of eating is important to people with arthritis
    d. All of the above
    e. Don't know
7. If an arthritis medication doesn't work within a few days, you should:
    a. Keep taking it as the prescription says
    b. Probably be taking more of it
    c. Probably be taking something else with it
    d. Consider exercising to help speed up your system
    e. Don't know
8. Pain is one of the biggest problems in arthritis. This can:

    a. Never be completely controlled
    b. Only can be controlled with some medication
    c. Can be controlled by a very few people using a combination of medication and other methods
    d. Can be controlled by most people using a combination of medications and other methods
    e. Don't know

9. Allergies to medications:
    a. Are very common
    b. Will happen to anyone who takes too much of a medication
    c. Are the same thing as side effects
    d. Are rare reactions that mean you should not use that drug again
    e. Don't know

10. Constipation is often a problem for many people who have arthritis. This is because:
    a. They are not as physically active
    b. Their medications tend to be constipating
    c. People with arthritis are often under stress
    d. All of the above
    e. Don't know

11. Medications are used in arthritis to:
    a. Reduce inflammation
    b. Slow down the progress of arthritis
    c. Help control symptoms of arthritis
    d. All of the above
    e. Don't know

12. Acetaminophen (Tylenol):
    a. Helps reduce inflammation in arthritis
    b. Only provides temporary relief of mild pain
    c. Should be used regularly with your other arthritis medications
    d. Can be used as a substitute for aspirin in arthritis
    e. Don't know

13. Prednisone:
    a. Can stop the progress of arthritis
    b. Is a steroid like the ones athletes use
    c. Helps reduce inflammation in arthritis
    d. Is a very safe drug with few side effects
    e. Don't know

14. Side effects of prednisone:
    a. Can include cataracts, brittle bones, muscle wasting
    b. Can be reduced by keeping the dose low
    c. Are the most common with long-term use (more than a month)
    d. All of the above
    e. Don't know

15. The synovial membrane (or sac):
    a. Secretes a fluid that oils the joint
    b. Protects the nerve endings

c. Covers the muscles like a sheath
d. Lies between the tendons and the bursa
e. Don't know

Shipley Vocabulary Test (Shipley, 1940)

In the test below, the first word in each line is printed in capital letters. Opposite it are four other words. <u>Draw a line</u> under the <u>one word</u> which means the <u>same thing</u>, or most nearly the same thing, as the first word. A sample has been worked out for you. If you don't know, <u>guess</u>. Be sure to underline the <u>one word</u> in each line which means the same things as the first word.

sample

	LARGE	red	<u>big</u>	silent	wet

1.	TALK	draw	eat	speak	sleep
2.	PERMIT	allow	sew	cut	drive
3.	PARDON	forgive	pound	divide	tell
4.	COUCH	pin	eraser	sofa	glass
5.	REMEMBER	swim	recall	number	defy
6.	TUMBLE	drink	dress	fall	think
7.	HIDEOUS	silvery	tilted	young	dreadful
8.	CORDIAL	swift	muddy	leafy	hearty
9.	EVIDENT	green	obvious	skeptical	afraid
10.	IMPOSTOR	conductor	officer	book	pretender
11.	MERIT	deserve	distrust	fight	separate
12.	FASCINATE	welcome	fix	stir	enchant
13.	INDICATE	defy	excite	signify	bicker
14.	IGNORANT	red	sharp	uninformed	precise
15.	FORTIFY	submerge	strengthen	vent	deaden
16.	RENOWN	length	head	fame	loyalty
17.	NARRATE	yield	buy	associate	tell

18.	MASSIVE	bright	large	speedy	low
19.	HILARITY	laughter	speed	grace	malice
20.	SMIRCHED	stolen	pointed	remade	soiled
21.	SQUANDER	tease	belittle	cut	waste
22.	CAPTION	drum	ballast	heading	ape
23.	FACILITATE	help	turn	strip	bewilder
24.	JOCOSE	humorous	paltry	fervid	plain
25.	APPRISE	reduce	strew	inform	delight
26.	RUE	eat	lament	dominate	cure
27.	DENIZEN	senator	inhabitant	fish	atom
28.	DIVEST	dispossess	intrude	rally	pledge
29.	AMULET	charm	orphan	dingo	pond
30.	INEXORABLE	untidy	involatile	rigid	sparse
31.	SERRATED	dried	notched	armed	blunt
32.	LISSOM	moldy	loose	supple	convex
33.	MOLLIFY	mitigate	direct	pertain	abuse
34.	PLAGIARIZE	appropriate	intend	revoke	maintain
35.	ORIFICE	brush	hole	building	lute
36.	QUERULOUS	maniacal	curious	devout	complaining
37.	PARIAH	outcast	priest	lentil	locker
38.	ABET	waken	ensue	incite	placate
39.	TEMERITY	rashness	timidity	desire	kindness

40.	PRISTINE	vain	sound	first	level

Palliative Care Knowledge Scale (PaCKS)

1. A goal of palliative care is to addresses any psychological issues brought up by serious illness. (T)

2. Addressing feelings of depression brought up by serious illness is not a part of palliative care. (F)

3. Stress from serious illness can be addressed by palliative care. (T)

4. Palliative care focuses exclusively on physical symptoms. (F)

5. Palliative care can help people manage the side effects of their medical treatments. (T)

6. A goal of palliative care is to cure serious illness. (F)

7. When people receive palliative care, they must stop treatments aimed at curing their illness. (F)

8. A goal of palliative care is to address any spiritual issues associated with serious illness (T)

9. A goal of palliative care is to address any social issues related to having a serious illness, such as community involvement and relationships. (T)

10. Palliative care is not designed to address practical issues (for example, housing, transportation, finances, and insurance) associated with serious illness. (F)

11. When people receive palliative care, they must give up their other doctors. (F)

12. Hospice care is another name for palliative care. (F)

13. People can receive palliative care at any time during a serious illness. (T)

14. Palliative care is exclusively for people who are in the last six months of life. (F)

15. Palliative care is specifically for people with cancer. (F)

16. Palliative care can have the most impact when it starts at the time a serious illness is diagnosed. (T)

17. People can receive palliative care at home. (T)

18. People must be in the hospital to receive palliative care. (F)

19. Palliative care is designed specifically for older adults. (F)

20. A health care provider must be a physician in order to be on a palliative care team. (F)

21. Palliative care is a team-based approach to care. (T)

22. There is a specific test doctors have to pass in order to become a palliative care doctor (T)

23. A goal of palliative care is to help people better understand their treatment options. (F)

24. Palliative care helps people decide if and when to stop treatments aimed at curing their illness. (T)

25. Palliative care encourages people to stop treatments aimed at curing their illness. (F)

26. Medicare covers some of the costs associated with palliative care. (T)

27. Medicaid covers some of the costs associated with palliative care. (T)

28. A goal of palliative care is to improve a person's ability to participate in daily activities. (T)

29. Improving communication among people, their family, and their healthcare team is a focus of palliative care. (T)

30. People can learn more about their illness from palliative care professionals (T)

31. People with serious illness who receive palliative care generally have higher medical costs than people who do not receive palliative care. (F)

32. Palliative care is not designed to address the needs of family members of people with serious illness. (F)

33. Palliative care helps the whole family cope with a serious illness. (T)

34. A goal of palliative care is to prolong life for people with serious illness. (F)

35. Palliative care is for anyone with a serious illness. (T)

36. Palliative care ends when a person with serious illness dies. (F)

37. In order to receive palliative care, people must have been diagnosed with a serious illness for at least 2 months. (F)

38. In order to receive palliative care, people must have been hospitalized for their serious illness. (F)

Final Palliative Care Knowledge Scale (PaCKS)

1. A goal of palliative care is to address any psychological issues brought up by serious illness. (T)

2. Stress from serious illness can be addressed by palliative care (T)

3. Palliative care can help people manage the side effects of their medical treatments. (T)

4. When people receive palliative care, they must give up their other doctors. (F)

5. Palliative care is exclusively for people who are in the last six months of life. (F)

6. Palliative care is specifically for people with cancer. (F)

7. People must be in the hospital to receive palliative care. (F)

8. Palliative care is designed specifically for older adults. (F)

9. Palliative care is a team-based approach to care. (T)

10. A goal of palliative care is to help people better understand their treatment options. (T)

11. Palliative care encourages people to stop treatments aimed at curing their illness. (F)

12. A goal of palliative care is to improve a person's ability to participate in daily activities. (T)

13. Palliative care helps the whole family cope with a serious illness. (T)