Effect of Knowledge on Evaluations of Palliative Care as an Appropriate Treatment Intervention

by

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A thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Science
(Psychology)
in the University of Michigan–Dearborn
2020

Master's Thesis Committee:

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Acknowledgements

I would like to acknowledge and thank all of the many people without whose support and encouragement this project would not have been possible. I would like to thank Dr. Nancy Wrobel and Dr. Michelle Leonard for their patience, commitment and belief in this project. I learned so much from you both in this process, and without your expertise, advice, and encouragement this project would not have become what it is. I would also like to thank all of the faculty that I have had the privilege of learning from over the course of this Master's program. The challenges and lessons of the past two years have provided invaluable experiences that I will always remember. My cohort has been a consistent source of support throughout this process and I appreciate their encouragement through all the changes that have occurred in our years together. Lastly, I would like to thank my family and friends for their unconditional love and support. Your belief in me and your pride in my accomplishments have made every challenge easier and every achievement more exciting. I truly could not have done this without you.

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Abstract

Palliative care is a treatment approach specifically designed to help patients and caregivers manage the physical, psychological, and social burdens that accompany chronic or life-threatening diseases. Despite the research supporting its inclusion in standard care for a number of diseases, the gap between those who would benefit from palliative care services and those who receive them continues to widen. A critical part of improving utilization of palliative care services includes understanding the barriers that restrict access. Lack of knowledge of palliative care has been identified as a persistent barrier to utilization. Many in the general public have not heard of it and, for those who have, there is still a great degree of uncertainty about its design and purpose. Using a vignette design, this study set out to test the effectiveness of an educational intervention to improve palliative care knowledge and to examine how pre-existing knowledge impacts individuals' evaluations of the applicability or helpfulness of palliative care for a fictional patient. It was hypothesized that a brief educational intervention would be sufficient to improve knowledge of palliative care and lead to improved evaluations of palliative care. It was also hypothesized that those with less pre-existing knowledge of palliative care would make different evaluations based on diagnosis or disease stage. Data were collected online from 331 participants. Results found that the educational intervention broadly improved participant knowledge of palliative care and those who received the intervention gave higher evaluations of palliative care. Diagnosis and disease type were not found to have an effect on evaluations of palliative care; however, pre-existing knowledge was found to have an effect such that those individuals with greater levels of pre-existing knowledge gave higher evaluations of palliative care. The results of this study highlight one way in which lack of knowledge about palliative care acts as a barrier to those services. This information can be used to guide public health education efforts to improve awareness of the services and benefits of palliative care.

Chapter 1

Introduction

For individuals diagnosed with a life-threatening or chronic life-limiting disease, the challenges extend beyond those of symptom management. These conditions place social, psychological, physical, and financial burdens on patients and caregivers alike (National Alliance for Caregiving (NAC) & AARP Public Policy Institute, 2015; Rainville et al., 2016; Wilkinson & Lynn, 2005). Medical interventions are designed to manage disease symptoms and side effects of treatment, but often have little to do with addressing the broader effects of the disease on the patient's life as a whole. Palliative care is an approach to care for life-threatening diseases that focuses on the quality of life of the person as a whole with the goal of relieving suffering through the treatment and prevention of symptoms and side effects of the disease. Palliative care is also aimed at the provision of support and resources to address the psychological, social, and spiritual challenges that the patients and their families face (Connor & Bermedo, 2014).

Palliative care is provided by a multidisciplinary team and is primarily comprised of nurses, physicians, social workers, chaplains (Phongtankuel et al., 2018), though additional health professionals are included depending on the needs of the patient. The team works closely with the patients' primary care team to coordinate services and ensure continuity of care. There are a wide range of services that are provided by the palliative care team depending on the specific needs of the patient and their family. These include psychological support, disease education, assistance with symptom management and medical decision-making, social services, care coordination, and bereavement support (Phongtankuel et al., 2018). Services are available along the entire disease trajectory, so participation may increase over time as more support is needed.

In addition to the wide range of services provided through palliative care teams, patients also have options when it comes to how those services are delivered. Depending on the organization, patients can receive palliative care at home, in outpatient clinics, at short- or long-term care facilities, or in the hospital. At home, team members visit in person on a weekly to monthly basis, providing education and counselling, assessing patient and caregiver well-being, or reviewing treatment plans (Fernandes et al., 2010). Outpatient services require the individual to come into the clinic for consultations or meetings with the members of their care team (Kamal et al., 2013). Services provided at short- and long-term facilities may vary based on the facility. In some cases, a palliative team is embedded within the healthcare system and coordinates care and support with the facility staff members (Comart et al., 2013), while others may rely on attending physicians from the community and must coordinate care between facility staff and external service providers (Brazil et al., 2006; Winn & Dentino, 2005). Within the hospital system, palliative care specialists coordinate care with the patient's primary care team. Depending on the size and resources of the hospital, patients may receive services from a large multi-disciplinary team or from a few specialists (Meier, 2006).

Palliative care was initially developed in response to the needs of cancer patients who, having been deemed incurable, were largely overlooked by the larger medical establishment (Clark, 2007). The focus, then, was on protecting and promoting quality of life for the short time the patients had left. However, as the field has grown and services have expanded, it has been recognized that individuals living with other chronic or life-limiting conditions may also benefit from the services provided by palliative care, and not just when all other treatment options have been exhausted. Research has demonstrated the need for palliative support in the areas of symptom burden, psychological distress, and family anxiety for non-cancer conditions (Field & Addington-Hall, 1999). Pain, breathlessness, reduced mobility, adjusting to role changes, worries about job loss and family members, anxiety, and existential questions are symptoms and burdens common across medical conditions (O'Brien et al., 1998) and are often experienced at levels that are difficult to tolerate (Lynn et al., 1997). Beyond more typical application in cancer treatment, specific conditions where the integration of palliative care with standard care has been recommended include long-term neurological conditions like multiple sclerosis, Parkinson's disease, and spinal cord injury (Turner-Stokes & Whitworth, 2005), AIDS (Selwyn et al., 2003), heart failure (Goodlin, 2009), major neurocognitive disorders, kidney failure, and chronic obstructive pulmonary disease (Connor & Bermedo, 2014).

Benefits of Palliative Care

Research evidence demonstrates that palliative care is effective in accomplishing its stated goals. Randomized controlled trials have found that patients receiving standard care plus palliative services show improved quality of life, reduced symptom burden, and lower rates of depression or anxiety (Aiken et al., 2006; Rogers et al., 2017; Sidebottom et al., 2015; Temel et al., 2010). Participation in palliative care also impacts involvement in decision-making regarding care at the end of life. Specifically, patients are more likely to opt for less aggressive care at the end of life and have higher rates of advanced directive or living will completion (Aiken et al., 2006; Sidebottom et al., 2015; Temel et al., 2010). Palliative care services also provide needed supports for patients and caregivers (Jaarsma et al., 2009), improve referrals to and utilization of hospice, (Ferrell et al., 2017), reduce costs of care (May et al., 2018; McIlvennan & Allen, 2016), and may increase length of survival (Ferrell et al., 2017).

A number of major health organizations, including the American Heart Association, American Stroke Association, World Health Organization, and the American Society of Clinical Oncology, recommend the inclusion of palliative care services alongside standard care beginning at the time of diagnosis (American Heart Association/American Stroke Association, 2013; Connor & Bermedo, 2014; Ferrell et al., 2017). Research has found that early referrals improve symptom management and coordination of care (Evangelista et al., 2012) and reduce emergency department visits, inpatient care costs, and admissions to intensive care units (Scibetta et al., 2015). Early referrals also show some effect on improving patient and family outcomes for quality-of-life and caregiver burden (Higginson et al., 2011; Smith et al., 2012).

Barriers to Palliative Care

Despite research supported benefits and recommendations, palliative care services are still underutilized and many who need care and support are going without. An estimated 20 million patients around the world need care at the end of life, but only about 1 in 10 of those who would benefit from the care provided by palliative services actually receives it (Connor & Bermedo, 2014). A major focus of palliative care research has been to identify and understand the barriers that prevent those who need this care from accessing it.

Systemic Issues Impacting Care

Issues preventing access to palliative care exist at all levels of the healthcare system. Some of these require top down policy changes within the system to improve availability of palliative services. Difficulty with reimbursement and lack of standardized referral criteria have been identified as significant barriers to the widespread provision of palliative care (National

Hospice and Palliative Care Organization, 2018). The current models of fee-for-service reimbursement promote the use of acute interventions and reward complex specialized procedures (Institute of Medicine, 2014) providing little incentive for health care providers to prioritize palliative services. Services provided by non-physician team members (i.e. social workers, chaplains) and consultations without the patient present are not reimbursed (Aldridge et al., 2016). Additionally, the Affordable Care Act does not require at-home palliative care to be covered by insurance (Institute of Medicine, 2014). Each of these factors increases the difficulty of integrating high-quality palliative care with standard of care and creates additional barriers preventing widespread access to palliative care.

In addition to systemic issues for more widespread usage of palliative care services, there are no standardized criteria for which to refer patients to palliative care teams (Kavalieratos et al., 2014). Common referrals are driven by the need for psychological support, managing symptom burden, and pain control are frequently cited reasons for referrals to palliative care(Ahmed et al., 2004); however, referral decisions rely heavily on the provider's knowledge and evaluation of patient need, creating a great deal of subjectivity and variation in when patients access palliative care services. Patient prognosis or proximity to death is often a significant or primary deciding factor in referral decisions (Ahmed et al., 2004), however, given the unpredictable nature of many diseases, it is difficult to calculate (Coventry et al., 2005). This makes it an unreliable decision-making tool, and it misses those for whom the integration of palliative care would be beneficial from start to finish.

Lack of Knowledge

Although systematic issues are highly problematic in and of themselves, One of the biggest and most consistent barriers throughout the history of palliative care, however, has been a lack of knowledge about its purpose, goals, and services (Patel & Lyons, 2019) and this is the main focus of the current study In one recent national survey, over 70% of respondents had never heard of palliative care and only 11% reported having enough knowledge to explain its services (Trivedi et al., 2019). Furthermore, lack of knowledge from both sides of the desk. can interfere with access to appropriate palliative services

Physician Gaps in Knowledge. While the current study focuses on the effects of lack of knowledge in patients, unfamiliarity with palliative care on the part of, or other medical staff, may ultimately contribute to the gaps in knowledge for patients and their families. One study found that nearly all primary care providers and cardiologists interviewed did not have clear understanding of palliative care, confusing it with hospice care and believing patients had to stop curative care in order to be eligible for services (Kavalieratos et al., 2014). Some providers hesitate to introduce palliative care as a treatment option for fear of being perceived as giving up on the patient (Ahmed et al., 2004). Those who do have more experience with palliative care services were more likely to make referrals to palliative care at diagnosis or before beginning chemotherapy (Wentlandt et al., 2012). Patients, especially those newly diagnosed, rely on their physicians for a significant amount of information about their health and treatment options. If physicians themselves are unfamiliar with the services and benefits of palliative care, they are unlikely to spend time explaining the purpose and goals of palliative care to their patients or refer them for a palliative care consultation.

Patient and Family Gaps in Knowledge. Patient or caregiver gaps in knowledge can act as a barrier to palliative care in several ways. Perhaps the most obvious barrier is that people cannot ask for services that they are unaware of. Referrals to palliative care rely on the knowledge and resources of patients and their families as well as that of the providers (Ahmed et al., 2004). Additionally, familiarity and knowledge are important factors influencing attitudes and preferences for receiving care (Cagle et al., 2016; Dionne-Odom et al., 2019). Widespread unfamiliarity with palliative care reduces the likelihood that patients or caregivers would choose to engage with those services.

Common Misperceptions about Palliative Care. In addition to a direct lack of knowledge about palliative care, there are common misperceptions or incorrect assumptions about the nature of palliative care that contribute to underutilization. There are several misperceptions about palliative care that are consistently reported in the literature which impact both how patients and families perceive palliative care and how physicians make referrals. As noted earlier with physicians, this could include the belief that palliative care is only for those who are dying or near the end of life or that palliative care services are primarily for those who are diagnosed with cancer.

Palliative Care is only for those Individuals whose Condition is Terminal. The belief that palliative care is only for the dying is reflected in the strong association between palliative care and death as well as the misidentification of palliative care as hospice care. In a recent survey of family caregivers, nearly 40% indicated belief that palliative care was the same as hospice care and 44% expressed a strong association between palliative care and death (Dionne-Odom et al., 2019). When asked specific questions about the nature and requirements of palliative care, people most often incorrectly indicated that palliative care was applicable only for the last 6 months of life and that it required the stoppage of curative care (Kozlov et al., 2018). These are, in fact, characteristic of hospice care, which is care provided at the end of life with the goal of maintaining the comfort and dignity of the dying (Connor & Bermedo, 2014). If these associations are all that comes to mind when a person thinks of palliative care, they are likely to be resistant to considering it as a treatment option when they are not close to death. They may not see it as being able to meet their needs or they may interpret engaging with palliative care as giving up on life.

Healthcare providers also expressed similar beliefs and hesitations about recommending palliative care as a treatment option. One qualitative study found that many physicians used hospice and palliative care interchangeably (Kavalieratos et al., 2014) while a review of the literature found that many physicians associated palliative care with end-of-life treatment (Aldridge et al., 2016). Oncologists indicated they would be more comfortable making referrals to palliative care for patients who were not close to death if the services were described by a different name (Wentlandt et al., 2012). Physicians were also most likely to refer patients to palliative care when the diagnosis was terminal or when the patient had a life expectancy of less than 6 months (Wentlandt et al., 2012). The data suggest that many individuals tend to only think about palliative care in terms of the very end of life when death is expected, and that may interfere with the consideration of palliative care as a viable option for treatment shortly after diagnosis.

Palliative Care is for those Individuals with a Cancer Diagnosis. The assumption that palliative care is primarily for those with a cancer diagnosis has been a persistent issue throughout the development of palliative care and has an impact on the perceptions of physicians and families alike. Patients diagnosed with cancer are more frequently referred to palliative services and receive attention earlier compared to patients with heart failure (Gadoud et al., 2014), most research interventions focus on cancer patients (Phongtankuel et al., 2018), and oncologists are the most likely to be familiar with palliative care compared to other specialties (Ahmed et al., 2004). Patients and their families report strong associations between palliative care and cancer as well (Patel & Lyons, 2019). This data suggests that patients diagnosed with non-malignant conditions are less likely to be considered eligible for palliative services.

Summary and Study Aims

There is a growing consensus in the research that early access to palliative care services demonstrates benefits in a number of outcome areas including family and caregiver burden, symptom burden, advanced care planning, and healthcare costs. Despite this evidence, these services are widely underutilized, and those who do receive them typically do so near the very end of life when prognosis is short or all other options have been exhausted. In order to improve rates of access at earlier stages of the illness, it is important to address the barriers that stand in the way. Looking closely at how knowledge functions as a barrier preventing the consideration of palliative care as a treatment option provides important information for addressing the removal of that barrier. In order to make treatment decisions, patients need to be well-informed. If the knowledge they have is incomplete or inaccurate, they may incorrectly assume that palliative care is not an appropriate treatment option. Therefore, this study specifically examined the relationship between layperson level of knowledge of palliative care and their evaluation of those services as an appropriate treatment option for different types of patients, presented in vignettes. A secondary goal of the study is to examine the effectiveness of a brief educational intervention about palliative care.

The four vignettes used reflect characteristics of commonly held misperceptions about palliative care. By determining whether those with low levels of knowledge make evaluations that align with those misperceptions, this study will be able to identify specific areas of focus for interventions. Results that support the strong association between palliative care and the late stages of an illness will indicate a need for educational interventions that explain how palliative care services are applicable throughout the course of the disease. Raising awareness of how these services can be adapted to meet specific needs as they arise may increase patients' openness to engaging with palliative care earlier in the course of their disease. Results that support the strong association between palliative care and cancer will indicate a need for educational interventions focusing on populations with non-cancer diagnoses. Raising awareness of how palliative care effectively addresses symptoms and burdens for patients with a wide range of diagnoses will help people see it as a viable treatment option.

The second goal of the study was to examine the impact of a brief educational intervention on evaluation decisions to determine whether this method is an effective way to improve individuals' knowledge of palliative care. The results of this study will provide important information for the development of future educational interventions to improve laypersons' knowledge of the nature and goals of palliative care. The information from this study can also be used by physicians and health providers to gain insight into how newly diagnosed patients may respond to the suggestion of palliative care and highlight the importance of checking patient knowledge when discussing treatment options.

Hypotheses

The first goal of this study was to determine whether level of knowledge of palliative care predicts evaluations of the appropriateness and effectiveness of palliative care to meet specific patient needs and whether the pattern of response reflect the prominent misperceptions of palliative care. The second goal of this study was to assess whether a brief educational intervention is effective in improving knowledge of palliative care. Based on these goals, the following hypotheses will be addressed:

1. Reflecting the association between palliative care and death or dying, those with lower levels of pre-existing knowledge of palliative care will rate services as less appropriate or helpful treatment for patients in the early stages of a disease compared to those in the late stages.
2. Reflecting the association between palliative care and cancer, those with lower levels of pre-existing knowledge of palliative care will rate services as less appropriate or helpful treatment for patients with a heart failure diagnosis compared to patients with a cancer diagnosis.
3. A brief fact sheet explaining the services and goals of palliative care will improve knowledge of palliative care. Those who receive the palliative care fact sheet will score higher on the Palliative Care Knowledge Scale post-test than those who did not receive the fact sheet.
4. Participants who receive a fact sheet explaining the nature and goals of palliative care will rate palliative care as more appropriate and effective treatment regardless of diagnosis or stage of disease.

Chapter 2

Methods

Participants

Data collection for this study took place entirely online. Participants were recruited via the TurkPrime Cloud Research platform. Inclusion and exclusion criteria required that participants be between the ages of 18 and 75, able to read English, and live in the United States. Turk Prime does not collect personally identifiable information but assigns a unique ID to each participant. Surveys were completed using Qualtrics. Upon completion of the survey, participants were redirected to the Turk Prime page where they were compensated $2.00 for approximately 25 minutes of their time.

Data collected from 331 participants. Due to concerns about participant attention to item content when responding, the original sample was refined using the length of time participants took to complete the survey. The cutoff was established by calculating the median time to complete in seconds and dividing that value by half. Cutoff values were calculated separately for the group that received the fact sheet (median =394, cutoff = 197) and for the group that did not receive the fact sheet (median = 316, cutoff = 158) based on the assumption that completion time would be impacted by the extra time needed to read the fact sheet. A total of 45 participants were eliminated leaving a sample of 286 participants. The sample was 54.9% female (n=157), and average age was 48.1 (S.D. =17.1). When asked about palliative care, 53.8% (n=154) indicated that they had not heard of it. Of those who had heard of palliative care, the most common reason was due to receiving or knowing someone who had received care (62.9%, n=83), followed by educational experience (44.7%, n=59) and work/volunteer experience (39.4%, n=52).

Materials/Measures

Demographic Questionnaire (Appendix A)

Participants were asked to respond to demographic questions regarding age, race, sex, education, income level, caregiving role, and familiarity with palliative care.

Palliative Care Knowledge and Experiences Questionnaire (Appendix B)

Participants who indicated that they had heard of palliative care were asked several additional questions about palliative care. They were asked about caregiving roles, how they had heard of palliative care, and to rate their level of knowledge of palliative care on a 5-point scale.

Palliative Care Knowledge Scale (Appendix C)

The Palliative Care Knowledge Scale (PaCKS) was designed to be a brief assessment of knowledge of palliative care (Kozlov, 2016). This scale was chosen as it was designed to be used with the general population as compared to other measures (e.g. Palliative Care Quiz for Nurses (PCQN) and Palliative Education Assessment Tool (PEAT)), which are targeted for use in health professionals (Kozlov, 2016; Meekin et al., 2000; Ross et al., 1996). The scale consists of 13 items broadly covering the nature, goals, and services of palliative care. Participants respond to each statement with “true”, “false”, or “I don’t know”. Sample items include, “Palliative care can help people manage the side effects of their medical treatments” and “People must be in the hospital to receive palliative care.” Scores range from 0 to 13 with higher scores representing greater knowledge. Cronbach’s alpha for the current sample was .96.

The PaCKS has been demonstrated to be psychometrically sound. Analysis of internal consistency (KR-20 = .71) and test-retest reliability (ICC = .70) indicate that the scale is reasonably consistent and stable over time (Kozlov, 2016). Several measures of validity were reported. Content validity was demonstrated through significant, positive correlations with questions of experience with palliative care. Convergent validity was established by moderate correlations between scores on the PaCKS and a measure of health literacy ($r = .33$. $p < .001$) and a measure of general intellectual functioning ($r = .36$, $p < .001$) (Kozlov, 2016). Discriminant validity was established by demonstrating sensitivity to differences in knowledge. Significant differences were found between the scores of professionals (M = 12.73, SD = .58) and community members who had never heard of palliative care (M = 8.70, SD = 2.74; t(55) = 7.86, p < .001, Cohen’s d = .81) (Kozlov, 2016).

Patient Vignettes (Appendix D)

Four vignettes describing sample patients were created. One set described patients diagnosed with heart failure, one in the early stages of the disease and one in the late stages. The other set described patients diagnosed with lung cancer, one in the early stage and one in the late stage. Selection of the disease types was guided by statistics on leading causes of death, needs for palliative care, and similarity of symptoms. Heart disease and cancer are the two leading causes of death (Heron, 2019) and the two groups with the highest rate of need for palliative care (Connor & Bermedo, 2014). Heart failure and lung cancer were chosen as the specific diagnoses to be used in this study due to the similarity of common physical symptoms and emotional effects of the illness: fatigue and loss of energy, shortness of breath, pain, anxiety, irritability, and depression (Goodlin, 2009; Mayo Clinic, n.d.; "Lung Cancer," n.d.; Lou et al., 2017; Wilkinson & Lynn, 2005).

Each vignette briefly described the symptoms the patient is experiencing and the psychological, social, or physical impacts of the disease. As detailed below, effort was taken to ensure that the most salient differences between patients were the reported diagnosis or stage of the disease. Patient vignettes primarily reported the symptoms shared by both diagnoses described above to ensure similarity. However, there are characteristic symptoms of each diagnosis that are not shared, and the standard treatments differ as well. These were included to maintain an accurate description of the symptom burden and course of each disease. In order to maintain continuity between stages of the same disease, changes in symptom description followed the standard progression of each disease by increasing symptom burden, side effects of treatment, and emotional impacts.

Palliative Care Evaluations (Appendix E)

An evaluation questionnaire was presented following each vignette. Participants were asked to rate palliative care in terms of how appropriate they believe this treatment was for the patient and how helpful they believe the services would be in meeting patient needs. They are asked to rate how effective palliative care would be in managing physical symptoms, psychological distress, providing support for family, attention to personal beliefs and values, assistance with legal and employment issues, facilitating communication, and helping with treatment decisions.

Palliative Care Fact Sheet (Appendix F)

Using information adapted from the National Cancer Institute’s (2017) *Palliative Care in Cancer* resource, the fact sheet defines the purpose of palliative care. It explains the services provided, when they are available, who provides care, and how to access it. It also briefly defines the difference between palliative care and hospice, and identifies benefits demonstrated in the research.

Procedure

The study was reviewed and approved by the University of Michigan Institutional Review Board before data collection began. As mentioned previously, the entirety of the data collection for the study was completed online. Participants were recruited through the TurkPrime Cloud Research platform and provided a link to the Qualtrics survey. Participants were first presented with a consent form detailing the purpose of the study, estimated completion time, anticipated risks and benefits, the right to withdraw at any time, and confidentiality. Following the consent form, the participants had to select either "I consent" or "I do not consent". Those who responded "I do not consent" were thanked for their interest and redirected to the CloudResearch homepage. Those who responded "I consent" proceeded to the first section of the study consisting of a demographic questionnaire questions about familiarity with palliative care. Following the questionnaire, participants completed the Palliative Care Knowledge Scale. Participants were then randomized to either receive the palliative care fact sheet or to receive no fact sheet. Each participant was then presented with two patient vignettes describing patients with a diagnosis of either heart failure or lung cancer. After reading each vignette, participants completed an evaluation of the appropriateness of palliative care for each patient. In the last section of the survey, participants completed the Palliative Care Knowledge Scale a second time. When finished with the survey, participants were automatically redirected to the CloudResearch site where they were compensated $2.00 for approximately 25 minutes of their time.

Data Analysis

Study data were analyzed using IBM SPSS 25.0.1. Descriptive statistics were used to summarize participant data and responses to the PaCKS pre- and post-tests. To examine PaCKS pre-test scores by participant demographics, *t*-tests were used to compare PaCKS pre-test scores by gender and by reported pre-existing familiarity with palliative care. One-way analysis of variance (ANOVA) was also used to compare scores between age groups, education level, and racial group.

Participants were separated by who received the fact sheet and who did not. The following analyses were run only for those who did not receive the fact sheet in order to investigate the effect of prior knowledge of palliative care (as measured by the PaCKS pre-test) on the variables without the potential interference of the fact sheet. Participants were grouped by level of knowledge using a median split. Participants with a PaCKS pretest score of 6 or less were labeled as Low and those with a pre-test score greater than 6 were labeled as High. Two-way ANOVAs were then used to determine the effect of participant knowledge and diagnosis on evaluations of the appropriateness of palliative care and helpfulness of palliative care.

Bivariate Pearson correlations were calculated for the PaCKS pre-test scores and participant evaluations of appropriateness for early stage conditions and appropriateness for late stage conditions. The significance of the difference between the two correlations was calculated to determine whether the strength of the correlation was significantly different based on disease stage.

To examine differences in scores for the PaCKS pre- and post-tests related to possible acquired knowledge, *t*-tests were used to compare pre- and post-test scores for participants who received the fact sheet and those who did not receive the fact sheet. Chi-square analyses were used to compare individual item response frequencies to the PaCKS post-test between participants who received the fact sheet and those that did not receive the fact sheet in order to determine whether the fact sheet accounted for the change in correct responses. A two-way ANOVA was used to examine the effects of pre-existing knowledge and receipt of the fact sheet on PaCKS post-test scores.

Bivariate Pearson correlations were used to identify significant correlations between scores on the PaCKS pre-test and ratings of appropriateness across conditions, helpfulness across conditions, appropriateness for early stage conditions, helpfulness for early stage conditions, appropriateness for late stage conditions, and helpfulness for late stage conditions. These correlations were calculated separately for those who received the fact sheet and for those who did not receive the fact sheet. T-tests were also used to compare mean ratings of appropriateness and helpfulness by fact sheet condition.

Chapter 3

Results

Descriptive Statistics

Descriptive statistics were run on the demographic variables collected and are provided in Table 1. Descriptive statistics were also run for the PaCKS pre- and post-test scores. Table 2 provides percentage of “true”, “false”, and “I don’t know” responses for each item for the PaCKS pre-test for all participants. The statement with the fewest correct responses was “Palliative care is exclusively for people who are in the last six months of life” with 28% of the sample correctly identifying it as a false statement. This was followed by “Palliative care is designed specifically for older adults” (38%) and “Palliative care encourages people to stop treatments aimed at curing their illness” (38%). The statement with the most correct responses was “Palliative care helps the whole family cope with a serious illness” with 52% of participants identifying it as true. This was followed by “Palliative care is a team-based approach to care” (50%) and “Palliative care can help people manage the side effects of their medical treatments” (50%).

For the sample overall, the percentage of correct answers was much higher for each item of the PaCKS. There were differences in which items had the most and fewest correct responses. The statement with the fewest correct responses was still “Palliative care is exclusively for people who are in the last six months of life” with 58% of the sample correctly identifying it as a false statement. This was followed by “Palliative care encourages people to stop treatments aimed at curing their illness” (57%) and “Palliative care is designed specifically for older adults” (60%). The statement with the most correct responses was still “Palliative care helps the whole family cope with a serious illness” with 78% of participants identifying it as true. This was followed by “Stress from serious illness can be addressed by palliative care” (74%), “Palliative care is a team-based approach to care” (72%), and “A goal of palliative care is to improve a person’s ability to participate in daily activities” (72%).

Participant Characteristics

In order to investigate differences in PaCKS pre-test scores due to gender or pre-existing familiarity with palliative care, independent samples *t*-tests were run for each variable. No difference in means was found for gender. There was a significant difference in PaCKS pre-test scores based on reported pre-existing familiarity with palliative care ($t(284)=14.79$, $p<.001$). Those who had heard of palliative care scored higher on the PaCKS (M=9.06, S.D.=3.19) than those who had not heard of palliative care (M=2.6, S.D.=4.02), indicating that familiarity is related to level of knowledge of palliative care. Results are presented in Table 4. However, a self-rating of knowledge of palliative care (on a 5-point scale) was not correlated with PaCKS pre-test scores ($r=-.072$, $n=132$, $p=.413$).

A one-way analysis of variance (ANOVA) was used to examine difference in PaCKS pre-test scores based on age group, education level, and race. There were no differences in scores based on age group or race. There was a significant difference in scores based on education level ($F(6,277)=10.413$, $p<.001$) such that participants with higher levels of education (graduate, professional, 4-year degree) scored higher on the PaCKS pre-test than those with lower levels of education (high school diploma, some college). This indicates that those with higher levels of education have more reported knowledge of palliative care. Results are provided in Table 5.

Hypothesis 1

In order to determine whether prior participant knowledge, as measured by the PaCKS pre-test, predicted evaluations of palliative care appropriateness based on disease stage, the pre-test scores of those who did not receive the fact sheet were correlated with ratings of appropriateness for patients in the early and late stage of their disease. There was a significant correlation between level of prior knowledge and rating of appropriateness for the early stage (r=-.194, n=139, p=.022) and for the late stage (r=-.300, n=139, p<.001). The significance of the difference between correlations was then calculated to determine whether ratings differed based on stage of the disease. The results were not significant (Z=.932, p=.351) indicating that disease stage was not a factor in determining appropriateness of palliative care.

Hypothesis 2

Two-way ANOVA was used to determine whether prior participant knowledge, as measured by the PaCKS pre-test, predicted evaluations of palliative care appropriateness and helpfulness based on diagnosis. Results for the participants who did not receive a fact sheet are provided in Tables 6 and 7. A significant effect was found for prior participant knowledge on ratings of appropriateness ($F(1,135)=13.697$, $\eta^2=.092$, $p<.001$). Those with a low level of knowledge (i.e., pretest score less than or equal to 6) rated palliative care as less appropriate (M=4.477, SD=1.699) than those with a high level of knowledge (i.e. pre-test score greater than 6) M=3.472, SD=1.583). A similar significant effect was found for participant knowledge on ratings of helpfulness ($F(1,135)=11.483$, $\eta^2=.078$, $p=.001$). Those with a low level of prior knowledge rated palliative care as less helpful (M=5.044, SD=1.995) than those with a high level of prior knowledge (M=3.972, SD=1.830). There was no effect found for diagnosis or for the interaction of diagnosis and level of knowledge for either rating, indicating that participant knowledge was the primary factor driving ratings of appropriateness and helpfulness.

Hypothesis 3

In order to explore changes in participant knowledge across the survey, paired samples *t*-tests were used to compare PaCKS pre- and post-test scores for both fact sheet conditions. There was a significant difference in PaCKS scores for the group that did not receive the fact sheet (*t*(138)=3.374, *p*=.001). Scores were higher on the post-test (M=6.60, S.D.=4.73) than on the pre-test (M=5.71, S.D.=4.78), indicating that some learning occurred over the course of the survey. There was also a significant difference in PaCKS scores for the group that received the fact sheet (*t*(146)=11.378, *p*<.001). Scores were higher on the post-test (M=10.47, S.D.=3.2) than on the pre-test (M=5.50, S.D.=4.96), indicating that the fact sheet improved participant knowledge. Results are provided in Table 8.

A two-way ANOVA was then used to determine the effect of the fact sheet and self-reported pre-existing familiarity with palliative care on PaCKS post-test scores and to investigate interaction effects. Results are provided in Table 9. There was a significant effect for reported pre-existing familiarity with palliative care (*F*(1,282)=70.107, η^2=.199, *p*<.001). Those who indicated that they had heard of palliative care scored higher on the PaCKS post-test than those who had not. There was a significant effect for receiving the fact sheet (*F*(1,282)=52.183, η^2=.156, *p*<.001), with those who received the fact sheet scoring higher on the post-test than those who did not receive the fact sheet. The interaction between self-reported pre-existing familiarity with palliative care and receiving the fact sheet was also significant (F(1,282)=21.165, η2=.07, p<.001). Those who received the fact sheet performed better on the post-test than those who had not received the fact sheet regardless of pre-existing familiarity, but those who had not heard of palliative care and received a fact sheet showed the greatest improvement in post-test scores.

Chi-square analyses were run for each item of the PaCKS pretest and the PaCKS post-test to compare frequency of correct responses. There was no difference in response rates for the pretest between those who received the fact sheet and those who did not receive the fact sheet. There was a significant difference for each item on the post-test *($p < .05$)*, with participants who received the fact sheet providing a greater number of correct responses than those who did not receive the fact sheet. This indicates that all item responses improved with the fact sheet. Table 3 provides the percentages of “true”, “false”, and “I don’t know” responses for the group that received the fact sheet.

Hypothesis 4

Bivariate Pearson correlations were used to examine the relationship between receipt of the palliative care fact sheet, pre-existing knowledge as measured by the PaCKS pre-test, and ratings of helpfulness and appropriateness of palliative care for patients in early and late stages of their illness Correlation tables were calculated separately for the group that received the fact sheet and the group that did not. Results are provided in Table 10. For the group that did not receive the fact sheet, PaCKS pre-test scores were significantly correlated with ratings of appropriateness across all vignettes (r=.284, n=139, p=.001), helpfulness across all vignettes (r=-.283, n=139, p=.001), appropriateness for patients in the early (r=-.194, n=139, p=.022) and late stage of their disease (r=-.300, n=139, p<.001), and helpfulness for patients in the early (r=-.212, n=139, p=.012) and late stage of their disease (r=-.280, n=139, p=.001). For the group that received the fact sheet, PaCKS pre-test scores were significantly correlated with ratings of appropriateness across all vignettes (r=-.170, n=147, p=.04) and with ratings of helpfulness for patients in the early stage of their disease (r=-.209, n=147, p=.01). The difference in correlations suggest that prior knowledge had a greater impact on how participants rated palliative care for those who did not receive the fact sheet and had little impact for those who did receive the fact sheet.

Independent samples t-tests were then used to investigate differences in the ratings of appropriateness across all vignettes and helpfulness across all vignettes based on whether participants received a fact sheet or not. Those who received a fact sheet rated palliative care as more appropriate across all vignettes (M=2.98) than those who did not receive a fact sheet (M=3.96, t(285)=5.633 , p<.001). Those who received a fact sheet rated palliative care as more helpful across all vignettes (M=3.48) than those who did not receive a fact sheet (M=4.49, t(285)=4.929, p<.001). Results are presented in Table 11.

Chapter 4

Discussion

This study set out to explore the relationship between knowledge of palliative care and evaluations of how appropriate or helpful those services are in order to provide useful information to aid in addressing some of the barriers that prevent widespread access to palliative care. Several studies have established that there are significant gaps in knowledge of palliative care and persistent misperceptions regarding the nature of palliative care. However, there has been limited research on the degree to which knowledge of palliative care impacts evaluations of the appropriateness or helpfulness of those services based on specific patient characteristics.

Some prior national and state-wide studies reported that over 70% of participants had no familiarity with palliative care (Shalev et al., 2018; Trivedi et al., 2019). Consistent with a third study (Kozlov et al., 2018) nearly half of the participants in this internet-based general population sample study reported that they had heard of palliative care. This study also confirmed previous findings by Kozlov et al. (2018) demonstrating a significant difference in scores on the PaCKS for those who had heard of palliative care compared to those who had not. Pre-existing familiarity with palliative care was found to be significantly related to participants level of knowledge, as measured by the PaCKS pre-test, suggesting that exposure to palliative care, whether through personal experience or otherwise is related to greater levels of knowledge about the nature and purpose of palliative care. Interestingly, self-rated level of prior knowledge of palliative care was not correlated with scores on the PaCKS pre-test, indicating that an individual's perceived level knowledge may not always match up with their actual level of knowledge of palliative care. It cannot be assumed then, that, simply because a person reports knowledge of palliative care, their knowledge is complete.

This study also demonstrated that level of education is related to knowledge of palliative care. Consistent with prior research (Kozlov et al., 2018), those with higher levels of education scored higher on the PaCKS pre-test. Of those who reported familiarity with palliative care, over 60% had completed a 4-year degree or higher. Educational experience was the also the second most common reason participants cited for their familiarity with palliative care. Taken together this suggests that those who receive a higher education are more likely to be exposed to palliative care and either be knowledgeable about it or are better equipped to reason out what how it may be beneficial. This raises additional concerns about access to palliative care. Those with lower levels of education may not be aware that certain treatment options exist, and they may also be at a disadvantage when it comes to navigating health care systems due to lower health literacy (van der Heide et al., 2013). This leaves a large group of people missing the opportunity to access beneficial care..

The use of “I don’t know” as a response option was intended to prevent guessing and to gather a more accurate reflection of participant knowledge. On all items of the pre-test nearly half of participants responded with “I don’t know”, indicating that there is a widespread lack of knowledge about many aspects of palliative care.

The items most often answered incorrectly on the PaCKS pre-test reflected the influence of one of the most problematic misperceptions about palliative care. A prognosis of 6 months or less and the cessation of curative interventions are requirements for eligibility to receive hospice care, not palliative care. This highlights a strong association between palliative care and end of life as well as the lack of clarity about the nature of palliative care versus hospice care. While correct response rates were much improved on the PaCKS post-test, these two items still received the fewest correct responses. This indicates a need for information that emphasizes the role of palliative care beyond end of life and clarifies the different purposes of palliative care and hospice care.

Hypothesis 1

Due to the strong association between palliative care and the end of life, held by physicians and laypersons alike, it was predicted that those with less knowledge about palliative care would be less likely to view it as appropriate or helpful treatment for patients in the early stages of a disease. Despite the fact that this association was demonstrated in the pattern of responses to the PaCKS, it was not supported in actual evaluations of palliative care for the described patients. Regardless of disease stage, palliative care was viewed as an appropriate and helpful treatment for patients. This appears to be contradictory to the research finding that many individuals associate palliative care with end of life (Dionne-Odom et al., 2019) and physicians typically refer patients to palliative care when their prognosis is 6 months or less (Wentlandt et al., 2012). It is possible that this finding is due to response bias within the sample. Participants may have provided what they believed to be the socially expected answer instead of their personal evaluation of palliative care.

Prior knowledge of palliative care, however, did have an effect on ratings of the appropriateness and helpfulness of palliative care. Those with higher PaCKS pre-test scores rated it as more appropriate and helpful than those who did not. One reason for this may be that they are more aware of the many different ways palliative care supports patients and caregivers and have a better understanding of how beneficial those services may be. This is supported by earlier research that has found that familiarity and knowledge of services increases receptivity to those services and is associated with more positive attitudes towards them (Cagle et al., 2016; Dionne-Odom et al., 2019).

Hypothesis 2

It was also predicted that, due to the strong association between palliative care and cancer, those with less knowledge about palliative care would be less likely to view it as appropriate or helpful treatment for patients diagnosed with heart failure. This was not supported. Regardless of disease type, palliative care was rated as an appropriate and helpful treatment option. It may be that the association between cancer and palliative care was not as prevalent in the study sample. Item 6 on the PaCKS directly addressed whether palliative care was designed specifically for those diagnosed with cancer or not. The percentage of incorrect responses for this item was similar to many of the other items, indicating that it was not necessarily a major point of uncertainty or lack of knowledge. . Another possible explanation for this result may be that the association between cancer and palliative care is more characteristic of those involved in the medical system and research than the general public. While patients and families expressed strong associations between palliative care and cancer (Patel & Lyons, 2019), the more explicit examples of how other diagnosis are left out of consideration for palliative care are found in provider referrals rates (Gadoud et al., 2014) and in the focus of studies (Phongtankuel et al., 2018). Since individuals in the general public typically have very little knowledge of palliative care, they are not as likely to be aware of the long history of palliative care and cancer or which groups of patients are typically referred for palliative care.

As found before, prior knowledge of palliative care was related to higher evaluations of the appropriateness and helpfulness of palliative care for the patients presented in this study. This effect is likely due to the same reasons stated above. Those with more knowledge of palliative care are more likely to have a good understanding of the extent to which those services are beneficial to patients and their families and value them more.

Hypothesis 3

It was predicted that a brief fact sheet explaining the services and goals of palliative care would improve knowledge of palliative care. This was supported, confirming prior research that found both an informational fact sheet and video to be effective methods of improving palliative care knowledge (Kozlov et al., 2017). Separating participants, who received the fact sheet, into groups based on reported familiarity with palliative care enabled the examination of the effect of the fact sheet on the knowledge of those who had heard of palliative care and those who had not. The fact sheet improved overall knowledge of palliative care regardless of previous knowledge and individual item response rates. The improvement in scores for those who had prior familiarity with palliative care suggests again that even though an individual has knowledge of or reported familiarity with palliative care, it cannot be assumed that they know all there is and would not benefit from further information or discussion. The significance of the improvement in scores following the fact sheet for those who had not heard of palliative care particularly highlights the importance of targeting interventions towards those with no exposure to palliative care. The improvement in correct item response rates demonstrates that the fact sheet was effective in improving knowledge about each of the specific services and characteristics of palliative care.

Hypothesis 4

Finally, it was predicted that those who received the fact sheet would rate palliative care as appropriate and helpful regardless of disease type or stage. The rationale for this expectation was that the information provided in the fact sheet would be sufficient to correct any misperceptions of palliative care and help participants understand that palliative care is widely appropriate and helpful. While disease type or stage were not found to have an effect on evaluations of palliative care, those who received the fact sheet did rate palliative care as more appropriate and helpful than those who did not receive the fact sheet. What this finding does is highlight once again the important role that knowledge plays individuals' perceptions of palliative care. Not only did the fact sheet improve participant knowledge of palliative care, it also improved their perception of how palliative care applies to specific patients. This confirms previous research which found that greater exposure to information about palliative care led to more positive perceptions and improved knowledge about palliative care (Akiyama et al., 2016), and that higher levels of knowledge about palliative care were associated with more positive attitudes towards palliative care (Wilson et al., 2016). Taken together with the support for this study's first hypothesis, there is strong support for using brief educational interventions to both improve individuals' knowledge of palliative and to increase receptivity to palliative care as a valuable treatment option for individual across the course of their disease.

Strengths and Limitations

There are several limitations to this study that must be acknowledged. First, the use of an online survey platform to collect data carries some risks. While the CloudResearch platform enabled the use of parameters to make the sample representative of the larger population based on age, race, and gender, these were not set for income or education level. The income distribution of this study's sample did not match nationwide income distribution, and a greater percentage of participants had completed higher levels of education than national averages. Both of these factors may have affected results and limit generalizability. Despite steps taken to limit the effects of inattention, it is difficult to ensure that participants give sufficient time and attention to each of the survey questions and do not respond in a randomized manner.

The use of a non-patient or non-caregiver sample also limits the generalizability of these results. They do not reflect the knowledge or perceptions of patients and caregivers who are actually making treatment decisions. There may be differences in attitudes and perceptions when the decisions to be made are not hypothetical, but very real. The results of this study are also unable to speak to the knowledge and perceptions of specific healthcare providers. Thus, it leaves the door open for future research to focus on the knowledge and perceptions of these important groups.

While the vignettes were well balanced with regard to matching symptoms across diagnoses, the inclusion of a specific prognosis might have created a sharper distinction between the patients in the late stage of the disease compared to the earlier stage.

That being said, there were also strengths to the study. The use of the CloudResearch platform enabled the collection of a large sample of data in a short period of time. The study design also allowed for participants to be easily randomized for both the fact sheet and diagnosis conditions and the vignettes represented both varying diagnoses and stage of disease processes.

Implications

It is predicted that there are over 20 million people who are in need of palliative care at the end of life. This number only increases when considering the strong recommendations that palliative care be integrated early on after a diagnosis is received. In order to address the problem of underutilized services and to improve access to palliative care, it is imperative to understand the role that knowledge plays. This study specifically demonstrated that a brief, relatively simple educational intervention was effective to improve knowledge about the nature and services of palliative.

The results of this study can be used by public health initiatives to focus efforts on providing the general public with more exposure to and education about nature and services of palliative care. These efforts should extend beyond outreach in clinics where people are already patients and intentionally seek ways to bring information to those who are least likely to have heard of palliative care due to lack of experience or lower education. It is also important that education efforts focus on clarifying the differences between palliative care and hospice care, particularly when it comes to requirements for eligibility.

This information may also be important for physicians and other health care providers to consider as they prepare to present treatment options. Exploring how much a person understands about palliative care is necessary because reported knowledge does not necessarily guarantee actual or accurate knowledge. Additionally, the continued presentation of information is likely to increase openness to treatment along with improving knowledge.

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Tables

Table 1
Descriptive Statistics (n=286)

	n/M	% of total/S.D.
Age	48.1	17.1
18-34	75	26.2
35-49	66	23.1
50-64	71	24.8
65-75	67	23.4
Gender		
Female	157	54.9
Male	128	44.9
Education		
Some high school	9	3.1
High school graduate	45	15.7
Some college	64	22.4
2-year degree	27	9.4
4-year degree	78	27.3
Professional degree	15	5.2
Graduate degree	46	16.1
Income		
Less than $10,000	25	8.7
$10,000-$19,000	30	10.5
$20,000-$29,000	33	11.5
$30,000-$39,000	22	7.7
$40,000-$49,000	21	7.3
$50,000-$59,000	30	10.5
$60,000-$69,000	13	4.5
$70,000-$79,000	26	9.1
$80,000-$89,000	12	4.2
$90,000-$99,000	16	5.6
$100,000-$149,000	33	11.5
More than $150,000	25	8.7
Race		
Caucasian/Non-Hispanic White	212	74.1
Black/African American	37	12.9
American Indian/Alaska Native	12	4.2
Asian	18	6.3
Other	7	2.4

Heard of Palliative Care		
Yes	132	46.2
No	154	53.8

Table 2

PaCKS Responses -Pretest

	% True	% False	% I don't know
A goal of palliative care is to address any psychological issues brought up by serious illness	**42**	10	47
Stress from serious illness can be addressed by palliative care	**48**	6	45
Palliative care can help people manage the side effects of their medical treatments	**50**	5	44
When people receive palliative care, they must give up their doctors	11	**40**	49
Palliative care is exclusively for people who are in the last six months of life	21	**28**	51
Palliative care is specifically for people with cancer	11	**42**	48
People must be in the hospital to receive palliative care	11	**42**	47
Palliative care is designed specifically for older adults	14	**38**	48
Palliative care is a team-based approach to care	**50**	3	47
A goal of palliative care is to help people better understand their treatment options	**43**	11	45
Palliative care encourages people to stop treatments aimed at curing their illness	14	**38**	47
A goal of palliative care is to improve a person's ability to participate in daily activities	**46**	7	48
Palliative care helps the whole family cope with a serious illness	**52**	5	43

Note. Bolded items indicate correct answers.

Table 3

PaCKS Responses - Posttest for those who Received the Fact Sheet

	% True	% False	% I don't know
A goal of palliative care is to address any psychological issues brought up by serious illness	**86**	3	11
Stress from serious illness can be addressed by palliative care	**89**	3	8
Palliative care can help people manage the side effects of their medical treatments	**80**	6	14
When people receive palliative care, they must give up their doctors	14	**73**	13
Palliative care is exclusively for people who are in the last six months of life	17	**75**	8
Palliative care is specifically for people with cancer	12	**80**	8
People must be in the hospital to receive palliative care	**8**	**80**	12
Palliative care is designed specifically for older adults	10	**75**	14
Palliative care is a team-based approach to care	**84**	4	11
A goal of palliative care is to help people better understand their treatment options	**77**	5	18
Palliative care encourages people to stop treatments aimed at curing their illness	11	**76**	13
A goal of palliative care is to improve a person's ability to participate in daily activities	**82**	7	9
Palliative care helps the whole family cope with a serious illness	**91**	3	6

Note. Bolded items indicate correct answers.

Table 4

Results of *t-tests* for PaCKS Pre-test Knowledge Scores by Reported Pre-existing Familiarity with Palliative Care

	Condition				
	Had Heard of PC		Not Heard of PC		
	M	S.D.	M	S.D.	*p*
PaCKS Pre-test	9.06	3.19	2.6	4.02	<.001

Note. PaCKS scoring (Correct=1, All others=0; range=0-13)

Table 5

PaCKS Pre-test Scores by Highest Level of Education

PaCKS Pre-test	df	F	*p*
Between Groups	6	10.413	<.001
Within Groups	277		
Total	283		

Post Hoc Tests

Tukey HSD[a,b]

		Subset for alpha = 0.005		
What is your highest level of education?	N	1	2	3
Some high school	9	2.6667		
High school graduate	45	2.8444		
Some college	64	3.5781	3.5781	
2-year degree	27	6.2222	6.2222	6.2222
4-year degree	78		6.7564	6.7564
Graduate degree	46			8.2174
Professional degree	15			8.4000
Sig.		.079	.162	.607

Note. Means for groups in homogenous subsets are displayed. a. Uses Harmonic Mean Sample Size = 24.371

Table 6

Univariate Analysis of Effect of Level of Prior Knowledge and Diagnosis on Ratings of Appropriateness

Source	*Df*	*F*	η^2	*p*
(A) Level of Prior Knowledge (PaCKS Pre-test)	1	13.697	.092	<.001
(B) Diagnosis	1	.194	.001	.661
A x B (Interaction)	1	2.061	.015	.153
Error	135			

Note. Low Level of Knowledge (PaCKS pre-test score $\leq$ 6), High Level of Knowledge (PaCKS pre-test score > 6).

Mean Rating of Appropriateness of Palliative Care by Level of Prior Knowledge

	M	S.D.
Low Level of Prior Knowledge	4.477	1.699
High Level of Prior Knowledge	3.472	1.583

Note. Range 2-10. Lower scores indicate higher rating of appropriateness.

Table 7

Univariate Analysis of Effect of Level of Prior Knowledge and Diagnosis on Ratings of Helpfulness

Source	*Df*	*F*	η^2	*p*
(A) Level of Prior Knowledge (PaCKS Pre-test)	1	11.483	.078	.001
(B) Diagnosis	1	.003	.000	.959
A x B (Interaction)	1	2.758	.020	.099
Error	135			

Note. Low Level of Knowledge (PaCKS pre-test score $\leq$ 6), High Level of Knowledge (PaCKS pre-test score > 6).

Mean Rating of Helpfulness of Palliative Care by Level of Knowledge

	M	S.D.
Low Level of Prior Knowledge	5.044	1.995
High Level of Prior Knowledge	3.972	1.830

Note. Range 2-10. Lower scores indicate higher rating of appropriateness.

Table 8

Results of *t-tests* for PaCKS Scores by Fact Sheet Condition

	Condition				
	PaCKS Pre-test		PaCKS Post-Test		
	M	S.D.	M	S.D.	*p*-value
Fact Sheet	5.5	4.96	10.47	3.2	<.001
No Fact Sheet	5.71	4.78	6.60	4.73	.001

Note. PaCKS scoring (Correct=1, All others=0; range=0-13)

Table 9

Univariate Analysis of Effect of Reported Pre-existing Familiarity with Palliative care and Receipt of Fact Sheet on PaCKS Post-test Scores

Source	*Df*	*F*	η^2	*p*
(A) Pre-existing Familiarity	1	70.107	.199	< .001
(B) Fact Sheet	1	52.183	.156	< .001
A x B (Interaction)	1	21.165	.07	< .001
Error	282			

PaCKS Post-test Mean Scores for Conditions

	Received Fact Sheet		Didn't Receive Fact Sheet	
	M	S.D.	M	S.D.
Previously Heard of Palliative Care	11.06	2.55	9.44	2.99
Had not Heard of Palliative Care	9.93	3.65	4.38	4.66

Note. PaCKS scoring (Correct=1, All others=0; range=0-13)

Table 10

Bivariate Correlations Between PaCKS Pre-test Scores and Palliative Care Ratings: No Fact Sheet Condition

Variables	1	2	3	4	5	6	7
1. PaCKS score (Pre-test)	-						
2. Appropriateness Across Vignettes[a]	-.284**	-					
3. Helpfulness Across Vignettes[b]	-.283**	.800**	-				
4. Appropriateness Early Stage[c]	-.194*	.872**	.706**	-			
5. Helpfulness Early Stage[d]	-.212*	.731**	.878**	.796**	-		
6. Appropriateness Late Stage[e]	-.300**	.841**	.644**	.469**	.438**	-	
7. Helpfulness Late Stage[f]	-.280**	.649**	.850**	.406**	.493**	.724**	-

Note. [a]Appropriateness Across Vignettes: (1=Extremely Appropriate – 5=Extremely Inappropriate). [b]Helpfulness Across Vignettes (1=Extremely Helpful – 5=Extremely Helpful). [c]Appropriateness Early Stage: (1=Extremely Appropriate – 5=Extremely Inappropriate). [d]Helpfulness Early Stage: (1=Extremely Helpful – 5=Extremely Helpful). [e]Appropriateness Late Stage: (1=Extremely Appropriate – 5=Extremely Inappropriate). [f]Helpfulness Late Stage: (1=Extremely Helpful – 5=Extremely Helpful). *p<.05, **p<.01

Bivariate Correlations Between PaCKS Pre-test Scores and Palliative Care Ratings: Fact Sheet Condition

Variables	1	2	3	4	5	6	7
1. PaCKS score (Pre-test)	-						
2. Appropriateness Across Vignettes[a]	-.143	-					
3. Helpfulness Across Vignettes[b]	-.170*	.778**	-				
4. Appropriateness Early Stage[c]	-.122	.865**	.666**	-			
5. Helpfulness Early Stage[d]	-.209*	.651**	.817**	.725**	-		
6. Appropriateness Late Stage[e]	-.121	.831**	.655**	.439**	.361**	-	
7. Helpfulness Late Stage[f]	-.072	.825**	.825**	.372**	.348**	.711**	-

Note. [a]Appropriateness Across Vignettes: (1=Extremely Appropriate – 5=Extremely Inappropriate). [b]Helpfulness Across Vignettes (1=Extremely Helpful – 5=Extremely Helpful). [c]Appropriateness Early Stage: (1=Extremely Appropriate – 5=Extremely Inappropriate). [d]Helpfulness Early Stage: (1=Extremely Helpful– 5=Extremely Helpful). [e]Appropriateness Late Stage: (1=Extremely Appropriate – 5=Extremely Inappropriate). [f]Helpfulness Late Stage: (1=Extremely Helpful – 5=Extremely Helpful). *p<.05, **p<.01

Table 11

Results of *t*-tests for Palliative Care Ratings by Fact Sheet Condition

	Condition				
	Fact Sheet		No Fact Sheet		
	M	S.D.	M	S.D.	*p*-value
Appropriateness across vignettes	2.98	1.19	3.96	1.71	<.001
Helpfulness across vignettes	3.48	1.44	4.49	1.98	<.001

Note. Range 2-10. Lower scores indicate higher rating of appropriateness/helpfulness.

Appendix A: Demographics Questionnaire

What is your sex?

○ Male
○ Female

What is your age?

____

What is your race?

○ Caucasian/non-Hispanic White
○ Black/African American
○ American Indian/Alaska Native
○ Asian
○ Native Hawaiian/Pacific Islander
○ Other

What is your highest level of education?

○ Some high school
○ High school graduate
○ Some college
○ 2 year degree
○ 4 year degree
○ Professional degree
○ Graduate degree

What is your yearly income?

- ○ Less than $10,000
- ○ $10,000 - $19,999
- ○ $20,000 - $29,999
- ○ $30,000 - $39,999
- ○ $40,000 - $49,999
- ○ $50,000 - $59,999
- ○ $60,000 - $69,999
- ○ $70,000 - $79,999
- ○ $80,000 - $89,999
- ○ $90,000 - $99,999
- ○ $100,000 - $149,999
- ○ More than $150,000

Are you currently providing, or have you ever provided unpaid care for a family member or friend?

- o Yes
- o No

Have you heard of palliative care?

- o Yes
- o No

Appendix B: Palliative Care Follow-Up Questions

Please rate your knowledge of palliative care.
o Extremely knowledgeable
o Very knowledgeable
o Moderately knowledgeable
o Slightly knowledgeable
o Not knowledgeable at all

Have you or someone you know received palliative care?
o Yes
o No

Are you familiar with palliative care through educational experience?
o Yes
o No

Are you familiar with palliative care because of work or volunteer experience?
o Yes
o No

Appendix C: Palliative Care Knowledge Scale (PaCKS)

The following statements are about palliative care. Please respond to the best of your knowledge. If you are unsure, do not guess, but instead mark "I don't know."

Response Options:

- True
- False
- I don’t Know

1. A goal of palliative care is to address any psychological issues brought up by serious
2. illness.
3. Stress from serious illness can be addressed by palliative care.
4. Palliative care can help people manage the side effects of their medical treatments.
5. When people receive palliative care, they must give up their other doctors.
6. Palliative care is exclusively for people who are in the last six months of life.
7. Palliative care is specifically for people with cancer.
8. People must be in the hospital to receive palliative care.
9. Palliative care is designed specifically for older adults.
10. Palliative care is a team-based approach to care.
11. A goal of palliative care is to help people better understand their treatment options.
12. Palliative care encourages people to stop treatments aimed at curing their illness.
13. A goal of palliative care is to improve a person’s ability to participate in daily activities.
14. Palliative care helps the whole family cope with a serious illness.

Appendix D: Patient Vignettes

Patient A: Early Stage Lung Cancer

Patient A was recently diagnosed with lung cancer and has begun chemotherapy treatments. They are experiencing consistent fatigue and reduced energy. They have a persistent cough and are experiencing low levels of pain. Over-exertion leads to shortness of breath and has led them to limit physical activity. They frequently worry about their health and the future and are experiencing some symptoms of depression.

Patient B: Late Stage Lung Cancer

Patient B has late stage lung cancer. They experience frequent nausea and lack of appetite due to chemotherapy treatments and which has led to significant weight loss. Fatigue and lack of energy require significant periods of rest, up to half of their day. They frequently experience shortness of breath and high levels of pain. As a result, they have limited mobility and require assistance with daily personal care (ADLs). Difficulty leaving the house has caused them to miss family events and has reduced social interaction with friends. They feel helpless and hopeless in their situation, have little interest in participating in activities they once enjoyed, and have difficulty expressing how they feel to their family.

Patient A: Early Stage Heart Failure

Patient A was recently diagnosed with heart failure and has been placed on medication to manage the disease. They are experiencing consistent fatigue, reduced energy, and low levels of pain. Over-exertion leads to shortness of breath and has led them to limit physical activity. They are more irritable or anxious throughout the day and are experiencing some symptoms of depression.

Patient B: Late Stage Heart Failure

Patient B has advanced heart failure. They are taking multiple medications to manage their condition and, as a result, often experience headaches and dizziness. Fatigue and lack of energy require significant periods of rest, up to half of their day. They frequently experience shortness of breath and high levels of pain. As a result, they have limited mobility and require assistance with daily personal care (ADLs). Difficulty leaving the house has caused them to miss family events and has reduced social interaction with friends. They feel helpless and hopeless in their situation, have little interest in participating in activities they once enjoyed, and have difficulty expressing how they feel to their family.

Appendix E: Evaluation of Palliative Care Questionnaire

Response Options:

- ○ Extremely (appropriate/helpful/effective)
- ○ Very (appropriate/helpful/effective)
- ○ Moderately (appropriate/helpful/effective)
- ○ Slightly (appropriate/helpful/effective)
- ○ Not (appropriate/helpful/effective) at all

1. How appropriate is palliative care for Patient (A/B)?
2. How helpful would palliative care be for Patient (A/B)?
3. How effective would palliative care be in helping Patient (A/B) manage their physical symptoms as described above?
4. How effective would palliative care be in helping Patient (A/B) manage emotional distress?
5. How effective would palliative care be for providing support for Patient (A/B)'s family members and caregivers?
6. How effective would palliative care be in supporting Patient (A/B) by incorporating their personal beliefs and values?
7. How effective would palliative care be in providing Patient (A/B) with assistance with legal, financial, or employment issues?
8. How effective would palliative care be in facilitating communication between Patient (A/B) and their care team?
9. How effective would palliative care be in helping Patient (A/B) or their caregivers make decisions about treatment?

Appendix F: Palliative Care Fact Sheet

What is palliative care? Palliative care is care given to improve the quality of life of patients who have a serious illness. It is an approach to care that addresses the person as a whole, not just their disease. The goal is to prevent or treat, the symptoms and side effects of the disease and its treatment, in addition to any related psychological, social, and spiritual problems. Patients may receive palliative care in the hospital, an outpatient clinic, a long-term care facility, or at home under the direction of a physician.

Who gives palliative care? Palliative care is usually provided by palliative care specialists. They provide holistic care to the patient and family or caregiver focusing on the physical, emotional, social, and spiritual issues patients may face during the course of their illness. Often, palliative care specialists work as part of a multidisciplinary team that may include doctors, nurses, registered dieticians, pharmacists, chaplains, psychologists, and social workers. The palliative care team works in conjunction with your primary care physician or care team to manage your care and maintain the best possible quality of life for you. Palliative care specialists also provide caregiver support, facilitate communication among members of the health care team, and help with discussions focusing on goals of care for the patient.

What issues are addressed in palliative care? The physical and emotional effects of a serious illness and its treatment may be very different from person to person. Palliative care addresses a broad range of issues, taking into account an individual's specific needs in the following areas:

- **Physical.** Common physical symptoms include pain, fatigue, loss of appetite, nausea, vomiting, shortness of breath, and insomnia.
  Emotional and coping. Palliative care specialists can provide resources to help patients and families deal with the emotions that come with diagnosis and treatment.
- **Spiritual.** With a serious diagnosis, patients and families often look more deeply for meaning in their lives. An expert in palliative care can help people explore their beliefs and values so that they can find a sense of peace or reach a point of acceptance that is appropriate for their situation.
- **Caregiver needs.** Family members are an important part of patient care. Like the patient, they have changing needs. It's common for family members to become overwhelmed by the extra responsibilities placed upon them, such as patient care and household duties, as

- well as emotional reactions, such as worry and fear. Palliative care specialists can help families and friends cope and give them the support they need.
- **Practical needs**. Palliative care specialists can also assist with financial and legal worries, insurance questions, and employment concerns. Discussing the goals of care is also an important component of palliative care. This includes talking about advance directives (written statements about a person's wishes regarding medical treatment) and facilitating communication among family members, caregivers, and members of the primary care team.

When is palliative care an option? Palliative care may be provided at any age and at any stage in a serious illness, from diagnosis to the end of life. When a person receives palliative care, they may continue to receive curative treatment.

How does a person access palliative care? Your primary doctor is the first person you should ask about palliative care. They may refer you to a palliative care specialist, depending on your physical and emotional needs.

What is the difference between palliative care and hospice? Whereas palliative can begin at any stage of a serious illness, hospice care begins when curative treatment is no longer the goal of care and the sole focus is quality of life. Palliative care can help patients and their loved ones make the transition from treatment meant to cure or control the disease to hospice care by:

- preparing them for physical changes that may occur near the end of life
- helping them cope with the different thoughts and emotional issues that arise
- providing support for family members

Who pays for palliative care? Private health insurance usually covers palliative care services. Medicare and Medicaid also pay for some kinds of palliative care. For example, Medicare Part B pays for some medical services that address symptom management.

Is there any research that shows palliative care is beneficial? Research shows that palliative care and its many components are beneficial to patient and family health and well-being (1). In recent years, some studies have shown that integrating palliative care into a patient's usual care soon after a diagnosis can improve their quality of life and mood, and may prolong survival (2,3).

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1 Sidebottom, A. C., Jorgenson, A., Richards, H., Kirven, J., & Sillah, A. (2015). Inpatient palliative care for patients with acute heart failure: Outcomes from a randomized trial. *Journal of Palliative Medicine*, *18*(2), 134–142. https://doi.org/10.1089/jpm.2014.0192

2 Ferrell, B. R., Temel, J. S., Temin, S., Alesi, E. R., Balboni, T. A., Basch, E. M., Firn, J. I., Paice, J. A., Peppercorn, J. M., Phillips, T., Stovall, E. L., Zimmermann, C., & Smith, T. J. (2017). Integration of palliative care into standard oncology care:

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*material adapted from the National Cancer Institute's Palliative Care in Cancer

Appendix G: Consent Form

Welcome to the Study!

Purpose of the study: We are interested in learning more about attitudes towards treatment options and the factors that influence decision-making. You will be presented with information on this topic and asked to answer questions about it.

Description of Subject Involvement: The study should take you around 20-25 minutes to complete. Your participation in this research study is completely voluntary. You have the right to withdraw at any point during the study, for any reason, without prejudice. If you would like to contact the Principal Investigator (PI) of the study to discuss this research, please email Angela Tiemeyer at tiemeyer@umich.edu.

Eligibility Requirements:
- Between the ages of 18-75 years old
- Read and understand English
- Reside within the United States

Benefits: You may not experience direct benefits from this study. Others may benefit from this study as this research allows researchers to learn more about various factors that influence attitudes and how health decisions are made. This information can be used to raise awareness and guide the development of educational interventions.

Risks and Discomforts: The risks of participating in this study are minimal. You may experience some discomfort answering questions about your background or reading about medical treatment options. A resource page will be made available to all participants at the conclusion of the study (or by contacting the PI, Angela Tiemeyer at **tiemeyer@umich.edu** or

Nancy Wrobel, Ph.D., a Fully Licensed Psychologist, at **nwrobel@umich.edu** or **313-593-5088** if you choose not to complete the study).

Compensation: Upon satisfactory completion of the study, you will receive compensation in the amount that you have agreed to with the platform through which you entered this survey.

Confidentiality: Please find a quiet and private location to complete the survey. To protect your information, you will not be asked to identify yourself on the survey. Furthermore, TurkPrime adds a unique participant ID to your data file, so that your identity remains anonymous.

Voluntary Nature of the Study: Participating in this study is completely voluntary. Even if you decide to participate now, you may change your mind and stop at any time. If you decide to withdraw early, the data that you generate will be destroyed.

Contact Information: If you have questions about this research, you may contact Angela Tiemeyer at tiemeyer@umich.edu or Nancy Wrobel, Ph.D. at nwrobel@umich.edu.
If you have any questions regarding your rights as a participant in this study, or wish to obtain information, ask questions, discuss any concerns or complaints with someone other than the researcher(s), please contact the University of Michigan Health Sciences and Behavioral Sciences Institutional Review Board at (734) 936-0933 or toll free, (866) 9360933 (collect calls will be accepted if you identify yourself as a research participant) or via email at irbhsbs@umich.edu.

Written questions should be directed to University of Michigan Health Sciences and Behavioral Sciences Institutional Review Board, 2800 Plymouth Road Building 520, Room 1169, Ann Arbor, MI 48109-2800.

By clicking the button below, you acknowledge that your participation in the study is voluntary, you meet all of the eligibility requirements above, and that you are aware that you may choose to terminate your participation in the study at any time and for any reason.

Please note that this survey will be best displayed on a laptop or desktop computer. Some features may be less compatible for use on a mobile device.

- ○ I consent
- ○ I do not consent

Appendix H: Resource List

Resources

Thank you for your participation in this study. If, for any reason, this study happens to cause you discomfort or distress due to the subject matter involved (e.g. answering questions about your background and opinions or reading about patients and their illnesses), please do not hesitate to use any and all of the resources provided below. Additionally, if you are facing an immediate crisis, please call 9-1-1.

a. Nancy Wrobel, Ph.D., Fully Licensed Psychologist

Email: nwrobel@umich.edu

Phone number: 313-593-5088

b. https://getpalliativecare.org/

This is a website that provides information on palliative care, new, and resources for families and caregivers.

Please click the arrow at the bottom of the page to complete the study!