

END-OF-LIFE CONVERSATIONS: IMPROVING PROVIDERS' COMPETENCE IN EOL

CONVERSATIONS THROUGH AN EDUCATION MODULE

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## Abstract

Death and dying is complex, individual in nature, and often an intimidating topic for many. It is frequently a subject that is avoided or only discussed in private. However, it is essential for patients and providers to understand the resources available at the end of one's life to help facilitate patient centered care and increased quality of life. Hospice is an end of life (EOL) service that provides comfort care and support for individuals and their family members. Comprehensive comfort care and psychosocial and emotional support for both the patient and their family members are provided with EOL care services. One major barrier to receiving EOL care services is inadequate communication between providers and patients. This is often due to a lack of provider education on difficult conversations, which leads to a lack of confidence and competence in one's EOL discussion skills. The purpose of this Practice Inquiry Project (PIP) was to provide education for providers on strategies to engage in difficult conversations. The goal was to increase providers' confidence and competence in initiating conversations about EOL care through an educational module. A logic model was used to guide the designing and planning of the project and the Knowles' Theory of Andragogy theoretical framework helped guide the implementation and evaluation of this project. Participants completed an online education module. Pre- and post-surveys, pre- and post-Palliative Care Self Efficacy (PCSE) scale and pre- and post-Thanatophobia Instrument (TI) results were compared to determine if the education module was successful in increasing provider confidence and competence in EOL discussions. After providers completed the education module, there was an improvement in both PCSE and TI scores, which indicate an improvement in knowledge and confidence in EOL strategies, skills, and application in practice.

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**List of Abbreviations**

D.O.	Doctor of Osteopathy
EOL	End-of-Life
GOC	Goals of Care
GP	General Practitioner
ICU	Intensive Care Unit
IRB	Institutional Review Board
M.D.	Medical Doctor
NP	Nurse Practitioner
PA	Physician Assistant
PCP	Primary Care Provider
PCSE	Palliative Care Self Efficacy
PIP	Project Inquiry Project
SRC	Scientific Review Board
TI	Thanatophobia Instrument
TS	Thanatophobia Scale

## **Chapter 1: Statement of Problem, Project Aim and Objectives**

With the advancement in technology, improved curative treatments, and quality chronic illness management, people are living longer. As the number of elderly people, those 65 years and older, continues to increase, so do the number of chronic illnesses and comorbidities associated with them. Not only are people living longer, but their quality of life has also improved in comparison to previous generations. According to the United Nations (UN, 2017), there were 78.4 million individuals over the age of 60 in the United States in 2017 and it is projected to increase to 122.8 million individuals in the year 2050. The elderly population is growing the fastest in comparison to all other age groups and this population most often dies from chronic and non-communicable diseases (UN, 2017). It is therefore essential to understand the resources available to help accommodate patient centered care and increased quality of life at the end of one's life.

Palliative care and hospice care are two invaluable resources that promote quality end-of-life (EOL) care for both patients and their family members. Palliative care is an approach that improves the quality of life of patients and family members who are facing life-threatening illnesses by preventing and relieving suffering through early identification, assessment and treatment of pain and other problems relating to one's physical, psychosocial, or spiritual well-being (World Health Organization, 2018). Most individuals in need of palliative care live with chronic diseases such as cardiovascular disease, cancer, chronic respiratory diseases, and diabetes (World Health Organization, 2018). Hospice provides comfort care and support for one's family when it is determined by a provider that an individual with a terminal illness has six months or less to live if the illness runs its natural course (National Institute of Aging, 2017). Hospice care focuses on comfort care rather than curative treatments. Both programs provide

comprehensive comfort care and psychosocial and emotional support for both the patient and family members. Hospice services are essential in providing comfort at the end of one's life as well as respecting one's dignity and autonomy. Therefore, it is essential that providers engage in EOL conversations with patients and family members to ensure one's dignity and comfort are established and maintained.

### **Problem Statement**

The elderly population in the State of Hawai'i will continue to increase over the next few years. This particularly vulnerable population requires the attention and assistance of the community to ensure a high quality of life and dignity is maintained until the very end-of-life. Providers need more education in EOL discussions to ensure the best quality of EOL care for both patients and family members.

### **Background and Significance**

One's death and dying experience is individual in nature and no one experiences the same symptoms or EOL experiences as another person. In a study by Steinhauser et al. (2000), symptoms and personal care factors that were found to be most important to patients at the EOL were: lack of pain, lack of anxiety, lack of shortness of breath, importance of being kept clean, and engaging in physical touch. In preparation for EOL, patients found the following to be most important: having financial affairs in order, feeling prepared to die, believing one's family is prepared for one's death, and knowing what to expect about one's physical condition (Steinhauser et al., 2000). All the mentioned factors are congruent with the mission and comprehensive approach of hospice programs.

Hospice began in the 1970's in the United States as a social movement focused on providing a more dignified death than typically experienced in the hospital, where many

experienced significant pain and discomfort (Carlson et al., 2008). There are numerous benefits of hospice for both patients and family members: emotional support, autonomy, and dying with dignity. Hospice also provides psychosocial, emotional, respite, and bereavement care for family members. Palliative care provides a team-approach support system for patients and family members to help patients live as actively as possible (World Health Organization, 2018). The ultimate goal of hospice care is to help patients be as comfortable as they can be as they enjoy the last stages of their life.

Hawai'i has been found to have the fastest growing aging population in the United States in comparison to other states, and between 1990 and 2000, the older population in Hawai'i grew twice as fast as older populations nationally (Taira et al., 2017). Additionally, thirty-four percent of Hawai'i's population is made up of Japanese Americans, who have one of the longest life expectancies of any ethnic subgroup in the U.S. (Taira et al., 2017). In comparison to other states, hospice patients in Hawai'i tend to utilize home services more, with 21% of adults in the state identifying as caregivers, providing informal care for another adult (Taira et al., 2017). Such findings indicate there may be an increase in caregiver burden for families and friends in Hawai'i, who could greatly benefit from hospice services such as respite care and psychosocial support. These findings make it clear that the utilization of hospice care is therefore critical in the State of Hawai'i to ensure patient centered and high quality EOL care.

Although hospice has been around for over 30 years, it is one resource that is underutilized. Many people are not referred to hospice care services because providers sometimes deem themselves capable of providing the care needed, or because of the difficulty of initiating conversations regarding EOL care with patients and family (Kline & Panosky, 2017). Other studies have found that providers do not feel comfortable initiating such conversations. At

the University of Manoa John A. Burns School of Medicine (JABSOM), first year medical students were required to complete a twelve week, 60-hour hospice unit rotation before it was eliminated because of its conflict in scheduling with other required courses and rotations. A study was done by Bertao et al. (2003), to determine the rotations' influences on first year and fourth-year students' personal experiences and comfort regarding EOL care after these rotations. They found that most medical students do not feel comfortable in EOL discussions and only 21% of first year and 30% of fourth year students felt comfortable discussing the seriousness of an illness with patients and family members (Bertao et al., 2003). One third of the participants requested more formal training in palliative care or hospice EOL care from experts and requested more involvement of physicians as palliative care role models that students could shadow and collaborate with (Bertao et al., 2003). These findings paint a clear picture of the need for more training for providers to feel more confident engaging in EOL discussions and treatment when curative treatment is not desired or is no longer an option.

### **Significance**

This problem is significant to the field of nursing because it fills a gap in knowledge of EOL care and EOL discussions for both providers and patients alike. Providers need new skills and new knowledge to develop stronger communication skills and stronger relationships with patients through essential and heartfelt EOL conversations. Patients and family members will also benefit from this new breadth of knowledge because they too will be educated on EOL care options and can therefore make better informed decisions. This project will contribute to an increase in patient and family satisfaction through expanded knowledge and thus power to exert autonomy over EOL care decisions.

Rural communities often lack palliative care and end-of-life care resources, facilities, and clinicians to facilitate care. According to Robinson et al. (2009), the geographical inequities in access to palliative care are expected to increase as the elderly population continues to increase. A study done on rural palliative care barriers by Van Vorst et al. (2006), found that 82% of the respondents had difficulty communicating palliative care needs with patients and family members, which led to the transition from curative to end-of-life care much too late. There was also a large gap between the training each clinician received, and the experiences encountered, which led to a later transition to end-of-life care in rural communities. This project will benefit population health in rural communities because providers and clinicians will learn strategies to engage in difficult end-of-life care discussions so the transition from curative to end-of-life care measures do not need to be prolonged, and patients' wishes can be honored. There is a pressing need to increase access and resources to rural populations and that is one of the goals of this project.

### **Goal**

The purpose of this project was to provide education for providers on strategies to engage in difficult conversations. The goal was to increase providers' confidence and competence in initiating conversations about EOL care through an educational module.

### **Aims and Objectives**

#### **Aim One**

Determine providers' knowledge and confidence levels of using evidence-based communication strategies for sharing difficult news with patients.

**Objective 1:** Obtain baseline comfort and confidence levels of providers with the use of a pre-survey.

**Objective 2:** Obtain information on how applicable EOL conversations are to the participant's current practice.

### **Aim Two**

Educate primary care-trained providers on evidence-based techniques to initiate and conduct EOL conversations with patients and family members through an online education module, which took approximately 45 minutes to complete.

**Objective 1:** Recruit primary care-trained providers to participate in the EOL Conversations project.

**Objective 2:** Implement EOL Conversation online education module.

### **Aim Three**

Evaluate the effectiveness of the "SPIKES: A Six-Step Protocol for Delivering Bad News" (2020) education module.

**Objective 1:** Assess participants' likelihood of applying SPIKES (2020) strategies provided.

**Objective 2:** Evaluate participant's confidence in initiating EOL conversations and making changes in their practice.

## **Summary**

End-of-life care discussions are intimidating and often difficult to engage in. However, it is one's human right to live and die with dignity and autonomy. The utilization of EOL and hospice programs is essential in ensuring individuals do not suffer physically and emotionally at the end of one's life. These programs have been in place for decades and its underutilization is a disservice to the patients it is meant to serve. Understanding the significance and life altering affect a brief yet informative and compassionate conversation between providers and patients can

be is essential in making changes in the current practices of practitioners. It is the responsibility of providers to initiate these difficult conversations and the literature greatly supports these claims.

## **Chapter 2: Review of Literature**

End-of-life care discussions are essential to ensure patients, family members, and healthcare teams are on the same page when discussing one's prognosis and terminal illness. It is a difficult conversation to initiate and engage in, but is necessary to assure quality of life, autonomy, and closure for patients and family members alike. Many barriers to end-of-life discussions exist and practitioners' lack of experience and education on the topic is one major barrier consistently found in research. Overcoming this barrier is important to the field of nursing because it is the responsibility of practitioners to provide adequate education for patients so they can make informed decisions when exerting their patient autonomy. As the elderly population continues to grow older and increase in size, it is important for practitioners to be more comfortable engaging in end-of-life conversations to ensure patient's end-of-life wishes are met. Research indicates hospice and palliative care resources are underutilized, which can be attributed to the lack of end-of-life conversations between practitioners and patients. This portion of the paper will include the review of literature on the topic of end-of-life care options, end-of-life care barriers, and solutions to these barriers.

### **End-of-Life Care Resources**

EOL care and hospice are resources that may provide patients and their family members physical and emotional support at the end-of-life. Both resources provide patients and their family members physical and emotional support. Meier (2011) notes there is a prognosis distinction between palliative care and hospice, which is unique to the United States whereas other countries use the two terms and services synonymously. Palliative care is based on eligibility needs and may include curative treatments for chronic and serious illnesses whereas to be eligible for hospice, one's prognosis must be six months or less. These two resources greatly

affect one's quality of life when diagnosed with a serious and/or terminal illness and allow patients to exert autonomy over their plan of care and thus live and die with dignity. In a study by Etkind et al. (2017), it is estimated that by 2040, annual deaths in Wales and England will increase by 25.4% and the number of people requiring palliative care will also increase by 25%. These findings reflect the need for increased palliative care and hospice services worldwide. To do so, providers must be educated adequately on this important topic, so they feel more confident in engaging in both palliative and end-of-life care discussions with patients and family members.

**Palliative care.** The World Health Organization (WHO, 2018) notes that palliative care is an approach that helps improve the quality of life of patients and their families facing a life-threatening illness and estimates that “only 14% of people who need palliative care currently receive it.” Palliative care relieves physical symptoms, offers psychosocial and emotional support, as well as bereavement counseling for family members. Therefore, palliative care takes on a holistic and patient-centered approach to improve physical, psychological, social or spiritual quality of life during serious illness. It is a progressive medical specialty that helps patients navigate between relief and alleviating stress and confusion in addition to traversing familial dynamics (Omillion-Hodges & Swords, 2017).

In 2014, WHO (2016) put forth the resolution, WHA67.19, which urges WHO members to integrate palliative care in national healthcare standards, especially at the primary care level, because more than 40 million people require palliative care every year. Palliative care can be utilized in the hospital setting or community setting such as in care homes, nursing facilities, hospice, or at home. Hospice is an EOL resource available but has more stipulations than palliative care.

**Hospice.** Hospice provides many of the same services as palliative care but has the prerequisite of the patient's life expectancy to be six months or less if a terminal illness runs its natural course. Its focus is on caring rather than curing through holistic care and utilizing a multidisciplinary healthcare team of physicians, social workers, therapists, and nurses. Similar to palliative care services, patients can receive hospice in hospitals, care homes, nursing facilities, in one's home, and in hospice facilities. Taira et al. (2017) note that the ultimate goal of hospice is to provide both comfort and a sense of dignity to terminally ill patients as well as providing support for their families.

**Benefits.** The utilization and application of a team-based healthcare approach for patients and family members ensures the physical and emotional needs of both parties are met. Having a dedicated team to help communicate a patient's goals leads to better-informed decision making, a clear and precise plan of care, as well as consistent execution of their plan of care (Meier, 2011). These essential conversations relieve much of the burden that is often placed upon family members. A study by Hughes et al. (2019) surveyed patients and family members about the effects of hospice care services. They found that the availability, flexibility, compassion, and rapport of hospice care employees positively impacted their end-of-life experiences (Hughes et al., 2019). Family-caregivers were especially grateful for the around the clock support such as telephone assessments, reassurances, and help with everyday tasks.

Teno et al. (2004) conducted a study on patient and family-centered outcomes in hospice care and found that those who received hospice care, especially in the home setting, reported much higher satisfaction than those who did not receive any hospice or palliative care at the end-of-life. Those who did not have end-of-life care services reported higher unmet needs such as pain, shortness of breath, and emotional support in comparison to those who had home hospice

and reported that their needs were met and expectations exceeded (Teno et al., 2004). There are numerous benefits of utilizing hospice and palliative care resources, especially when placing value on physical and emotional needs as well as quality of life. A reduction in financial costs is another benefit for patients, families, and the healthcare system.

Duncan et al. (2019) notes that patients at the end-of-life constitute a disproportionate portion of Medicare's costs. As the aging American population increases, so do the health costs that accompany patients' numerous comorbidities, treatments, and hospitalizations. The highest spending at the EOL comes from acute hospitalizations where extensive lifesaving measures are often attempted, prolonging one's life, and not always abiding by their EOL wishes. EOL programs such as hospice care, bridge the gap between curative treatments, identifying patients' EOL requests, and making them a reality.

Approximately 25% of all Medicare beneficiaries die in inpatient hospitals and Medicare expenditures increase significantly in the last few days of life, especially for those who die in the hospital (Duncan et al., 2019). Cardona-Morrell et al. (2016) found that approximately 33-38% of EOL patients received non-beneficial treatments that had little effect on prolonging their lives or improving their quality of life. Thirty-three percent received chemotherapy and ten percent of EOL patients were admitted to the intensive care unit (ICU) unnecessarily (Cardona-Morrell et al., 2016). An average of 30% of EOL patients were found to receive non-beneficial treatments such as radiation, dialysis, and blood transfusions (Cardona-Morell et al., 2016). These patients who receive futile and expensive care at the EOL often do so against their personal wishes, which could have been prevented if EOL preferences were discussed beforehand. End-of-life care programs may ensure care that is consistent with patient and family goals, reduce costs, and also improve quality of life for patients and their families (Duncan et al., 2019, p. 709). EOL

conversations discussing patient and family EOL preferences is therefore key in both honoring patient's wishes, reducing healthcare costs in the long run, and ensuring quality of life.

**Quality end-of-life care.** The ultimate goal of hospice and palliative care is to provide comfort for patients and family members. This ensures quality of life and dignity. Singer et al. (1999) conducted a study to identify elements of quality end-of-life care from a patient's perspective, which can serve as focus points to improve upon. Respondents identified pain management and symptom control as the most important end-of-life care quality. By decreasing pain levels, patients were able to spend time with family members rather than dwell in their discomfort. Participants also noted it was important to avoid inappropriate prolongation of dying. Many expressed fears of living in a coma or being kept alive by a machine because they would no longer be enjoying their lives (Singer et al., 1999). Achieving a sense of control over end-of-life decisions was another important aspect identified by respondents as well as relieving the burden on family members.

Dalal and Bruera (2017) note there are two problems people face at the end-of-life: quality care that does not reach enough people and the rising costs of healthcare resulting in substantial financial burden on patients, families, and the healthcare system. At the end-of-life, symptoms such as pain, dyspnea, and depression are most prevalent among patients and families. Suffering, especially among terminally ill cancer patients, stems from uncontrolled symptoms, inadequate emotional support, unexpected financial burdens, lack of communication, disregard for patient goals, or prolongation of the dying process (Dalal & Bruera, 2017). It is essential communication between providers and patients occur so individual preferences are established and pursued. Dalal and Bruera (2017) found that when a patient's EOL preferences are not met, families experience regret, decreased quality of life, and a higher risk of developing major

depressive disorder. Families also perceive EOL care worse in the context of hospital deaths or if hospice enrollment occurred too late or not at all (Dalal & Bruera, 2017).

In an ideal model, palliative care would be incorporated early for individuals with high symptom burden and existential queries, preferably at the time of diagnosis of advanced illness. This could likely optimize quality of life by anticipating, preventing, and treating suffering as well as providing a platform for patients, families, and providers to communicate effectively about patient care goals (Dalal & Bruera, 2017). Involving palliative care early has shown improvements in physical and psychological symptoms, quality of life, patient satisfaction, and lower use of nonbeneficial life-prolonging treatments (Dalal & Bruera, 2017). Palliative care offers numerous benefits to patients and families and is truly underutilized.

Khandelwal et al. (2017) conducted a study on bereaved family members to assess if treatment decisions in the last month of life were consistent with patients' wishes. Among family members, 87.4% reported care that was consistent with decedents' wishes. However, when care was inconsistent with decedents' wishes, there were more concerns about quality of life in the last month of life. Those who received inconsistent care in comparison to those receiving goal-centered care reported having unmet needs for pain management (Khandelwal et al., 2017). Furthermore, those who received inconsistent care were also found to have a gap in communication between providers and family members, decisions that were made without enough input from the decedent or family, and that the patient was not always treated with respect (Khandelwal et al., 2017). Khandelwal et al. (2017) note that one in eight bereaved family members reported care that was not consistent with the decedents' last wishes during the last month of life. Decedents who received care inconsistent with their preferences were more likely to die in the hospital setting, especially in the intensive care unit (ICU). Hospitalization

prior to death has been shown to have lower quality of life, increased physical discomfort, and less psychological well-being for the dying patient and their families (Khandelwal et al., 2017). Although efforts to improve advance care planning has been ongoing, it appears as though decisions do not respect patients' wishes and are being made without enough input from the dying patient's family. It is therefore of utmost importance that providers continue to work on improving communication between patients and families to provide patient-centered care and honor patients' preferences at the end-of-life.

Teno et al. (2004) note that high quality end-of-life care occurs when health care professionals ensure physical comfort and emotional support, promote shared decision making between the patient and family members, provide emotional support for family members, and coordinate care. The concept of pain management, relieving family burden, and providing emotional support appears to be consistent among findings in ensuring quality end-of-life. These findings support the basis of end-of-life care programs. The domains mentioned in the study are important for clinicians to understand and keep in mind when discussing end-of-life plans with patients and family members. Death is inevitable and one of the most vulnerable moments patients and families experience (Sutherland, 2019). One's EOL experience should be guided by the patients' wishes and conversations about death and dying need to be destigmatized (Sutherland, 2019). End-of-life dialogues need to become a regular part of medical education to ensure providers feel confident and competent in engaging in these difficult conversations.

### **Barriers to EOL Care**

**Lack of provider education.** A recurring theme in various research articles was the lack of education in medical school regarding end-of-life discussions. This lack of education has led to a lack of confidence in engaging in difficult yet necessary discussions with patients and family

members. According to Kiluk et al. (2012), formal education for medical students on how to relay difficult news to patients has been limited and often, the only instruction students receive is through direct observations while in training. This shortcoming of formal education can be attributed to a lack of universal guidelines for communicating difficult news, unlike physical assessments and diagnostic tests (Kiluk et al., 2012). Bertao et al. (2003) also found that there has been inadequate education on end-of-life care curriculum and training in medical schools across the nation. Furthermore, it was found that medical students felt least comfortable in initiating and engaging in end-of-life discussions, whereas they felt most comfortable managing pain and other end-of-life symptoms clinically (Bertao et al., 2003). Christakis and Iwashyna (1998) found that 56.8% of the participants in their study report inadequate training in prognostication, which has impacted their reluctance to hold conversations about prognosis and end-of-life care plans. This lack of formal education affects providers and future providers' ability to engage in end-of-life discussions and ultimately affects patients' end-of-life care management.

End-of-life care services provide numerous benefits for both patients and family members and providers who are more comfortable engaging in EOL conversations are more likely to refer to EOL services, such as hospice (Schmit et al., 2016). Unfortunately, end-of-life training is minimal during medical school and residency (Schmit et al., 2016). Schmit et al. (2016) found that over half the participating medical residents reported inadequate EOL education during medical school and 90% reported inadequate education during residency (Schmit et al., 2016). Unfortunately, in residency, doctors are asked to independently lead EOL discussions with patients and families despite their lack of training or education on the topic. Poor EOL communication skills can negatively affect doctor-patient relationships and lead to

unnecessary testing, procedures, and result in increased healthcare costs and discomfort for the patient (Schmit et al., 2016). Providing doctors and practitioners with education on EOL care and EOL conversations increases comfort and confidence in such skills, which lead to earlier and more appropriate hospice and palliative care referrals, thus improving quality-of-life for terminal patients.

**Inadequate communication.** Patients and family members may not be introduced to the concept of hospice or palliative care until late in their diagnosis for various reasons. Because many practitioners lack experience and education on end-of-life discussions, treatments get prolonged, leading to invasive procedures and life prolonging measures. In a study by Cherlin et al. (2005), many caregivers and family members reported discussions on incurable illness and hospice options were initiated late in the course of illness. One quarter of these cases were told their family members' illness could not be cured only one month prior to the patients' death and approximately 41% of the participants noted that physicians discussed the possibility of hospice for the first time one month preceding the patient's death (Cherlin et al., 2005). Furthermore, Steinhauser et al. (2001) found that a delay in end-of-life conversations prolonged curative and invasive treatments whereas early recognition and discussions lessened physical and emotional suffering on behalf of patients and family members alike.

Christakis and Iwashyna (1998) note that 64% of physicians in their study found end-of-life discussions stressful and unpleasant. Sutherland (2019) notes providers and medical students often feel unprepared or uncomfortable mentioning the topic of death with their patients and families. Providers need to be better trained on how to deliver tough news, especially about death and dying, to ensure patient autonomy and quality of life. Increased guidance on how to have these difficult conversations can potentially prevent compassion fatigue and provider

burnout (Sutherland, 2019). Initiating these honest conversations early on can allow patients and families to make well-informed decisions regarding future medical care, minimize pain and fears, and ensure a “peaceful death” (Sutherland, 2019). Transparent communication throughout the dying process has been shown to decrease patient and family members’ anxiety, increase their sense of control over medical decisions, and enhance patient and goal-centered care (Sutherland, 2019). This improves patient satisfaction of care and quality of life and decreases patient anxiety, frustration, and stress. The culture of avoiding difficult topics continues to perpetuate itself because of the discomfort and stress experienced by providers. These are barriers that interfere with quality end-of-life care and must be addressed.

**Stigma.** Omilion-Hodges & Swords (2017) note that in Western cultures, especially the United States, the topic of death and end-of-life processes has become something which should be avoided and talked about in private. There is an underlying fear of end-of-life in the United States, which is apparent in the society’s reluctance to talk about death and dying (Omilion-Hodges & Swords, 2017). End-of-life conversations are often deflected due to this stigma and negative connotation related to death and dying. The false dichotomy of beliefs that one must choose curative treatment or palliative care is choosing to either fight or give up is a common view (Shen & Wellman, 2019). This point of view may be a deterrent to patient or family acceptance of a referral for palliative care. In a study by Shen and Wellman (2019), participants often viewed hospice or palliative care as “giving up the battle,” “quitting,” or being “lazy.” These negative stereotypes continue to drive the relationship between palliative care stigma and the impeding use of its potential services (Shen & Wellman, 2019). Highlighting improved quality of life at the EOL and providing education to providers and patients is key in breaking the stigma and negative connotations attached to death, dying, and EOL care.

## **Improving EOL Communication**

Because end-of-life care is a growing field, there have been numerous research studies conducted to understand end-of-life care barriers as well as solutions to such barriers. According to Sepúlveda et al. (2002), the WHO is advocating for palliative care to be a global health solution that requires policy development, education and training, and implementation of quality care programs. Furthermore, Sepúlveda et al. (2002) note that palliative care and treatment plans should be initiated as soon as one is diagnosed with chronic and potentially fatal illnesses because symptoms that are not treated at the beginning tend to become difficult to manage in the last few months and days of life. Understanding these concepts is essential in bridging the gap between barriers and solutions to end-of-life care.

**Communication Strategies.** Numerous studies have focused on end-of-life care management and education in medical schools across the world. Mindful communication practices have been effectively utilized by palliative care professionals when delivering difficult news to patients and families (Omilion-Hodges & Swords, 2017). These practices help providers develop a rapport with patients and have been found essential in meeting the needs of patients (Omilion-Hodges & Swords, 2017). This helps providers stay composed, focused on the task at hand, and empathetic to their patients. Mindful communication includes the following: getting to know the audience; asking questions and actively listening; discarding scripts and instead focusing on mindful and authentic communication; and remaining aware of the role practitioners play in each patient's life (Omilion-Hodges & Swords, 2017). Mindful communication provides practitioners with the ability to communicate effectively with patients when it comes to delivering difficult information.

End-of-life discussions allow providers to get a better understanding of patients' needs and preferences to establish a future care plan that is aligned with such preferences to meet anticipated needs. These conversations are associated with improved patient and healthcare outcomes and are increasingly relevant with the rising prevalence of aging and chronic diseases (Deckx et al., 2019). Deckx et al. (2019) conducted a study to illuminate general practitioner's (GP) approaches to initiating and engaging in EOL discussions. The initial step in the EOL conversation process was noted to be preparing the ground for discussion, which included establishing a strong provider-patient relationship and gauging the patient's readiness to engage. Next, entry points to the conversation included responding to patients' initiation, incorporating conversations into routine care, or conducting discussions about prognosis or hypothetical deterioration. This allowed patients and providers to engage in conversations regarding patients' views about death. Deckx et al. (2019) found that GPs believed it was most important to assess patients' readiness to participate in EOL discussions and picking up on cues or trigger moments to initiate these conversations. Their findings suggest approaches to support less experienced practitioners when conducting EOL discussions such as facilitating opportunities to regularly care for patients approaching EOL, supporting them in managing time pressures, and providing a checklist approach to guide them.

Baile et al. (2000) created a six-step strategy for clinicians to use when breaking bad news to a patient and family members. The strategy is titled SPIKES, which stands for: *Setting* up the interview, assessing the patient's *Perceptions*, obtaining the patient's *Invitation*, giving *Knowledge* and information to the patient, addressing the patient's *Emotions* with empathic responses, and *Strategy* and summary (Baile et al., 2000).

The SPIKES protocol is a framework for delivering bad news that helps providers improve communication and increase practitioner confidence while providing patient-centered care and facilitating shared decision making (Baile et al., 2000). In step one, the provider sets up the meeting, which should be private and include the patient and significant others. It is important to sit down at eye level with the patient, make culturally appropriate eye-contact, and avoid interruptions, using adequate time restraints (Corey & Gwyn, 2016). The second step is to assess the patient's perceptions, which involves listening to the way the patient describes their understanding and knowledge of their situation. Open-ended questions are best utilized to further understand their perceptions and therefore figure out how to best give the bad news in a way the patient will understand (Baile et al., 2000). The third step is preparing the patient for the news that is about to be introduced so they are best equipped to receive the serious and or complicated information. It is important to ask the patient if they are ready and willing to accept the information one is about to provide.

The fourth step involves sharing knowledge and information with the patient. This is best done by incorporating what was learned in step two; using the individual's level of understanding and vocabulary to relay the information in a way they will best understand it. Using nontechnical words and avoiding excessive bluntness is essential in being effective and empathetic (Baile et al., 2000). The fifth step is addressing the patient's emotions with empathic responses. The patient should be given time to take in and process the information given to them. The provider should observe the patient's reactions, respect such reactions, and offer support through empathic responses (Corey & Gwyn, 2016). Showing concern and empathy is key in making the patient feel comforted. The final step is summarizing the important points discussed and ensuring another appointment is set (Baile et al., 2000). Presenting treatment

options if available and reinforcing the importance of shared-decision making is essential during this step. Before ending the discussion, it is important to ask if the patient has any other questions and making sure the patient has no misunderstanding of the discussion (Baile et al., 2000).

Corey and Gwyn (2016) conducted a study where they educated oncology nurse practitioners on EOL discussions using the SPIKES framework. Participants found the SPIKES protocol helpful in practicing deliberation as the key to successful conversations, developing a sense of compassion, becoming more personable with patients and family members, and decreasing misunderstandings. Through interviews with participants, Corey and Gwyn (2016) found seven common themes of the SPIKES protocol. Participants noted the SPIKES protocol helped nurse practitioners (NPs) establish a relationship with patients, build and promote emotional support, support patient understanding, enable a positive environment when delivering bad news, promote dignity, allow shared decision making, and promote holistic patient care. The study showed an overarching concept that the experiences of NPs when delivering bad news are shaped by their own communication skills (Corey & Gwyn, 2016).

Oncologists at the 1998 Annual Meeting of the American Society of Clinical Oncology (ASCO) were asked to complete a survey about the SPIKES strategy and 99% of the respondents found it to be practical and easy to understand. The SPIKES protocol has been utilized in other research studies and found to be useful in breaking bad news to family and caregivers and has been found to give clinicians confidence when initiating such conversations.

**Confidence in EOL Conversations.** In a study by Pieters et al. (2019), final year medical students reported that they did not feel confident in providing palliative care or in engaging in end-of-life discussions and indicated that it is important to incorporate such

education in their medical school curriculum. In a study by Kurahashi et al. (2019), first- and second-year family medicine residents completed a 4-week palliative care rotation and were interviewed afterward regarding their experiences and knowledge gained. Participants described feeling more competent and comfortable conducting EOL and goals of care (GOC) conversations at the end of their rotations. Participants noted that having GOC conversations with patients and families were meaningful experiences that they believed would be relevant and applicable to future practices. Furthermore, they noted that having a constructive learning environment and specific learning activities helped facilitate their communication skill development.

Mason and Ellershaw (2004) conducted a study on final year medical students in Liverpool where students received a two-week course on palliative care education. The Self Efficacy in Palliative Care (SEPC) Scale and Thanatophobia Scale (TS) were used to measure students' efficacy in communication and palliative treatment as well as assess their attitudes toward death, respectively. The study found two things: the two scales were valid and reliable when evaluating the education programs and that the students' self-efficacy regarding end-of-life care increased greatly after receiving the two-week education course.

According to Gryscek et al. (2020), the social cognitive theory proposes that individuals learn and change their behaviors through personal motivational paradigms, known as self-efficacy and outcome expectancy. Self-efficacy relates to an individual's confidence in their ability to perform specific tasks. Self-efficacy can be learned through observed behaviors, gained knowledge and skills, and previous experiences. Outcome expectancy is the perceived consequence of the target behavior. In a study by Gryscek et al. (2020), medical students from two medical schools were taught about palliative care and its effects on students' Thanatophobia Scale (TS) and Self-Efficacy in Palliative Care (SEPC) scores. It was posited that through

appropriate training, the students' knowledge and self-confidence would increase and they would also learn the importance of their desired actions. Over two years, it was found that exposure to end-of-life care and palliative care programs improved the students' SEPC scores and decreased TS levels. Effective training in palliative care and EOL discussions therefore increased students' self-efficacy and outcome expectancy.

Phillips et al. (2010) state that education can increase self-efficacy and self-efficacy is a predictor in both personal and professional behavioral change. In the study conducted by Phillips et al. (2010), the Palliative Care Self-Efficacy Scale was utilized to measure participants' self-confidence, self-reliance, and assurance to perform palliative care related tasks. The study demonstrated that the Palliative Care Self-Efficacy Scale is a valid and reliable instrument with a strong internal consistency (Phillips et al., 2010). Understanding one's perceptions of self-efficacy is essential in understanding the need for change and increases one's reception to new information.

The Thanatophobia Scale (TS) is a seven-point ordinal instrument designed to assess healthcare professionals' attitudes toward caring for palliative care patients (Mason & Ellershaw, 2004). Merrill et al. (1998) created the Thanatophobia Scale, which identifies one's feelings associated with thanatophobia, or fear of death. Merrill et al. (1998) conducted a study, which analyzed the confidence of medical students, nursing students, and practicing physicians in emotional distress experienced when caring for terminally ill patients. It was found that higher thanatophobia scores predicted lower self-esteem and clinical uncertainty when treating elderly individuals. Of the seven predictors included in the survey, physician uncertainty about one's clinical capabilities regarding discussing EOL topics with patients, was the most significant personal trait that resulted in higher thanatophobia scores (Merrill et al., 1998). Therefore, those

with lower perceived self-efficacy and clinical capabilities had higher thanatophobia scores, which indicate higher emotional distress related to death and dying. This scale is helpful in identifying healthcare providers' sources of difficulty in counseling patients in EOL care.

### **Summary**

There is a vast amount of evidence supporting the need for end-of-life discussion education and dissemination clinically. As the elderly population continues to grow, so will the need for end-of-life care services. End-of-life care is considered a basic human right. It is thus essential clinicians and providers receive education on its importance and how to go about having these important discussions with patients and family members.

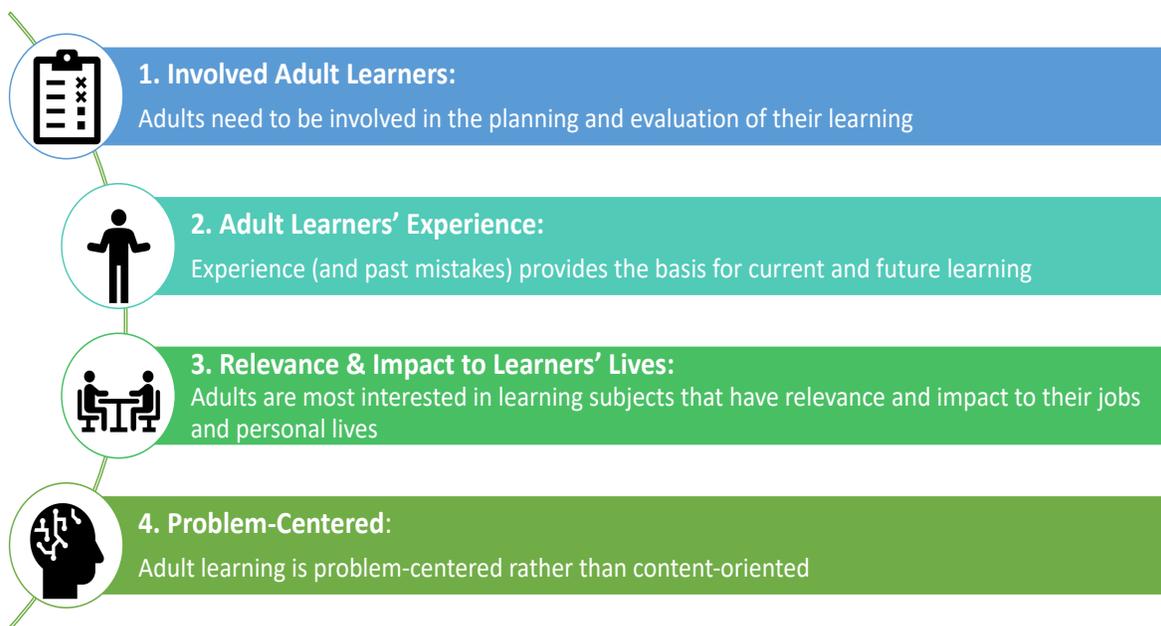
### **Chapter 3: Project Design and Evaluation Plan**

The goal of this Practice Inquiry Project (PIP) was to increase the knowledge, confidence, and competence of providers, particularly primary care-trained providers, in the skill of initiating and engaging in end-of-life discussions. Utilizing Knowles' Theory of Andragogy (1978) to implement a learning module for primary care providers promoted motivations to learn as well as retain and apply the information provided. In this chapter, the methods of achieving the previously described aims and objectives will be detailed as well as the project participants' consent and protection.

#### **Theoretical Framework**

##### **Knowles' Theory of Andragogy**

Malcolm Knowles was an educator in America who believed the term andragogy to be the art and science of adult learning. Knowles (1978) believed adults are problem-oriented participants who want to incorporate past experiences and self-direction into subjects that are relevant in their lives. He posited that there are four principles of andragogy that are applied to adult learning, which include: the involvement of adult learners, adult learners' past experiences, the relevance and impact to learners' lives, and problem-centered learning. See Figure 1 below.

**Figure 1***Knowles' Theory of Andragogy**Figure 1. Malcolm Knowles' 4 Principles of Andragogy (1978) applied to adult learning*

**Involved adult learners.** The first component of Knowles' Principles of Andragogy posits that for learning to be successful, adults must be involved in the planning and evaluation of their instruction (Knowles, 1978). Rather than passively learning the information teachers provide, adult learners move from dependency toward self-directedness and progress at their own pace. It is therefore the educator's responsibility to encourage this undertaking when possible. Thus, when executing this project on EOL discussions, it was essential to provide providers with education that is applicable to their professional lives and to allow for self-directed and self-paced learning as well. Capturing the attention of the targeted population has been essential in successfully executing the project.

**Adult learners' experience.** The experiences, including past mistakes, that individuals acquire over time constitutes the basis in which one learns. Therefore, people tend to learn more

and value lessons when they experience it themselves, rather than passively acquiring the knowledge from someone else. Working with providers who have had experience in EOL discussions, or the lack thereof, greatly influenced their ability to retain the information provided and apply it in their practices. Acquiring information regarding providers' experiences through an extensive literature review has been helpful in ensuring the material was relevant so learning and absorption occurred efficiently and effectively.

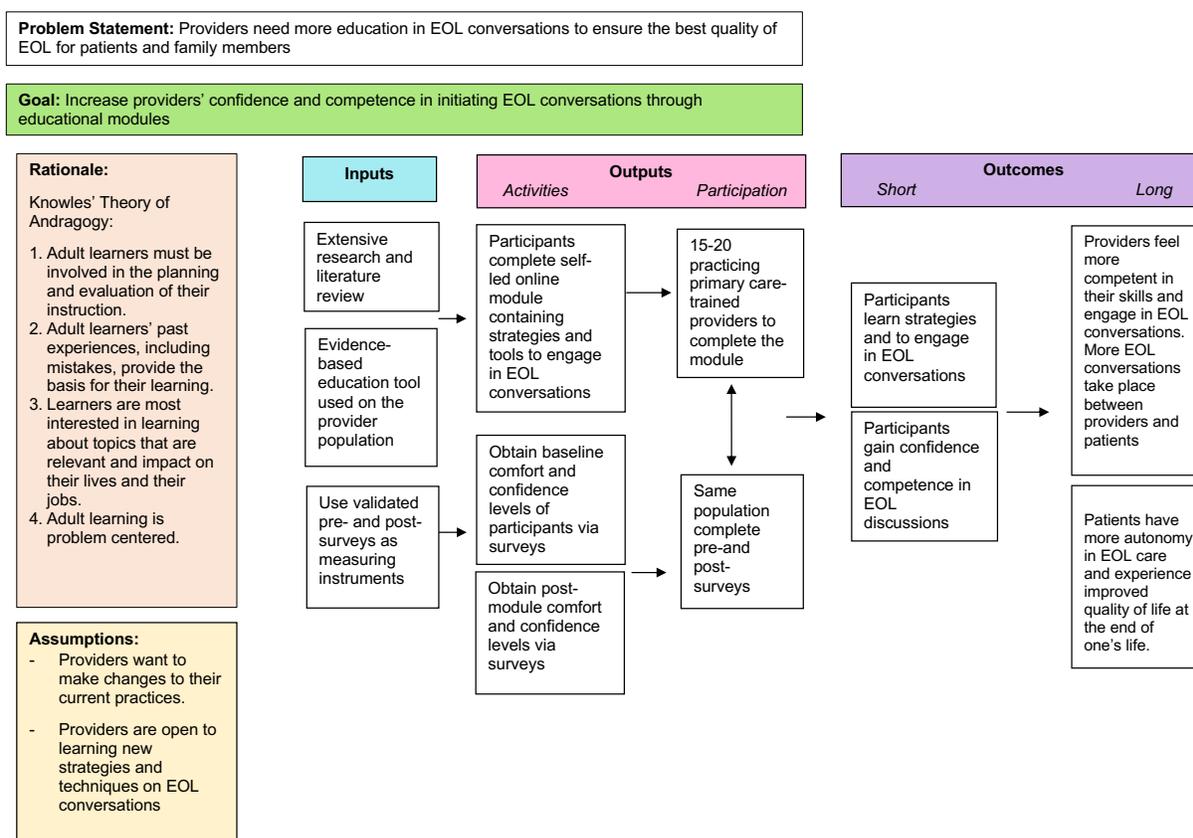
**Relevance and impact on learners' lives.** This point highlights the importance of the relevance and impact of the information being taught on a learners' life, which will in turn impact their ability to and willingness to receive and apply what they have learned. The learners' readiness to learn can be impacted by factors such as past experiences or its application to their actual lives. Therefore, the role as the educator was to help learners understand their need to know the information being provided; by reaching learners on a personal level, it will be more meaningful and thus applicable in their practices as primary care providers. Facilitating the bridge in the educational modules and real-life application has highlighted the relevance of EOL discussions and therefore impacted learners' lives, which will thus enact changes in practice.

**Problem-centered.** This last point stresses the concept of problem-centered learning rather than content-centered learning. By focusing on problem-centered education, the information becomes more personalized and therefore applicable to real life situations. Knowles (1978) believes adult learners view education as a process of improving self-potential, which helps one gain the skills to live more effectively in the long run. By utilizing education material that is problem-centered, one learns competency-development. This project focused on a module highlighting the importance of EOL discussions and how to gain confidence on these discussions. The aims of the project were to increase the confidence of providers, which

highlighted their ability to conquer this problem and better serve their patients and improve overall quality of life.

**Figure 2**

*Logic Model for Planning and Evaluation of Project*



*Note.* Logic Model created for Planning and Evaluation of this Project

The logic model in *Figure 2*, represents the incorporation of Knowles' Theory of Andragogy into the planning and evaluation of this project. The logic model outlines the steps in which this project occurred, based on the application of the Knowles' Theory of Andragogy as a rationale. The research has shown the need for education on EOL conversations, thus highlighting the relevance of this topic for providers. This project was problem centered, focusing on ways in which providers can overcome barriers to EOL conversations. The adult

learners have had the opportunity to provide input and evaluation of the project and strategies introduced. The surveys incorporated information regarding the providers' past experiences in engaging in EOL conversations, which has constituted the basis of their learning on this topic. The logic model will be discussed in further detail in the Methods portion of this paper, where the interventions will be elaborated on further.

### **Methods**

The goal of this project was to increase providers' confidence and competence in initiating EOL conversations through education modules. The Logic Model in *Figure 2* is an outline of the aims, objectives, and interventions of this project. To successfully educate providers, it is important to understand how adults learn. Therefore, the Knowles' Principles of Andragogy was applied to the aims and objectives of this project and was the guiding source of the interventions created. Knowles' four principles of andragogy state that adults learn best when they are involved in their learning, their past experiences provide the basis of their learning, the subject being taught is applicable to the learner's life, and the material is problem centered.

For this project, participants were asked to draw upon previous experiences in EOL conversations and what has worked in the past and what could be improved on. This helps providers reflect on past experiences and serves as a basis to bridge gaps in knowledge and barriers to EOL conversations. Furthermore, these past experiences highlight the relevance and importance of this subject matter for providers, which will likely impact their ability to and willingness to learn the new information. Participants received an email with instructions about the pre and post-tests and education module. This allowed the learner to be involved in their

learning and practice self-directedness in their learning. The application of the Knowles' theoretical framework is highlighted in the aims, objectives, and methods of this project.

## **Aims and Objectives**

### ***Aim One***

Determine providers' knowledge and confidence levels of using evidence-based communication strategies for sharing difficult news with patients.

**Objective 1:** Obtain baseline comfort and confidence levels of providers with the use of a pre-survey.

**Objective 2:** Obtain information on how applicable EOL conversations are to the participant's current practice.

**Methods:** To get an understanding of participants' confidence in EOL conversations, a pre-survey, titled End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education (see Appendix A) was electronically administered via email. The End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education pre-survey included demographic information such as how long they have been practicing, how many times in the last year they have engaged in EOL conversations with patients, how they rate their confidence and competence levels in EOL conversations, and how applicable EOL conversations knowledge is in their current practice. Participants also completed the PCSE (Appendix B) and TI (Appendix C) to assess a baseline knowledge of confidence in EOL conversations and thanatophobia level, before starting the module.

### ***Aim Two***

Educate primary care-trained providers on evidence-based techniques to initiate and conduct EOL conversations with patients and family members through "SPIKES: A Six-Step

Protocol for Delivering Bad News” (2020) education module. The “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020) education module contained a pre-survey, which evaluated one’s knowledge on EOL conversations and understanding of the SPIKES protocol. The learning outcomes of the “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020) education module included being able to define “bad news” and its relation to clinical outcomes, identifying barriers and strategies to engage in difficult conversations, and how to utilize the SPIKES protocol in practice. The module included a combination of videos for participants to watch, short snippets for participants to read, and interactive scenarios that provided participants with feedback on correct and incorrect responses.

Participants learned about the SPIKES protocol, which is a set of six steps that help providers deliver bad or difficult news to patients and families (“SPIKES: A Six-Step Protocol for Delivering Bad News,” 2020). The SPIKES protocol has four main goals, which include gathering information from the patient, communicating medical information to the patient, collaborate with the patient to develop a treatment plan, and provide support for the patient (“SPIKES: A Six-Step Protocol for Delivering Bad News,” 2020). To accomplish this goal, the “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020) framework utilizes a step-like strategy for providers when delivering difficult news. Participants were taken through each of the six steps to understand the importance of each step and how to accomplish them.

Upon completing the module, providers learned about each of the steps in the “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020), which include Setting up the interview, assessing the patients’ Perception, obtaining the patient’s Invitation, giving Knowledge to the patient, Empathic responses, and Strategy. Participants also applied their knowledge to

interactive scenarios and passed a post-test, which evaluated their knowledge after completing the SPIKES (2020) education module.

**Objective 1:** Recruit primary care-trained providers to participate in the EOL Conversations project.

**Methods:** A recruitment flyer (see Appendix D) was sent to various providers and clinics throughout the county of Hawai'i.

**Objective 2:** Implement EOL Conversation online education module.

**Methods.** The online education module used for this project was titled “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020), which was created by the University of North Texas Health Science Center at Fort Worth. Participants were sent an email with the link to the website. They created an account and completed the online module at their own pace. Upon completion, participants sent a copy of their certificate of completion via email.

### ***Aim Three***

Evaluate the effectiveness of the “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020) education module.

**Objective 1:** Assess participant’s likelihood of applying SPIKES (2020) strategies provided.

**Objective 2:** Evaluate participant’s confidence in initiating EOL conversations and making changes in their practice.

**Methods.** After completing “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020) education module, participants completed the End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education post-survey (see Appendix E). The post-survey aimed to assess participants’ level of confidence in engaging in EOL

conversations, their knowledge on the topic, and their willingness to make changes in their current practices. The completion certificate of the “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020) was proof that the participant completed the module and also passed the required post-test. Participants then completed the PCSE and TI scales again after completing the “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020) education module, to assess for changes in confidence and thanatophobia. Upon completion of the surveys and scales, participants emailed a copy of their “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020) education module certificate of completion and End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education pre- and post-surveys back. They had approximately six weeks to complete the “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020) education module and End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education pre/post-surveys and return them to the project coordinator via email.

### **Data Collection Tools**

The End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education pre-survey (see Appendix A) was administered prior to the initiation of the “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020) education module. The End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education pre-survey included the participant’s licensing type, years of experience, and the amount of EOL conversations held within the last year. The End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education pre-survey also included Likert Scale type questions for providers to rate their current knowledge of EOL care and their current confidence levels in EOL conversation skills. Finally, participants completed a Palliative Care

Self-Efficacy (PCSE) scale (see Appendix B) and Thanatophobia Instrument (TI) (see Appendix C) to get a baseline understanding of their confidence in EOL conversations and feelings associated with death and dying. Permission to utilize the PCSE Scale was obtained from the Elsevier Copyrights Coordinator (see Appendix F). The Thanatophobia Instrument (TI) was based upon the seven modified questions extracted from the 110-item survey described by Merrill et al. (1998).

The End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education post-survey evaluated if there was an increase in the participant's knowledge in EOL conversations as well as an increase in confidence and perceived competence in engaging in EOL conversations after the completion of the "SPIKES: A Six-Step Protocol for Delivering Bad News" (2020) education module. The End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education post-survey also evaluated the likelihood of applying the introduced strategies to current practice. There was a qualitative portion for feedback from providers in the form of open-ended questions, to evaluate what participants found to be important, what was missing, and what was found to be most applicable to their current practices. Participants were asked "What did you find most helpful about this module?", "What did you find least helpful about the module?", "What did you find most important and applicable to your practice as a provider?", and "Any feedback or comments?" Participants completed the PCSE and TI after completing the "SPIKES: A Six-Step Protocol for Delivering Bad News" (2020) education module to reevaluate if their confidence and competence has increased.

## Data Analysis

The data analysis of this project focused on measuring whether the “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020) education module has increased providers’ overall knowledge of EOL care and if it has increased their confidence and competence in EOL conversations. The End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education pre- and post-surveys completed by the participants were analyzed. Both quantitative and qualitative data were generated and analyzed. The End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education surveys included yes/no, multiple choice, Likert scale, and open-ended questions.

The data was entered in a password-locked Excel spreadsheet and all personal information was discarded. A set of 5-point Likert Scale questions on The End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education pre- and post-surveys was used to measure the effectiveness of the “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020) education module. The PCSE scale was formatted in a 4-point scale and its pre- and post- “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020) education module results were used to measure provider confidence in EOL conversations. Participants were asked to rate their degree of confidence in scenarios by selecting one, which indicated the need for further basic instruction; two, which indicated confidence to perform tasks with close supervision or coaching; three, which indicated confidence to perform with minimal consultation; or four, which indicated confidence to perform independently. The TI was formatted as a 7-question test with each question having a 7-point Likert scale, and the TI pre- and post-test results were used to measure the participants’ thanatophobia ratings. The number

one indicated strong disagreement, four indicated somewhat agreeing, and seven indicated strongly agreeing.

The participants' pre- and post- PCSE and TI scores were further compared with the use of graphs to determine if there was a positive change between the two sets of results. Graphs were created to display the amount of change for each question in the PCSE and TI. This compares the questions' data from before and after the "SPIKES: A Six-Step Protocol for Delivering Bad News" (2020) education module and shows if the results have significant differences.

The project's effectiveness was evaluated by questions on The End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education post-survey administered after the "SPIKES: A Six-Step Protocol for Delivering Bad News" (2020) education module was completed. Participants were given the opportunity to rate the effectiveness of the content provided and the likelihood of the application of the SPIKES (2020) strategies to their current practices. There were four open-ended questions on the End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education post-survey, which allowed participants to leave qualitative feedback and to evaluate the overall effectiveness of the EOL project. The End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education pre- and post-survey questions regarding confidence and competence were also compared with the use of graphs, which contributed to the evaluation of this project.

### **Project Timeline**

This project was submitted to the UH Hilo SRC in September 2021 and was approved in September 2021. After the approval of the PIP proposal by the chair and the committee member,

an oral presentation and defense of the project proposal was scheduled in November 2021. Once approved, the project was submitted to the University of Hawaii Office of Research Compliance, and after IRB approval was granted as exempt, the project was implemented in the Winter of 2021. Recruitment flyers were sent out by the end of December 2021. Participants who responded to the recruitment flyer received an email with the End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education pre- and post-survey, pre- and post-PCSE (see Appendix B) and pre- and post-TI (see Appendix C), and information on how to access the “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020) education module. This email was distributed by the first week of January 2022. Participants had until the third week of February to complete the End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education surveys, pre- and post-PCSE and TI, and “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020) education module, with the associated certificate of successful completion, and return them via email to the project coordinator. Data analysis began the last week of February. A detailed timeline of this project is attached below in Table 1.

**Table 1**

*Project Timeline*

	<b>Tasks</b>	<b>(Aimed) Completion Date</b>
	Complete literature review and proposal	July 2021
Aim 1	Identify an evidence-based education module	September 2021
	Submit proposal to SRC	September 2021
	Defend proposal	November 2021
	Submit to IRB	November 2021
	Recruit providers for participation	November 2021
Aim 2	Participants complete pre-surveys, pre-PCSE and pre-TS	January 2022
	Have providers complete modules	January 2022

	Providers complete post-surveys, post-PCSE and post-TS	January 2022
	Participants return SPIKES Module certificate of completion	February 2022
	Participants return completed surveys and scales	February 2022
Aim 3	Evaluate pre/post-tests (data analysis)	February 2022
	Reporting/write up of findings	March-April 2022

### **Human Subjects Protection**

The proposal of this project has been reviewed and approved by the University of Hawai'i at Hilo's (UHH) School of Nursing Scientific Review Committee (SRC). Online courses through the Collaborative Institutional Training Initiative (CITI) program were completed, which were peer-reviewed educational courses in research, ethics, and confidentiality (see Appendix G). The courses completed included: cultural competence in research, informed consent, internet-based research, privacy and confidentiality, and federal regulations.

Institutional Review Board (IRB) exempt status for this study Protocol ID: 2021-00881 was approved by the University of Hawaii Office of Research Compliance Human Studies Program on November 4, 2021 (See Appendix H). This research project posed less than minimal risk to participants (i.e., no known physical, emotional, psychological, reputational, or economic risk), and did not involve any vulnerable population. The investigator does not have any financial or business-related interest in the initiation and completion of this project. University of Hawai'i at Hilo's School of Nursing faculty comprise the committee overseeing this project.

### **Participant Recruitment and Protection**

A convenience sample of primary care providers in the County of Hawai'i region was utilized in this study. A flyer (see Appendix D) was sent to seven private primary care offices

and primary care clinics in East Hawai'i areas. There was minimal risk associated with this project and a consent to participate in this project (see Appendix I) was given to each participant to sign. The consent form explained the following: their participation was voluntary, they could opt out of the study at any time, their information would remain confidential, and there was little risk involved in participating. Strict confidentiality precautions were maintained, participant information remained anonymous for survey and demographic data, and all records were stored on a password-protected computer.

### **Project Participants**

The participants of this project were 13 primary care-trained providers in the County of Hawai'i. These practitioners largely work in the primary care field but vary in years of experience and populations in which they specialize.

**Inclusion criteria.** Inclusion criteria to be a participant in this project were primary care trained providers with an NP, MD, DO, or PA license who are practicing in the County of Hawai'i Region.

**Exclusion criteria.** Exclusion criteria for this project included providers who do not have an NP, DO, MD, or PA license or practitioners who are not formally trained in primary care. Providers who work in acute and long-term care were excluded.

### **Project Setting**

The setting of this project took place in Hilo, Hawai'i. Providers completed the "SPIKES: A Six-Step Protocol for Delivering Bad News" (2020) education module, End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education pre- and post-surveys, and PCSE and TI pre- and post-scales online and on their own time, which took approximately one hour to complete. Participants had six weeks to complete the "SPIKES: A

Six-Step Protocol for Delivering Bad News” (2020) education module, End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education surveys, PCSE and TI scales.

## Chapter 4: Results

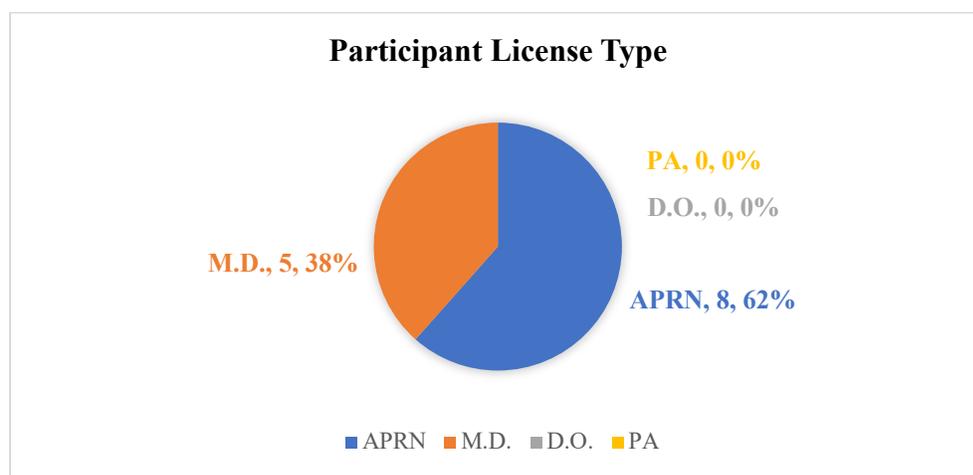
In this chapter, the results and data of this project will be discussed. The project's aims and objectives data will be analyzed and reviewed as having been addressed as well.

### Participants Background

There were a total of 13 participants in this project. Eight of the participants were Advanced Practicing Nurse Practitioners (APRNs) and five of the participants were M.D.s. There were no participants who held D.O. or P.A. licenses. See Graph 1 below.

### Graph 1

*Participant License Type*



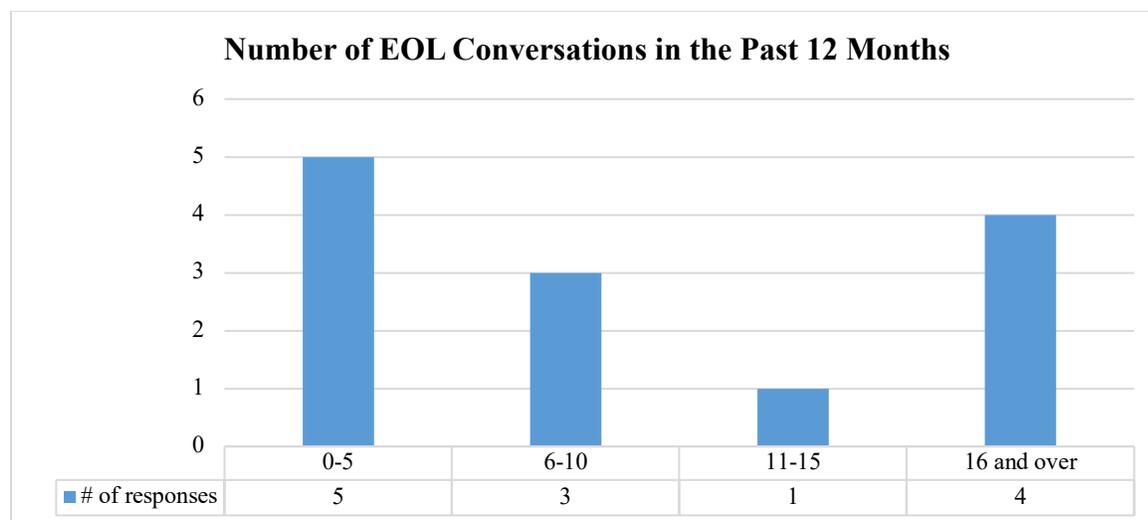
Nine of the participants (69%) have been practicing between 0-4 years, three participants have been practicing between 5-10 years, none of the participants have been practicing between 11-15 years, and one participant (8%) has been practicing for 16 years and over.

Each of the participants was trained in primary care and varied in terms of experience, specialization, and populations in which they work with. However, they each have had experience in delivering difficult news or having EOL discussions with patients. According to the question "In the past 12 months, how many EOL conversations have you had with patients?", five participants (38%) have had between 0-5 EOL conversations, three participants (23%) have

had between 6-10 EOL conversations, one participant (8%) has had between 11-15 EOL conversations, and four participants (31%) have had 16 and over EOL conversations with patients. See Graph 2 below.

## Graph 2

*Number of EOL Conversations in the Past 12 Months*



## Results – Objective Presentation of Data

### *Aim One*

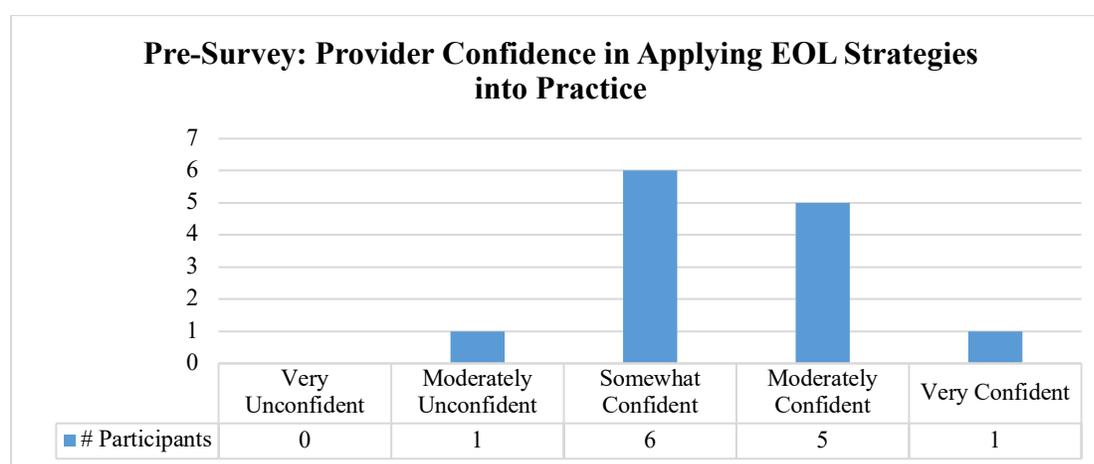
The first aim of this project was to determine participating providers' knowledge and confidence levels of using evidence-based communication strategies for sharing difficult news with patients.

The first objective of Aim One was to obtain baseline comfort and confidence levels of providers with the use of a pre-survey. To get an understanding of participants' confidence in EOL conversations, participants completed the pre-survey, titled End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education (see Appendix A), which was sent electronically via email. According to the question, "On a scale from 1 to 5, where 1 is 'very unconfident' and 5 is 'very confident,' how would you rate your confidence in

applying end-of-life strategies into your practice?”, none of the participants (0%) reported feeling very unconfident. One participant (8%) reported feeling moderately unconfident, six participants (46%) reported feeling somewhat confident, five participants (38%) reported feeling moderately confident, and one participant (8%) reported feeling very confident in applying EOL strategies into their practice. See Graph 3 below.

### Graph 3

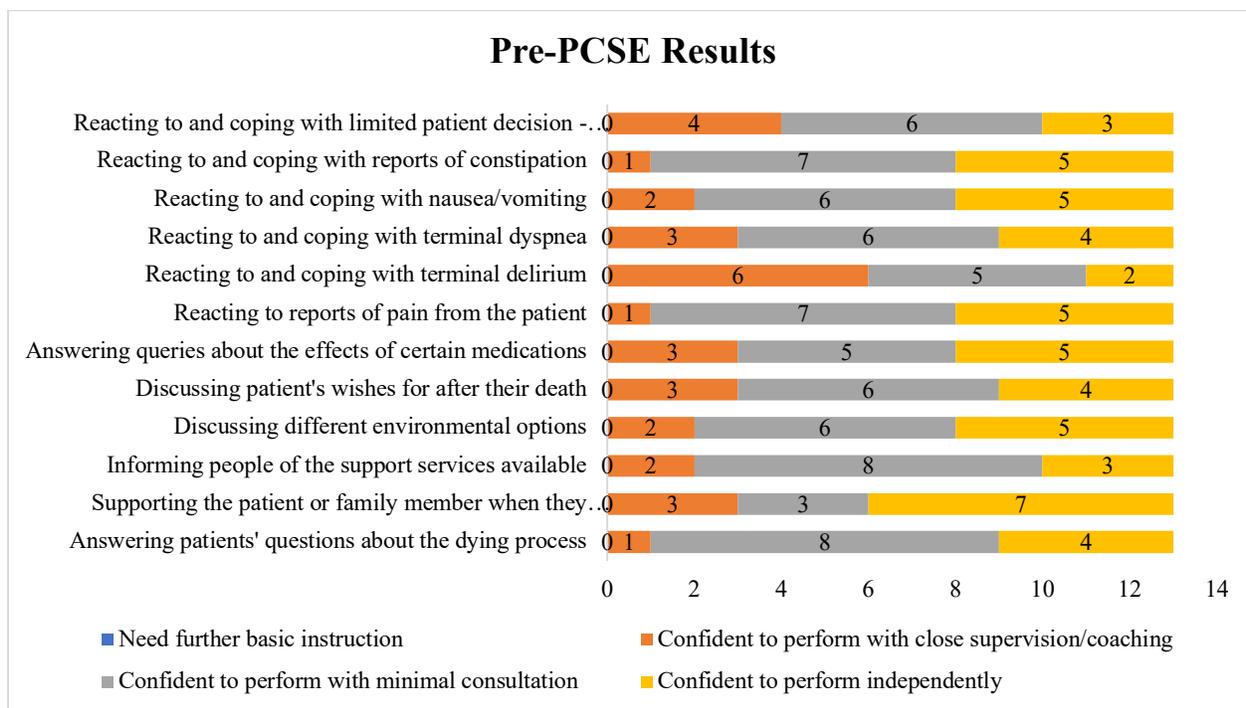
*Pre-Survey: Provider Confidence in Applying EOL Strategies into Practice*



Participants also completed PCSE (Appendix B) and TI (Appendix C) for a baseline comprehension of their confidence in EOL conversations and thanatophobia level. The PCSE included twelve questions, which assessed the participant’s degree of confidence in engaging with patients and families at the EOL. Graph 4 depicts the pre-PCSE results (See Graph 4). The TI included seven questions, which assessed the participant’s thanatophobia level, which measures one’s feelings of discomfort in dealing with the death and dying of patients. Graph 5 depicts the pre-TI results (see Graph 5). The results of the pre-PCSE and pre-TI will be discussed further in Aim 3.

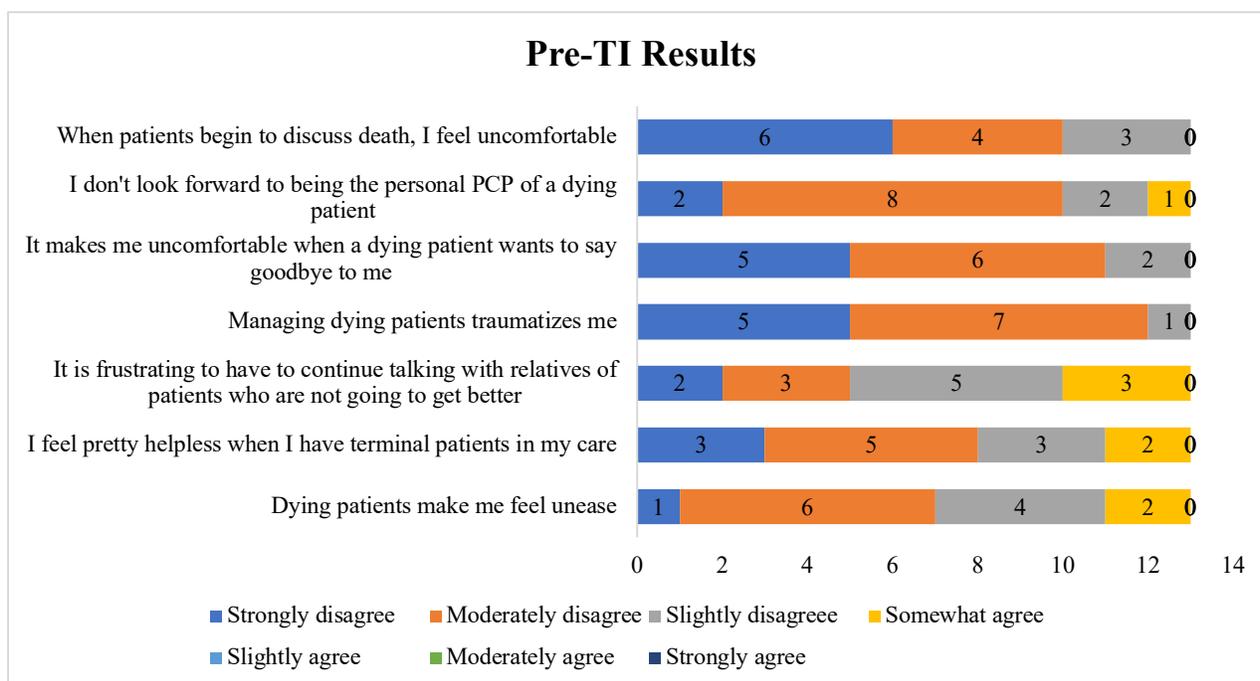
## Graph 4

### Pre-PCSE Results



## Graph 5

### Pre-TI Results

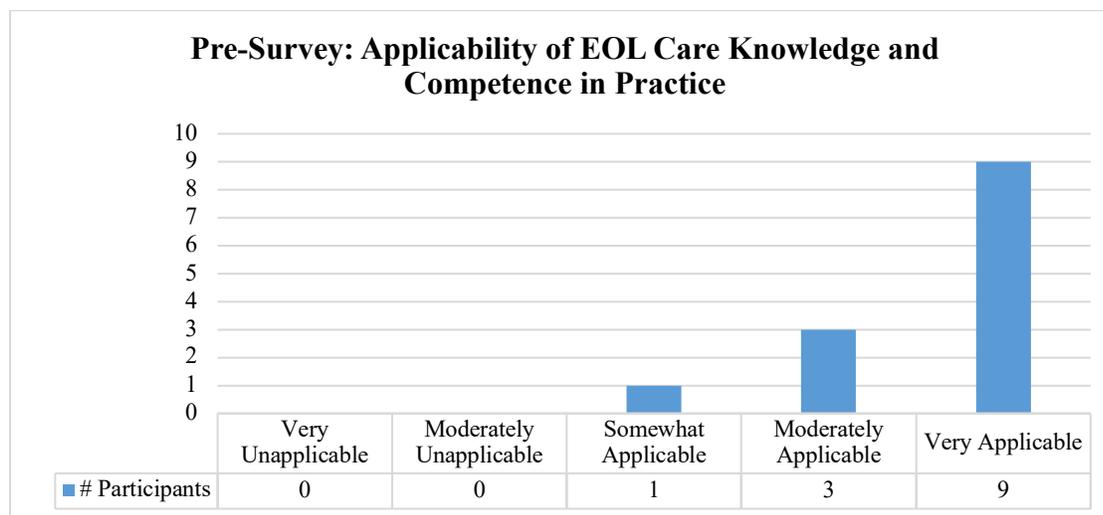


The PCSE Scale was used to measure participants' self-confidence and assurance to perform palliative care related tasks. Self-efficacy relates to an individual's confidence in their ability to perform certain tasks. Understanding one's self-efficacy was essential in understanding the need for change and increasing one's reception to new information. The TI assessed providers' attitudes toward caring for palliative care patients (Mason & Ellershaw, 2004). It helps identify one's feelings associated with thanatophobia, and higher thanatophobia scores predict lower self-esteem and increased uncertainty in clinical skills in EOL discussions when treating elderly or dying individuals.

The second objective of this aim was to obtain information on how applicable EOL conversations are to the participant's current practice. The pre-survey, *End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education* (see Appendix A) also included the question, "On a scale from 1 to 5, where 1 is 'very unapplicable' and 5 is 'very applicable,' how applicable is end-of-life care knowledge and competence in your current practice?" None of the participants noted the applicability of EOL care knowledge and competence to be very inapplicable or moderately inapplicable. One participant (8%) reported that EOL care knowledge and competence is somewhat applicable, three participants (23%) reported that EOL care knowledge and competence is moderately applicable, and nine participants (69%) reported that EOL care knowledge and competence is very applicable in their practice. See Graph 6 below.

## Graph 6

*Pre-Survey: Applicability of EOL Care Knowledge and Competence in Practice*



### *Aim Two*

The second aim of this project was to educate primary care-trained providers on evidence-based techniques to initiate and conduct EOL conversations with patients and family members through an online education module.

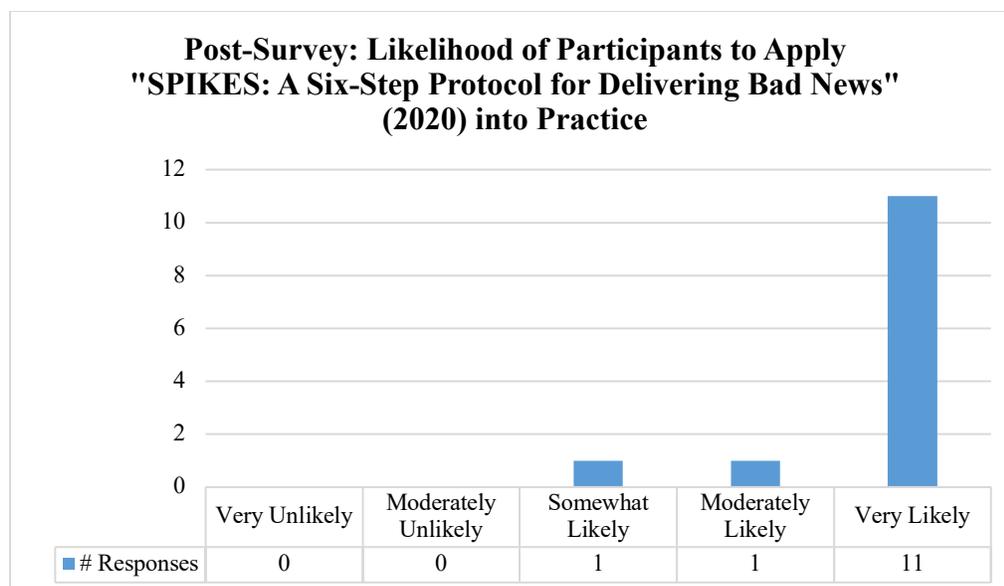
The first objective of this aim was to recruit primary care-trained providers to participate in the EOL Conversations project. The second objective was to implement the EOL Conversation online education module. A total of thirteen participants were recruited for this project. They each completed the pre-survey, End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education,” “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020) online module, and the End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education post-survey. Upon completion, participants returned their surveys and module completion certificate via email.

### ***Aim Three***

The third aim of this project was to evaluate the effectiveness of the “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020) education module. The first objective of Aim Three was to assess the participant’s likelihood of applying SPIKES (2020) strategies provided. The End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education post-survey asked the question, “On a scale from 1 to 5, where 1 is ‘very unlikely’ and 5 is ‘very likely,’ how likely are you to apply the strategies provided in the “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020) education module to your practice when discussing end-of-life care with your patients?” None of the participants reported being very unlikely or moderately unlikely to apply the strategies provided. One participant (8%) reported to be somewhat likely to apply the strategies, one participant (8%) reported to be moderately likely, and 11 participants (84%) reported to be very likely to apply the strategies provided. See Graph 7 below.

### **Graph 7**

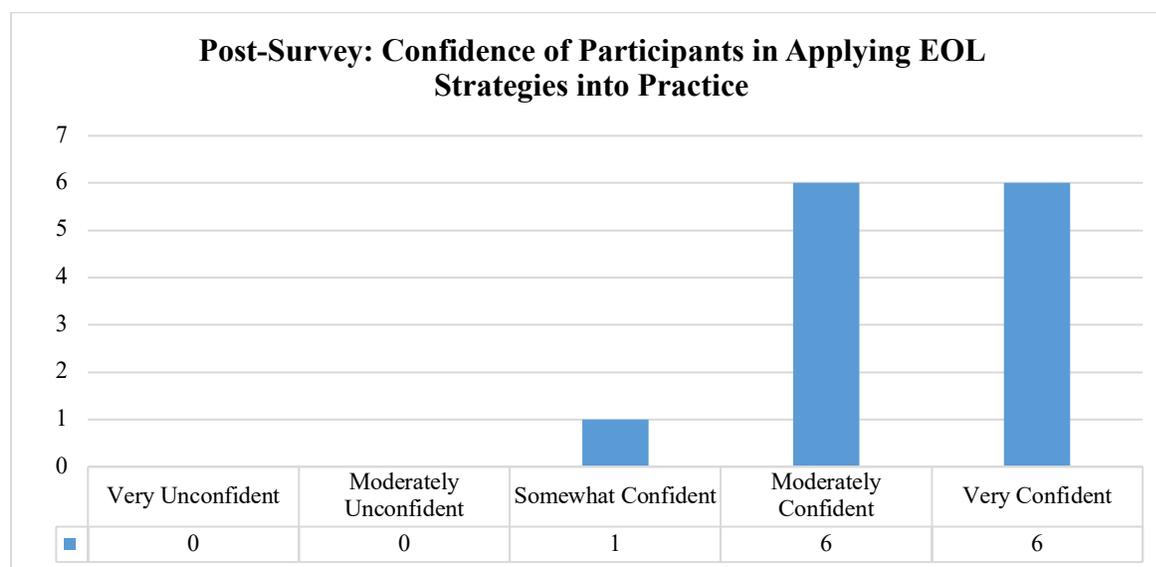
*Post-Survey: Likelihood of Participants to Apply “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020) into Practice*



The second objective of this aim was to evaluate participants' confidence in initiating EOL conversations and making changes in their practice after completing the "SPIKES: A Six-Step Protocol for Delivering Bad News" (2020) education module. After completing "SPIKES: A Six-Step Protocol for Delivering Bad News" (2020) education module, participants completed the End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education post-survey (see Appendix E). The post-survey aimed to assess participants' level of confidence in engaging in EOL conversations, their knowledge on the topic, and their willingness to make changes in their current practices. According to the question, "After completing this module, on a scale from 1 to 5, where 1 is 'very unconfident' and 5 is 'very confident,' how would you rate your confidence in applying end-of-life strategies into your practice?", none of the participants reported feeling very unconfident or moderately unconfident. One participant (8%) reported feeling somewhat confident, six participants (46%) reported feeling moderately confident and six participants (46%) reported feeling very confident. See graph 8 below.

**Graph 8**

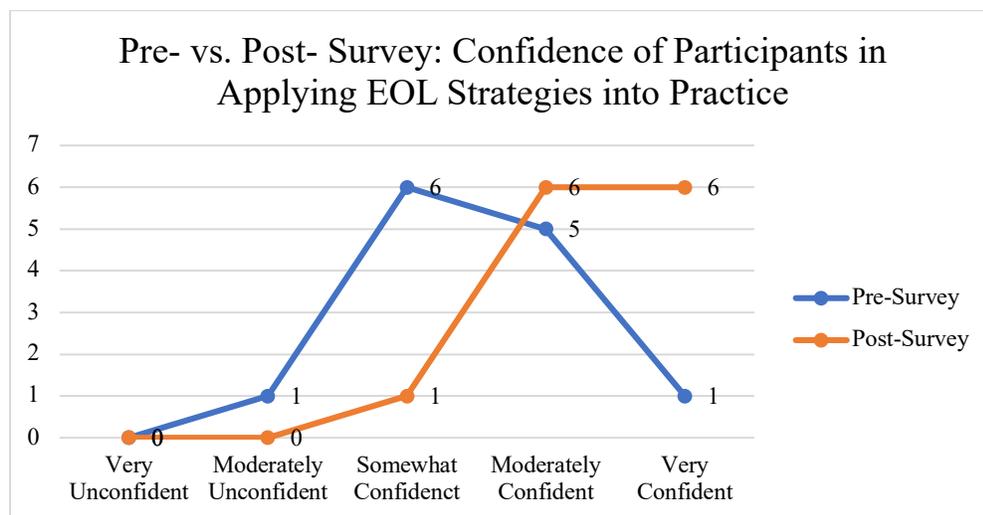
*Post-Survey: Confidence of Participants in Applying EOL Strategies into Practice*



There was an increase in participants' confidence in applying EOL strategies into practice after completing the "SPIKES: A Six-Step Protocol for Delivering Bad News" (2020) education module. In the pre-survey, one participant responded feeling moderately unconfident in applying EOL strategies into practice and in the post-survey, no respondents provided that response. In the pre-survey, six participants (46%) reported feeling somewhat confident and in the post-survey, one participant (8%) reported feeling somewhat confident. Five participants (38%) reported feeling moderately confident in the pre-survey and six participants (46%) reported feeling moderately confident in the post-survey. One participant reported feeling very confident in applying EOL strategies in the pre-survey and six participants (46%) reported feeling very confident in the post-survey. See Graph 9 below.

## Graph 9

*Pre- vs. Post-Survey: Confidence of Participants in Applying EOL Strategies into Practice*



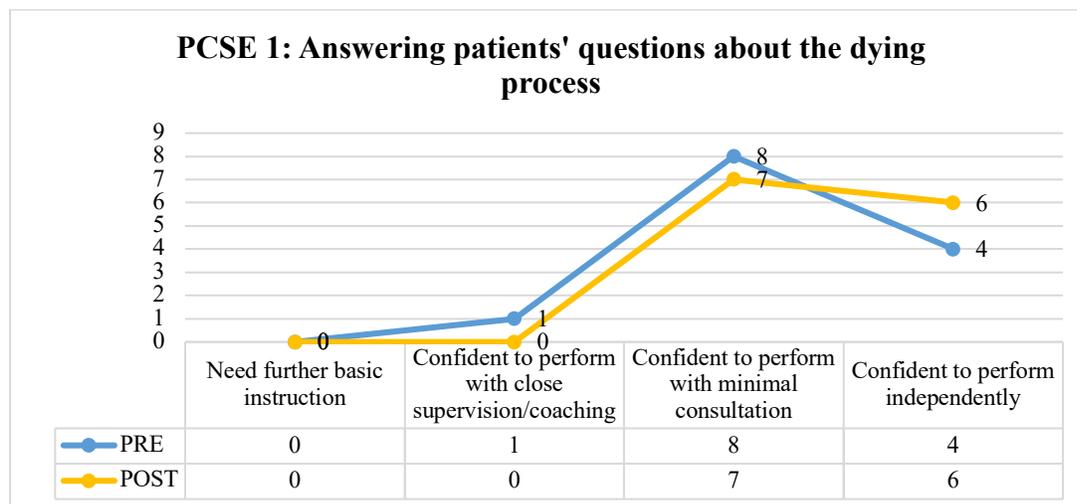
Participants also completed post-PCSE and post-TI scales after completing the “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020) online module. The following section will detail the pre- and post- results of both PCSE and TS scales.

**PCSE Q1. Degree of confidence in answering patients’ questions about the dying process.** None of the participants reported needing further basic instruction when answering patients’ questions about the dying process. One participant (8%) initially answered feeling confident to perform with close supervision or coaching when answering patients’ questions about the dying process before completing the “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020) online module. None of the participants provided this feedback in the post-PCSE. The number of participants feeling confident to perform with minimal consultation decreased from eight participants (62%) to seven participants (54%) and the number of participants feeling confident to perform independently increased from four participants (31%) in the pre-PCSE to six participants (46%) in the post-PCSE (see Graph 10). The average pre-PCSE score was 3.23

and the average post-PCSE score was 3.46 with an overall average of 7.1% increase in confidence in answering patients' questions about the dying process.

### Graph 10

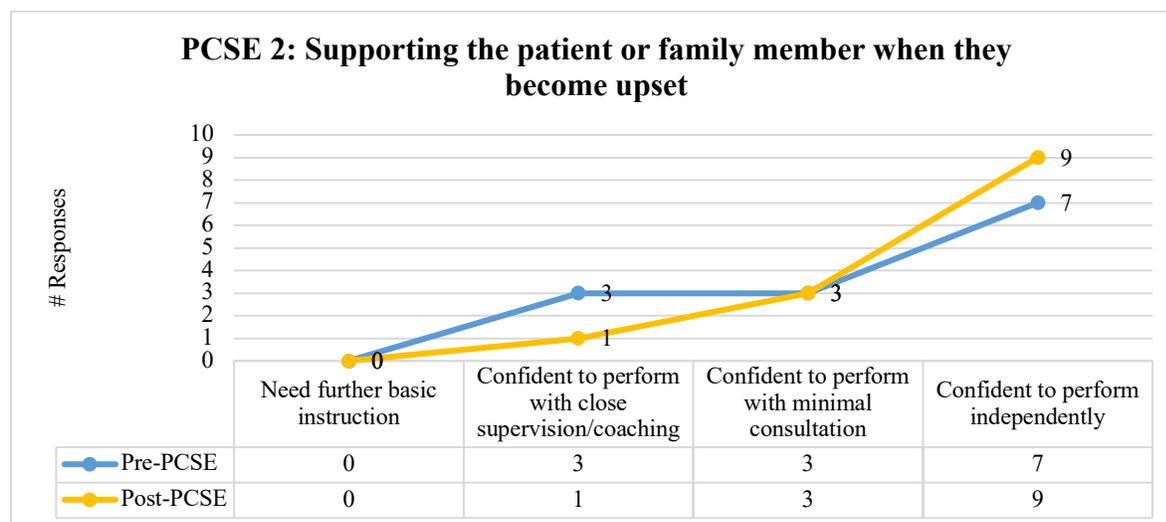
*PCSE Q1: Degree of confidence in answering patients' questions about the dying process*



**PCSE Q2. Degree of confidence in supporting the patient or family member when they become upset.** None of the participants reported needing further basic instruction when supporting patients or family members when they become upset in the pre- and post-PCSE. Three participants (23%) initially reported feeling confident to perform with close supervision or coaching and decreased to one participant (8%) in the post-PCSE. Three participants (23%) reported feeling confident to perform with minimal consultation in both the pre- and post-PCSE. Initially, seven participants (54%) reported feeling confident to perform independently and increased to nine participants (69%) in the post-PCSE (see Graph 11). The average pre-PCSE score was 3.31 and average post-PCSE score was 3.62. There was a 9.4% increase in confidence of participants in supporting the patient or family member when upset.

## Graph 11

*PCSE Q2: Degree of confidence in supporting the patient or family member when they become upset.*

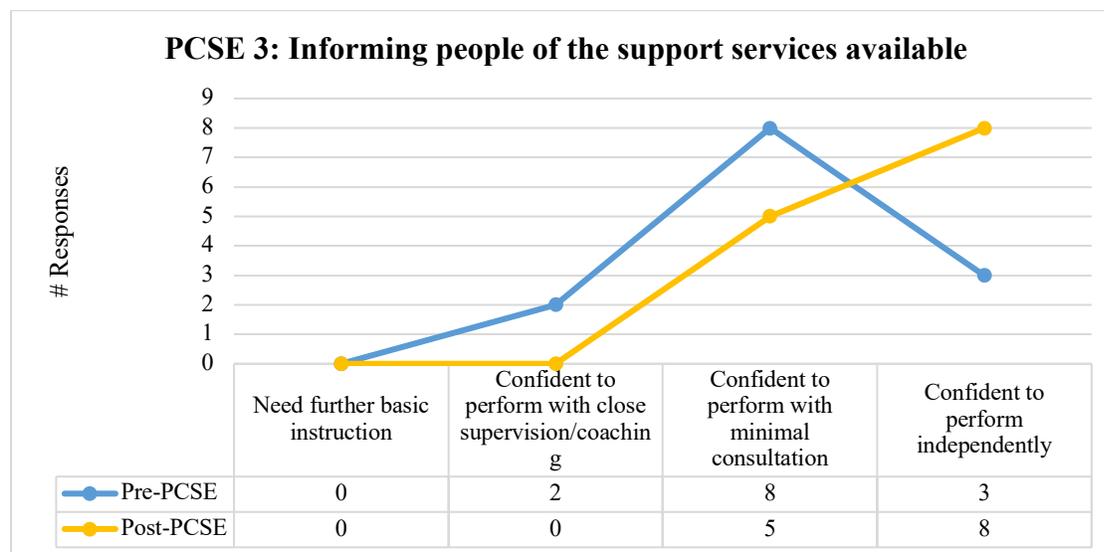


### **PCSE 3. Degree of confidence in informing people of the support services available.**

None of the participants reported needing further basic instruction on the pre- and post-PCSE when informing people of the support services available. Initially, two participants (15%) reported feeling confident to perform with close supervision or coaching but decreased to zero participants in the post-PCSE. Eight participants (62%) reported feeling confident to perform with minimal consultation in the pre-PCSE and decreased to five participants (38%) in the post-PCSE. Three participants (23%) reported feeling confident to perform independently and increased to eight participants (62%) in the post-PCSE (see Graph 12). The pre-PCSE average score was 3.07 and post-PCSE average score was 3.62. There was an overall average of 17.9% increase in confidence on informing people of the support services available.

## Graph 12

*PCSE 3: Degree of confidence in informing people of the support services available.*

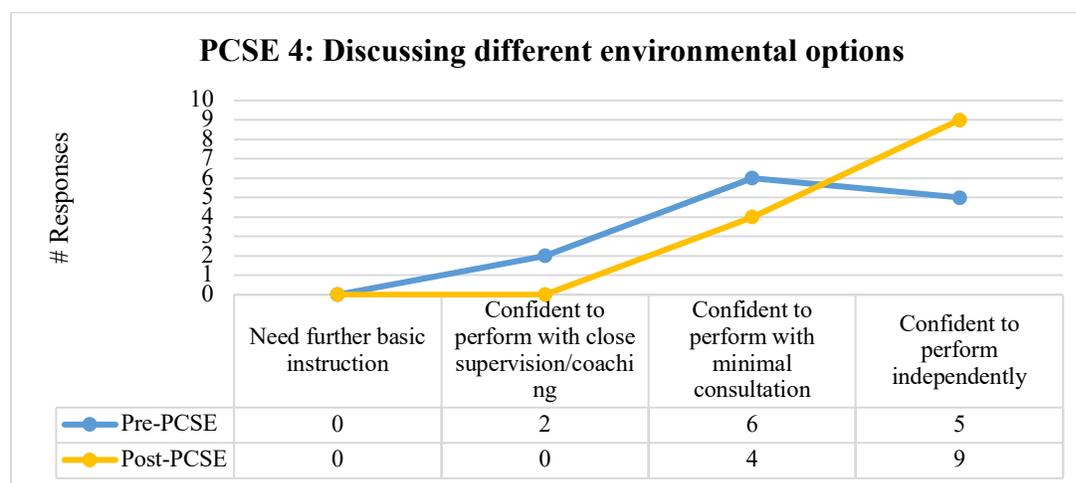


### **PCSE Q4. Degree of confidence in discussing different environmental options.**

None of the participants answered needing further basic instruction in discussing different environmental options. Two participants (15%) reported feeling confident to perform with close supervision or coaching in the pre-PCSE and decreased to zero participants in the post-PCSE. Six participants (46%) reported feeling confident to perform with minimal consultation and decreased to four participants (31%) in the post-PCSE. Five participants (38%) initially felt confident to perform independently in the pre-PCSE and increased to nine participants (69%) in the post-PCSE (see graph 13). The average pre-PCSE score was 3.23 and average post-PCSE score was 3.69 with an overall 14.2% increase in confidence in discussing different environmental options with patients.

### Graph 13

*PCSE Q4: Degree of confidence in discussing different environmental options.*

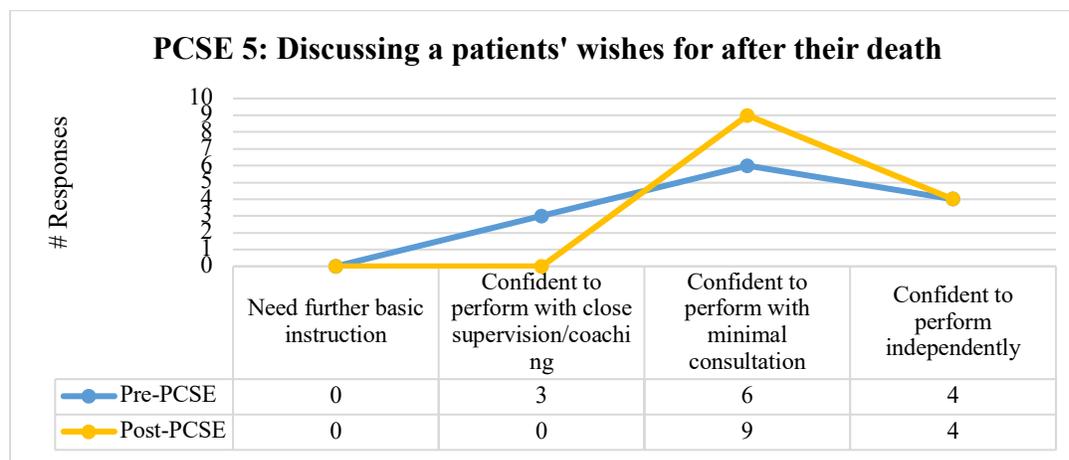


### **PCSE Q5. Degree of confidence in discussing a patients' wishes for after their death.**

When discussing patients' wishes for after their death, none of the participants reported needing further basic instruction in both the pre- and post-PCSE scales. Three participants (23%) initially reported feeling confident to perform with close supervision or coaching and decreased to zero participants in the post-PCSE scale. Six participants (38%) reported feeling confident to perform with minimal consultation in the pre-PCSE scale and increased to nine participants (69%) in the post-PCSE scale. Four participants (31%) reported feeling confident to perform independently in both the pre- and post- scales (see Graph 14). The pre-PCSE average score was 3.07 and post-PCSE average score was 3.31. There was an increase of 7.8% in confidence of participants in discussing patients' wishes for after their death.

## Graph 14

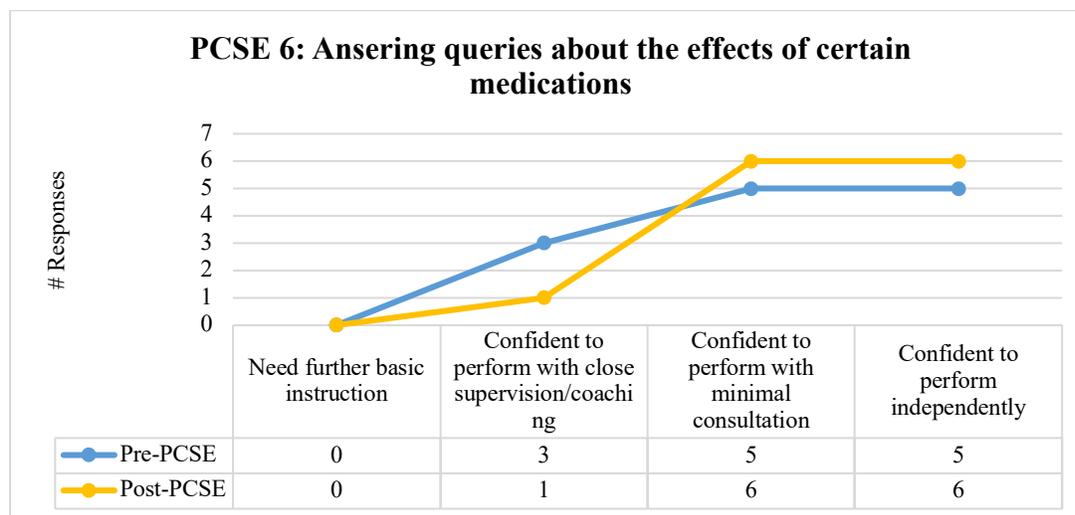
PCSE Q5: Degree of confidence in discussing a patient's wishes for after their death.



**PCSE 6. Degree of confidence in answering queries about the effects of certain medications.** None of the participants reported needing further basic instruction in both the pre- and post-PCSE scales. Three participants (23%) reported feeling confident to perform with close supervision or coaching in the pre-PCSE scale and decreased to one participant (8%) in the post-PCSE scale. Five participants (38%) initially reported feeling confident to perform with minimal consultation and increased to six participants (46%) in the post-PCSE scale. Five participants (38%) reported feeling confident to perform independently in the pre-PCSE scale and increased to six participants (46%) in the post-PCSE scale (see Graph 15). The average pre-PCSE score was 3.15 and average post-PCSE score was 3.38. There was a 7.3% increase in participant confidence in answering queries about the effects of certain medications.

## Graph 15

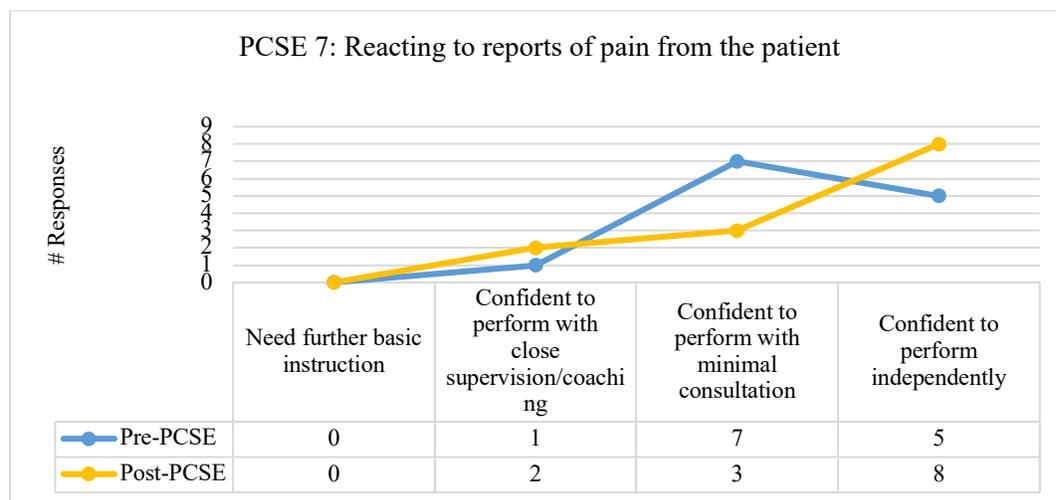
*PCSE 6: Degree of confidence in answering queries about the effects of certain medications.*



**PCSE 7. Degree of confidence in reacting to reports of pain from the patient.** None of the participants reported needing further basic instruction in reacting to reports of pain from the patient. One participant (8%) initially reported feeling confident to perform with close supervision or coaching and increased to two (15%) participants in the post-PCSE. Seven participants (54%) reported feeling confident to perform with minimal consultation in the pre-PCSE and decreased to three participants (23%) in the post-PCSE. Five participants (38%) initially reported feeling confident to perform independently and increased to eight participants (62%) in the post-PCSE (see Graph 16). The average pre-PCSE score was 3.31 and average post-PCSE score was 3.46, with an overall 4.5% increase in confidence in reacting to reports of pain from the patient.

## Graph 16

*PCSE 7: Degree of confidence in reacting to reports of pain from the patient.*

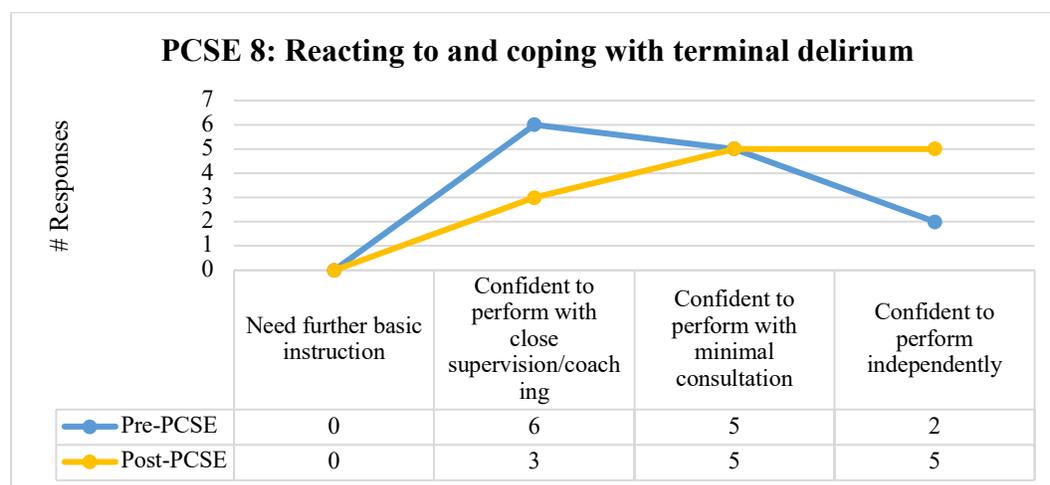


### **PCSE 8. Degree of confidence in reacting to and coping with terminal delirium.**

None of the participants reported needing further basic instruction in reacting to and coping with terminal delirium. Initially, six participants (46%) reported feeling confident to perform with close supervision or coaching and decreased to three participants (23%) in the post-PCSE. Five participants (38%) reported feeling confident to perform with minimal consultation in both the pre- and post-PCSE. Two participants (15%) initially reported feeling confident to perform independently and increased to five participants (38%) in the post-PCSE (see Graph 17). The average pre-PCSE score was 2.69 and average post-PCSE score was 3.15. There was a 17.10% increase in participant confidence in reacting to and coping with terminal delirium.

**Graph 17**

*PCSE 8: Degree of confidence in reacting to and coping with terminal delirium.*

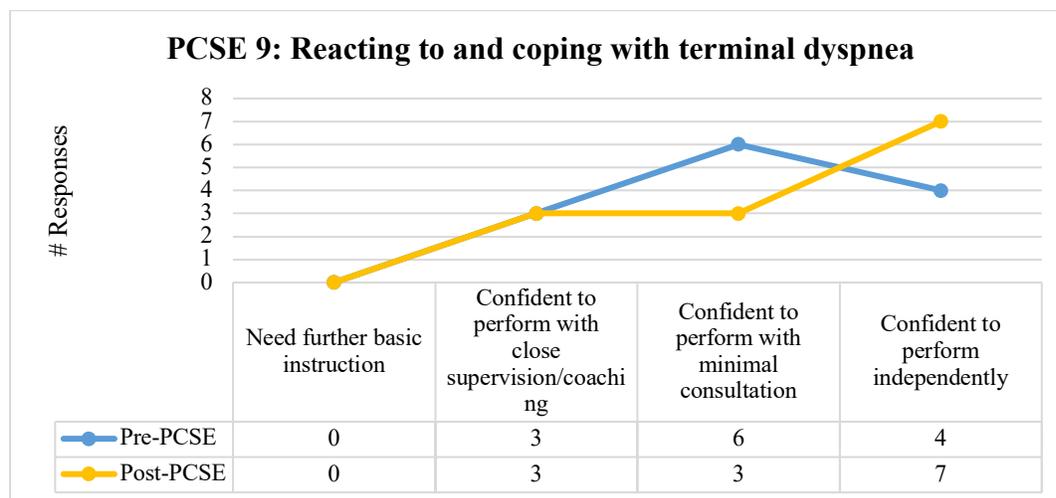


**PCSE 9. Degree of confidence in reacting to and coping with terminal dyspnea.**

None of the participants reported needing further basic instruction in both the pre- and post-PCSE in reacting to and coping with terminal dyspnea. Three participants (23%) reported feeling confident to perform with close supervision or coaching in both the pre- and post-PCSE. Six participants (38%) initially reported feeling confident to perform with minimal consultation and decreased to three participants (23%) in the post-PCSE. Four participants (31%) initially reported feeling confident to perform independently and increased to seven participants (54%) in the post-PCSE (see Graph 18). The average pre-PCSE score was 2.77 and average post-PCSE score was 3.31 with a 19.5% increase in confidence in reacting to and coping with terminal dyspnea.

## Graph 18

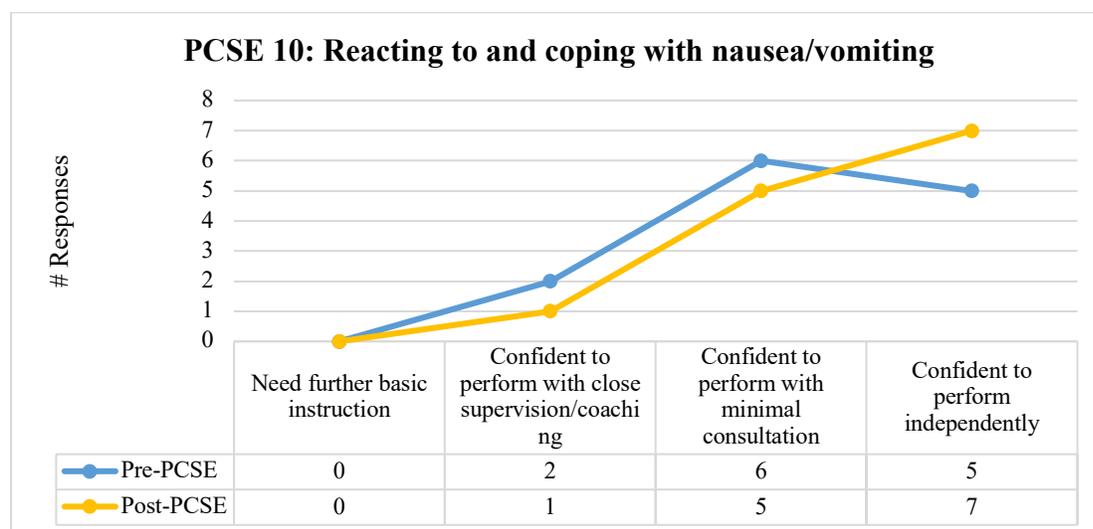
*PCSE 9: Degree of confidence in reacting to and coping with terminal dyspnea.*



**PCSE 10. Degree of confidence in reacting to and coping with reports of nausea/vomiting.** None of the participants reported needing further basic instruction when reacting to and coping with reports of nausea and vomiting. Two participants (15%) initially reported feeling confident to perform with close supervision or coaching and decreased to one participant (8%) in the post-PCSE. Six participants (46%) initially reported feeling confident to perform with minimal consultation and decreased to five participants (38%) in the post-PCSE. Four participants (31%) initially reported feeling confident to perform independently and increased to seven participants (54%) in the post-PCSE (see Graph 19). The average pre-PCSE score was 3.08 and average post-PCSE score was 3.46. There was a 12.3% increase in confidence in reacting to and coping with reports of nausea and vomiting.

## Graph 19

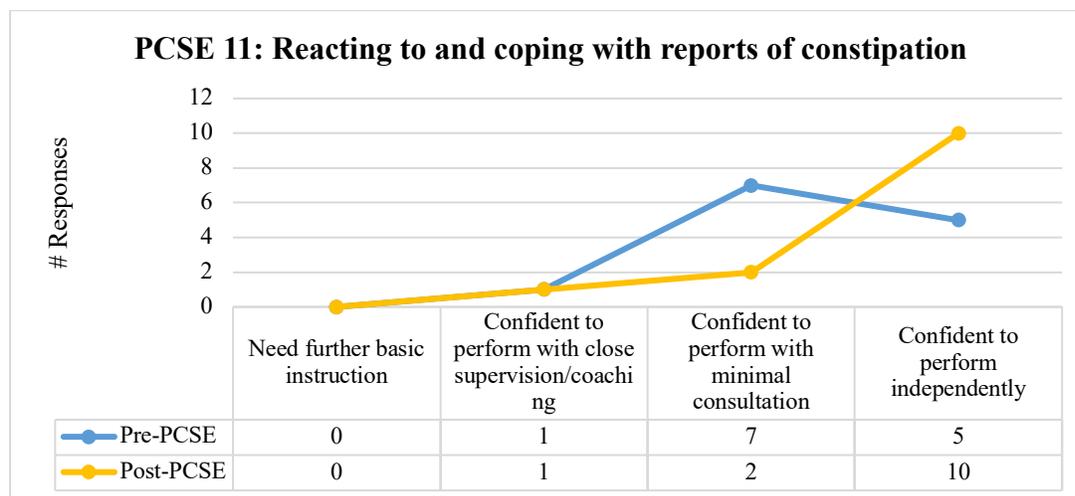
*PCSE 10: Degree of confidence in reacting to and coping with reports of nausea/vomiting.*



**PCSE 11. Degree of confidence in reacting to and coping with reports of constipation.** None of the participants reported needing further basic instruction in reacting to and coping with reports of constipation in both the pre- and post-PCSE. One participant (8%) reported feeling confident to perform with close supervision or coaching in the pre- and post-PCSE. Seven participants (54%) initially reported feeling confident to perform with minimal consultation and decreased to two participants (15%) in the post-PCSE. Five participants (38%) initially reported feeling confident to perform independently and increased to ten participants (77%) in the post-PCSE (see Graph 20). The average pre-PCSE score was 3.31 and average post-PCSE score was 3.69. There was an 11.5% increase in confidence in reacting to and coping with reports of constipation.

## Graph 20

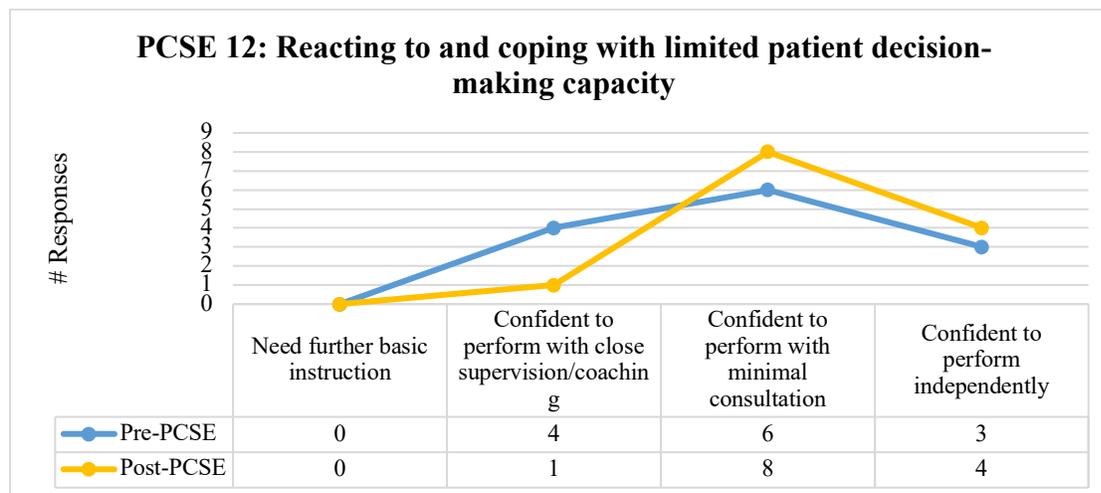
*PCSE 11: Degree of confidence in reacting to and coping with reports of constipation.*



**PCSE 12. Degree of confidence in reacting to and coping with limited patient decision-making capacity.** None of the participants reported needing further basic instruction when reacting to and coping with limited patient decision-making capacity. Initially, four participants (31%) reported feeling confident to perform with close supervision or coaching and decreased to one participant (8%) in the post-PCSE. Six participants (38%) reported feeling confident to perform with minimal consultation in the pre-PCSE and increased to eight participants (62%) in the post-PCSE. Three participants (23%) reported feeling confident to perform independently and increased to four participants (31%) in the post-PCSE (see Graph 21). The average pre-PCSE score was 2.92 and average post-PCSE score was 3.23. There was a 10.6% increase in confidence in reacting to and coping with limited patient decision-making capacity.

## Graph 21

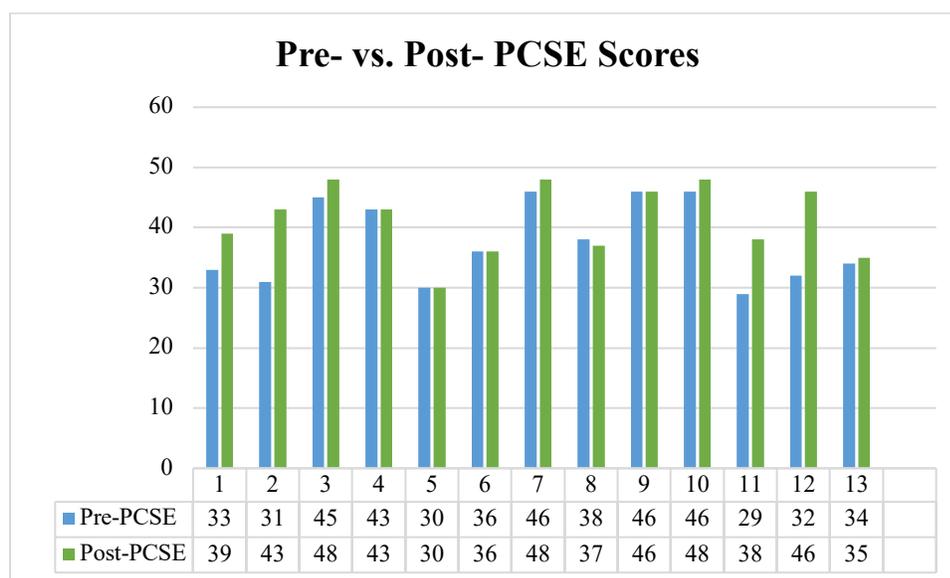
*PCSE 12: Degree of confidence in reacting to and coping with limited patient decision-making capacity.*



**Pre- vs. Post-PCSE Scores.** Of the thirteen participants, eight participants (62%) had an increase in PCSE scores. Four participants (31%) did not have any change in PCSE scores and one participant (8%) had a decrease in PCSE score by one point. See Graph 22 below.

## Graph 22

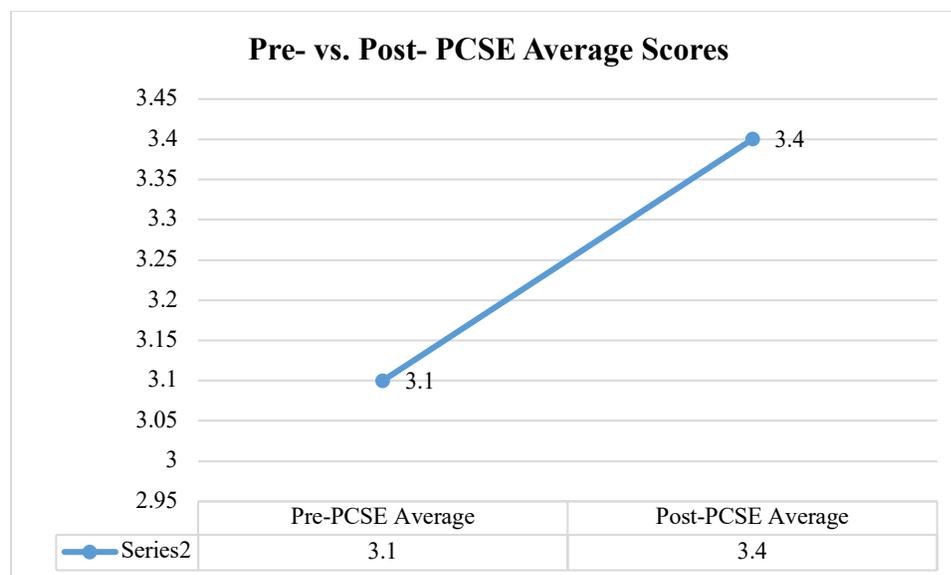
*Pre- vs. Post-PCSE Scores*



The average pre-PCSE score was 3.1 and it increased to an average of 3.4 in the post-PCSE. A higher PCSE score is associated with increased self-confidence in managing palliative care patients. See Graph 23 below.

### Graph 23

*Pre- vs. Post- PCSE Average Scores*



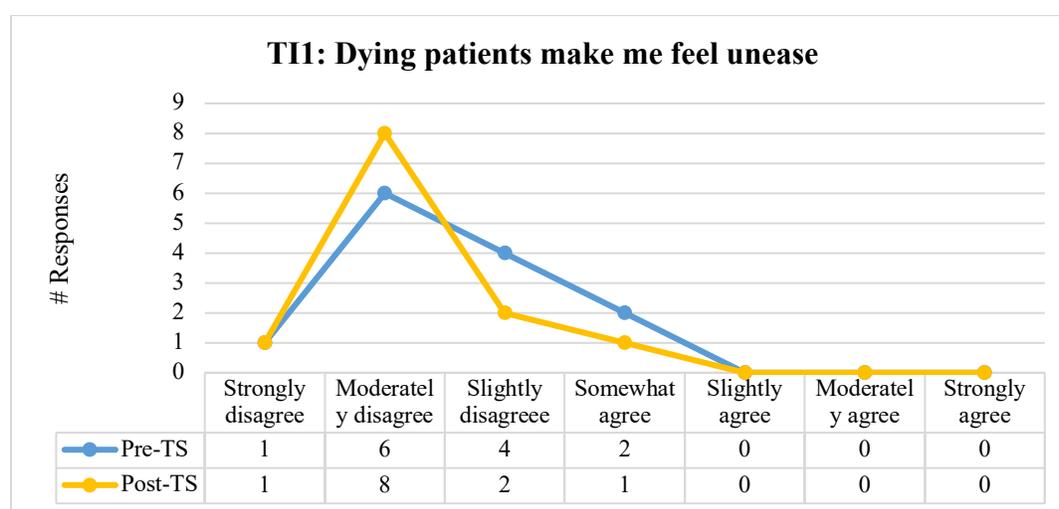
The Thanatophobia Scale measures one's feelings associated with the fear of death and addresses an individual's feelings of discomfort associated with death and dying. It is designed to assess one's attitudes and expected outcomes of providing care for palliative care patients (Mason & Ellershaw, 2004). Greater cumulative scores indicate more negative attitudes and perceived outcomes than lower cumulative scores.

**TI 1. Dying patients make me feel uneasy.** One participant (8%) reported strongly disagreeing with the statement that dying patients make them feel uneasy in both the pre- and post-TI. Initially, six participants (38%) reported moderately disagreeing and increased to eight participants (62%) in the post-TI. Four participants (31%) initially reported slightly disagreeing with the statement and decreased to two participants (15%). Two participants (15%) initially

reported feeling somewhat unease with dying patients and decreased to one participant (8%) in the post-TI. None of the participants reported feeling strongly, moderately, or slightly agreeable to the statement that dying patients make them feel unease in both the pre- and post-TI (see Graph 24). The average pre-TI score was 2.54 and average post-TI score was 1.31. There was a 48.4% decrease in discomfort in caring for dying patients.

### Graph 24

*TI 1: Dying patients make me feel unease.*

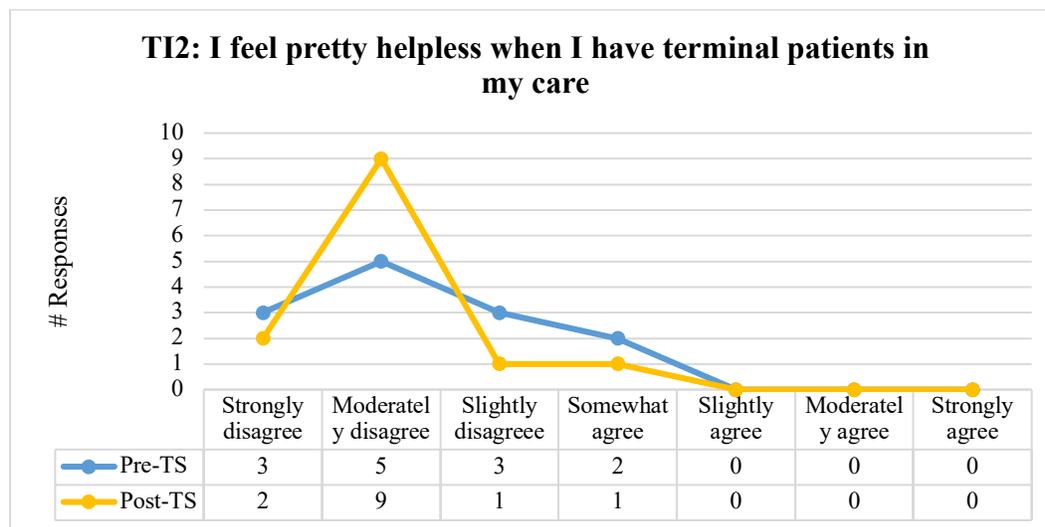


**TI2. I feel pretty helpless when I have terminal patients in my care.** Three participants (23%) initially disagreed with the statement of feeling pretty helpless when having terminal patients in their care in comparison to two participants (15%) on the post-TI. Five participants (38%) initially moderately disagreed with the statement and increased to nine participants (69%) on the post-TI. Three participants (23%) initially slightly disagreed with the statement and decreased to one participant (8%) in the post-TI. None of the participants reported feeling strongly, moderately, or slightly agreeable to the statement that they feel pretty helpless with terminal patients in their care, in both the pre- and post-TI (see Graph 25). The average pre-

TI score was 2.31 and average post-TI score was 2.08. There was a decrease of 10% in feelings of helplessness when caring for a terminally ill patient.

### Graph 25

TI2: *I feel pretty helpless when I have terminal patients in my care.*

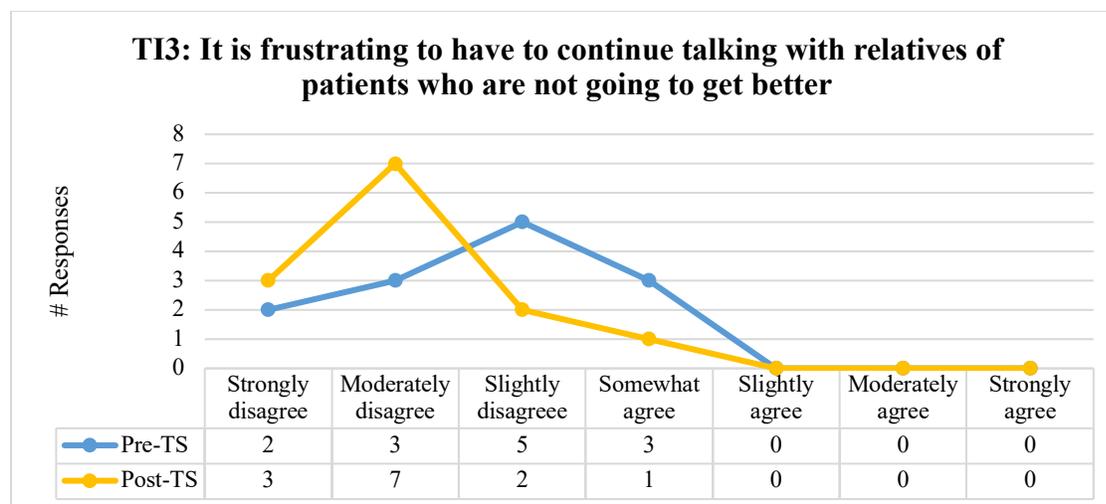


**TI3. It is frustrating to have to continue talking with relatives of patients who are not going to get better.** Two participants (15%) initially strongly disagreed with the statement that it is frustrating to have to continue talking with relatives of patients who are not going to get better with an increase to three participants (23%) in the post-TI. Three participants (23%) initially reported moderately disagreeing with the statement with an increase to seven participants (54%) in the post-TI. Five participants (38%) slightly disagreed with the statement and decreased to two participants (15%) in the post-TI. Three participants (23%) somewhat agreed with the statement and decreased to one participant (8%) in the post-TI. None of the participants slightly agreed, moderately agreed, or strongly agreed with the statement that it is frustrating to have to continue talking with relatives of patients who are not going to get better in both pre- and post-TI (see Graph 26). The average pre-TI score was 2.69 and average post-TI

score was 2.08. There was a decrease of 22.7% when it came to feelings of frustration when talking with relatives of patients who are not going to get better.

### Graph 26

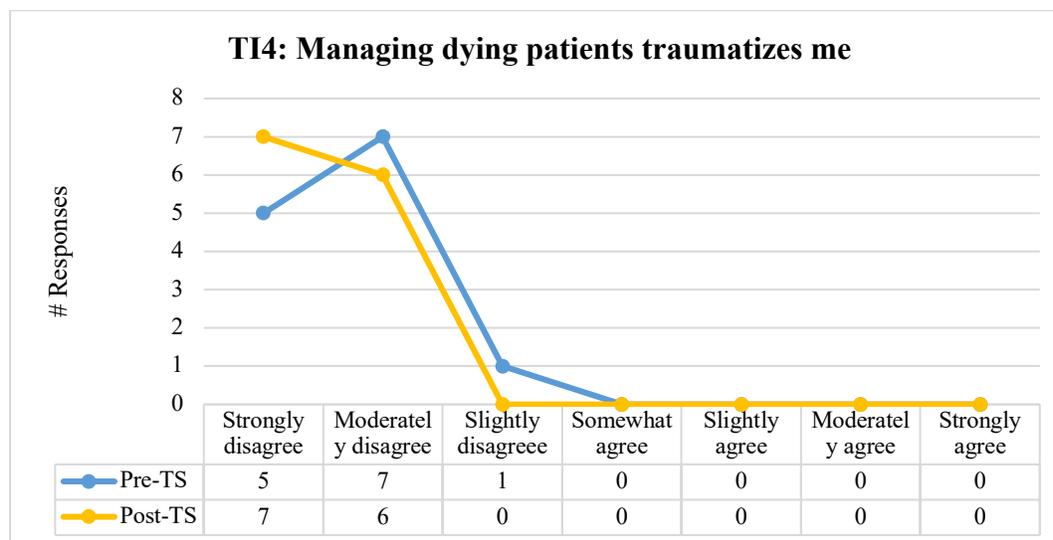
*TI3: It is frustrating to have to continue talking with relatives of patients who are not going to get better.*



**TI4. Managing dying patients traumatizes me.** Initially, five participants (38%) reported strongly disagreeing with the statement that managing dying patients is traumatizing whereas seven participants (54%) reported so in the post-TI. Seven participants (54%) initially moderately disagreed with the statement and decreased to six participants (46%). One participant (8%) initially slightly disagreed with the statement and none of the participants reported so on the post-TI. None of the participants slightly agreed, moderately agreed, or strongly agreed with the statement that managing dying patients is traumatizing, in both pre- and post-TI (see Graph 27). The average pre-TI score was 1.69 and average post-TI score was 1.46. This represents a 13.6% decrease in feelings of traumatization when managing dying patients.

## Graph 27

TI4: *Managing dying patients traumatizes me.*

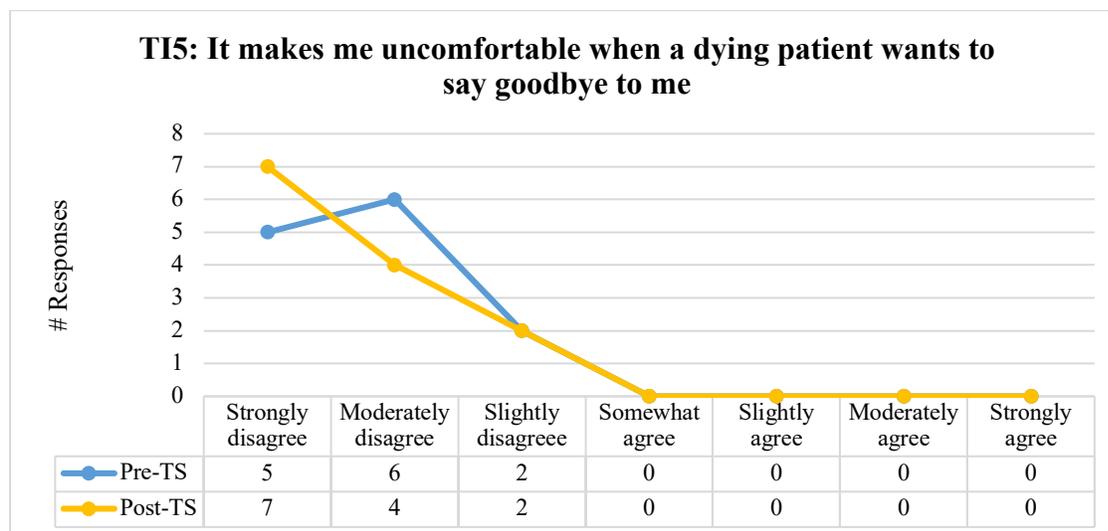


### TI5. It makes me uncomfortable when a dying patient wants to say goodbye to me.

Five participants (38%) initially reported strongly disagreeing with the statement that it is uncomfortable when a dying patient wants to say goodbye and increased to seven participants (54%) in the post-TI. Six participants (46%) initially responded that they moderately disagree with the statement and decreased to four participants (31%) in the post-TI. Two participants responded that they slightly disagree with the statement in both the pre- and post-TI. None of the participants somewhat agreed, slightly agreed, moderately agreed, or strongly agreed with the statement that it is uncomfortable when a dying patient wants to say goodbye, in both pre- and post-TI (see Graph 28). The average pre-TI score was 1.77 and average post-TI score was 1.62, which represents an 8.5% decrease in discomfort when a dying patient wants to say goodbye.

## Graph 28

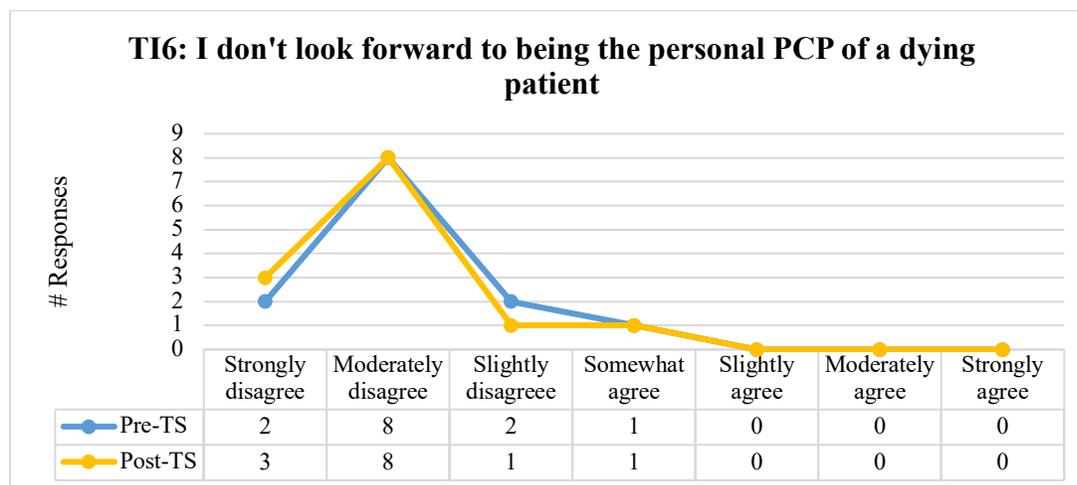
TI5: *It makes me uncomfortable when a dying patient wants to say goodbye to me.*



**TI6. I don't look forward to being the personal PCP of a dying patient.** Initially, two participants (15%) strongly disagreed with the statement that they do not look forward to being the personal PCP of a dying patient. Responses increased to three participants (23%) who strongly disagreed with this statement in the post-TI. Eight participants (62%) moderately disagreed with this statement in the pre- and post-TI. Two participants (15%) slightly disagreed with this statement and decreased to one participant (8%) in the post-TI. One participant (8%) somewhat agreed with this statement in both the pre- and post-TI. None of the participants slightly agreed, moderately agreed, or strongly agreed that they do not look forward to being the personal PCP of a dying patient (see Graph 29). The average pre-TI score was 2.15 and average post-TI score was 2.0. There was a 7.0% decrease in feelings of discomfort when it came to being the personal PCP of a dying patient.

## Graph 29

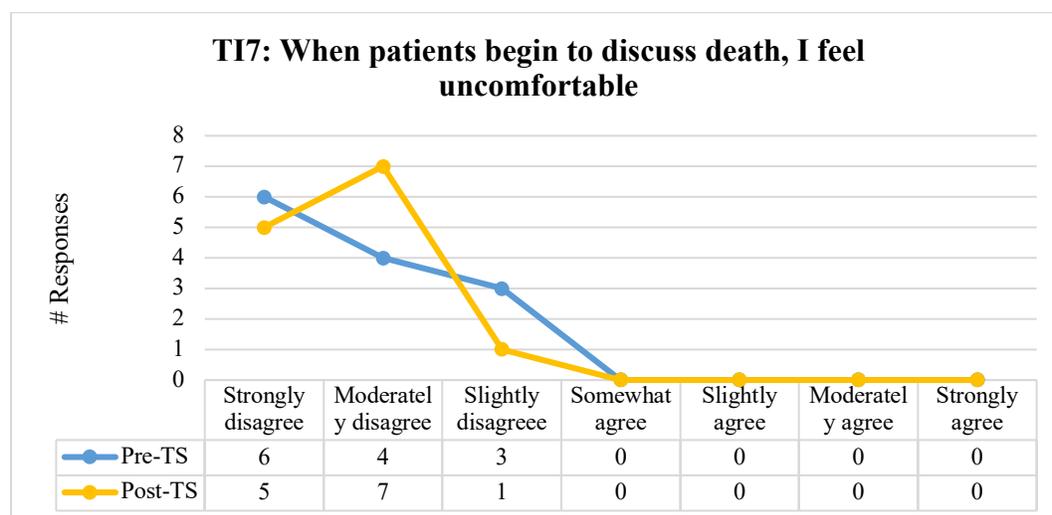
TI6: *I don't look forward to being the personal PCP of a dying patient.*



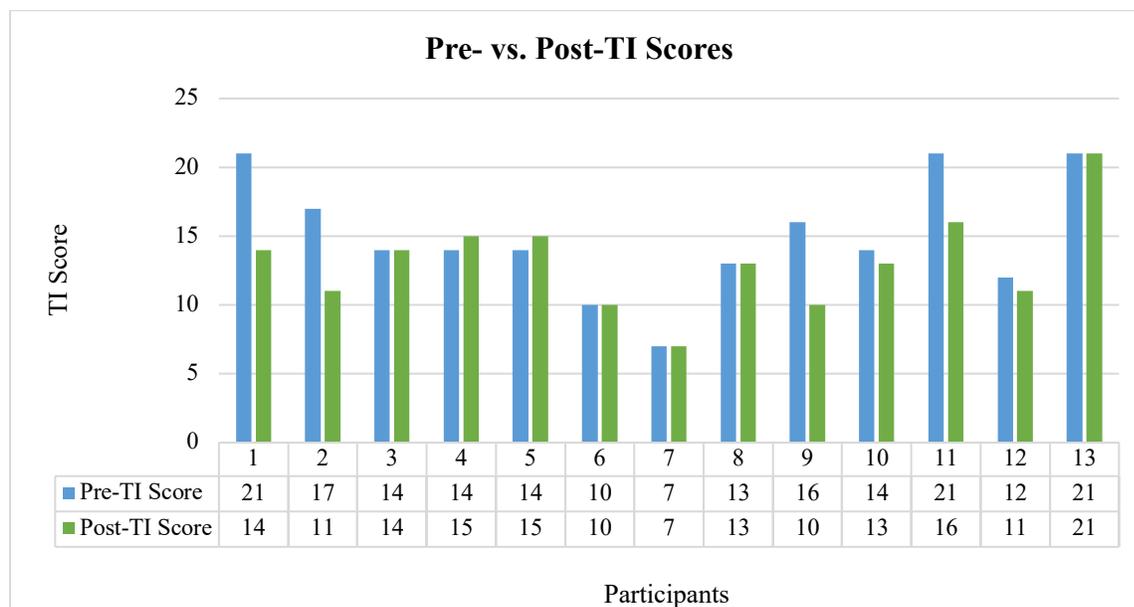
**TI7. When a patient begins to discuss death, I feel uncomfortable.** Initially, six participants (38%) strongly disagreed with the statement of feeling uncomfortable when a patient begins to discuss death, which decreased to five participants (38%) in the post-TI. Four patients initially moderately disagreed with this statement and increased to seven participants (54%) in the post-TI. Three participants (23%) slightly disagreed with the statement initially and decreased to one participant (8%). None of the participants somewhat agreed, slightly agreed, moderately agreed, or strongly agreed with the statement (see Graph 30). The pre-TI score was 1.77 and post-TI score was 1.69. There was a decrease of 4.5% of feelings of discomfort when patients discuss death after completing the “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020) education module.

### Graph 30

TI7: When a patient begins to discuss death, I feel uncomfortable.



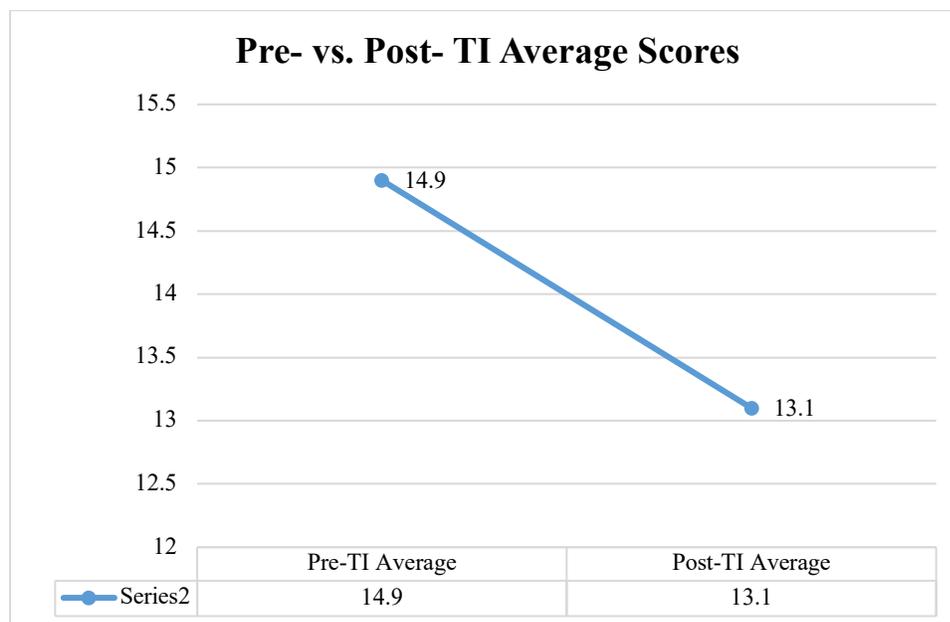
**Pre- vs. Post-TI Scores.** Of the thirteen participants, six participants (46%) had a decrease in TI scores. Five participants (38%) did not have any change in TI scores and two participants (23%) had an increase in TI score by one point. See Graph 31 below.

**Graph 31***Pre- vs. Post-TI Scores*

The pre-TI average score for all thirteen participants was 14.9. The post-TI average score was 13.1. The average score decreased by 1.8 points. Lower TI scores are associated with more positive attitudes and perceived outcomes of dying patients. See Graph 32 below.

## Graph 32

*Pre- vs. Post-TI Average Scores*



## Results – Qualitative Feedback

In the EOL Conversations: Quality Assurance in EOL Conversations Through Continuing Education Post-Survey, participants were asked to evaluate the module and provide feedback on the project. Responses from participants are depicted in the table below (Table 2).

**Table 2**

*EOL Conversations: Quality Assurance in EOL Conversations Through Continuing Education*

*Post-Survey Evaluation*

Evaluation Question	Feedback
What did you find most helpful about the module?	<ul style="list-style-type: none"> <li>• “It was straight forward and helped plan out delivering bad news.”</li> <li>• “The interactive interview activity with the patient, ‘Derick’ was helpful.”</li> <li>• “I appreciated being made to select both answers in the dialogue to see why the answer was correct or incorrect.”</li> <li>• “Following a set protocol makes these discussions easier.”</li> <li>• “The aspect of having a structured tool that could be used to deliver bad news was helpful.”</li> </ul>

	<ul style="list-style-type: none"> <li>• “The SPIKES framework and tools.”</li> <li>• “The SPIKES model is taught as part of the medical school curriculum. It was a good review. Good to review examples of phrases to use to validate patients’ emotions.”</li> <li>• “Step-by-step explanation of how to best implement SPIKES.”</li> <li>• “The different scenarios and example responses.”</li> <li>• “Case studies”</li> <li>• “Using the mnemonic makes it easy to remember the steps to take when talking with patients about bad news.”</li> <li>• “Examples of conversations about palliative care and how to respond to patient’s inquiries.”</li> <li>• “It broke down the SPIKES in a simple and understandable manner.”</li> </ul>
<p>What did you find least helpful about the module?</p>	<ul style="list-style-type: none"> <li>• Six (46%) of the 13 participants wrote “N/A”</li> <li>• “Overall, I think all the information was valid and helpful”</li> <li>• “All components of the module were helpful”</li> <li>• “It would have been better if it was a PowerPoint”</li> <li>• “I felt the videos throughout the video were least helpful, as I preferred reading through the information and completing the interactive activity”</li> <li>• “The short video snippets giving the definitions was not necessary”</li> <li>• “Nothing about EOL treatment”</li> </ul>
<p>What did you find most important and applicable to your practice as a PCP?</p>	<ul style="list-style-type: none"> <li>• “It will help me prepare so that patients are not feeling rushed when they have bad news.”</li> <li>• “I found the methods in how to enter the conversations to deliver the bad news helpful. These methods would be taking into consideration patients’ perceptions of what they know about their situation and allowing them to tell you how much or little they want to know about the ‘bad news.’ I didn’t take these things into consideration before this module.”</li> <li>• “I like the acronym – SPIKES. PDF handout as a reminder is also helpful.”</li> <li>• “Ways to communicate with patients using this protocol.”</li> <li>• “The takeaway for me was the invitation portion of ‘SPIKES.’”</li> </ul>

	<ul style="list-style-type: none"> <li>• “EOL discussions are inevitable as a PCP caring for adults.”</li> <li>• “SPIKES was useful during residency training in both in the inpatient and outpatient setting and was good practice for my current work as a PCP”</li> <li>• “SPIKES is a great strategy that I will try to follow in my practice”</li> <li>• “Exploring patient and family’s understanding of current disease process/progression”</li> <li>• “Strategy emphasizing patient point of view”</li> <li>• “The ‘S’ in SPIKES, preparing to deliver the bad news”</li> <li>• “Having a protocol helps me feel more confident and helps me feel more confident in delivering difficult news. Knowing how to initiate conversations about EOL with patients and family.”</li> <li>• “PCPs deal with a lot of elderly patients and discussing code status is a regular discussion”</li> </ul>
What was missing from the module?	<ul style="list-style-type: none"> <li>• 8 participants (62%) wrote “N/A”, 1 participant (8%) wrote, “Nothing that I can think of”, 1 participant (8%) wrote, “The module was complete as an introduction to the SPIKES framework”</li> <li>• “Maybe an example of how to deal with a family who is in denial and other difficult situations”</li> <li>• “Real-life interview/example of a ‘bad news’ conversation”</li> <li>• “More interaction”</li> </ul>
Feedback or Comments	<ul style="list-style-type: none"> <li>• 11 participants (85%) wrote “N/A”</li> <li>• “Great that the module was short, engaging, and informative.”</li> <li>• “Excellent modules.”</li> </ul>

## **Chapter 5: Recommendations and Conclusions**

### **Explanation of How the Theoretical Framework Guided Outcome Evaluation**

The Knowles' Principles of Andragogy was applied to this project and outcome evaluation because it is a theory based on the art and science of adult learning. The four components of the theory that are applied to adult learning include: the involvement of adult learners, adult learners' past experiences, the relevance and impact to learners' lives, and problem-centered learning. When evaluating this project, it was essential to include all four components of Knowles' Theoretical Framework.

Because the EOL Conversations project was self-paced and voluntary, participants were what Knowles' (1978) called "involved adult learners." They took the initiative to complete the pre- and post-surveys and scales as well as complete the module on their own time. The adult learners were thus involved in the planning and evaluation of their own learning. This resulted in thirteen participants returning their surveys and pre- and post- PCSE and TI in a timely manner.

Participants were also asked to draw upon previous EOL discussions and breaking difficult news to patients, which was the second component of Knowles' Principles of Andragogy. When going through the module and completing the pre- and post-surveys, participants reflected on previous experiences and what they learned from them as well as how they could improve on their skills or lack thereof. This portion of the Knowles' Theoretical Framework was applied to the pre- and post-surveys, pre- and post- PCSE and TI scales, and "SPIKES: A Six-Step Protocol for Delivering Bad News" (2020) education module. It was especially applicable to the questions that asked about one's confidence in EOL conversations and applicability of strategies learned. The third component of Knowles' Theoretical Framework

posits that adults are more interested in learning about subjects that have relevance and impact to their lives and personal lives. Participants were asked about the applicability of EOL conversations and strategies as well as how many EOL conversations they have had in the past 12 months. The End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education post-survey assessed the relevance and impact of the module and strategies learned to one's current and future practice.

Finally, the fourth component, which posits that adult learning is problem-centered rather than content-oriented, was applied to the pre- and post- PCSE and TI as well as the "SPIKES: A Six-Step Protocol for Delivering Bad News" (2020) education module. The participants noted in the End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education pre-survey the applicability of EOL strategies, which was reassessed with the End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education post-survey.

The overall goal of this project was to increase the confidence of providers in both difficult and EOL conversations. Knowles' Principles of Andragogy were used to evaluate the aims and objectives because the project targeted adult learners who are primary care-trained providers. The project's strengths and limitations as well as implications for practice will be further discussed in this chapter.

## **Discussion of Data Linked to Specific Aims and Objectives**

### ***Aim One***

The first aim of this project was to determine providers' knowledge and confidence levels of using evidence-based communication strategies for sharing difficult news with patients.

**Objective 1:** The first objective was to obtain baseline comfort and confidence levels of providers with the use of a pre-survey. Participants completed the End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education pre-survey. At baseline, one participant felt moderately unconfident in their ability to apply EOL strategies into practice, six participants felt somewhat confident, five participants felt moderately confident, and one participant felt very confident. The average TI score of the thirteen participants was 14.9, which indicated slightly low Thanatophobia overall.

**Objective 2:** The second objective was to obtain information on how applicable EOL conversations are to the participant's current practice. One participant (8%) reported that EOL care knowledge and competence was somewhat applicable to their practice, three participants (23%) noted it to be moderately applicable, and nine participants (69%) noted it to be very applicable. For the most part, participants believed EOL conversation strategies and knowledge to be applicable to their practice.

### ***Aim Two***

The second aim of the project was to educate primary care-trained providers on evidence-based techniques to initiate and conduct EOL conversations with patients and family members through an online education module, which took approximately 45 minutes to complete.

**Objective 1:** The first objective was to recruit primary care-trained providers to participate in the EOL Conversations project. A total of thirteen participants responded to the flyer distributed to clinics in the County of Hawai'i.

**Objective 2:** The second objective was to implement the EOL Conversation online education module. Participants were recruited in the second week of December 2021 and had

until the third week of February to complete the pre- and post-surveys as well as the “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020) education module.

### ***Aim Three***

The third aim of this project was to evaluate the effectiveness of the “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020) education module.

**Objective 1:** The first objective was to assess participants’ likelihood of applying SPIKES (2020) strategies. The participants completed the End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education post-survey, which asked participants to rate the likelihood of applying the “SPIKES: A Six-Step Protocol for Delivering Bad News” strategies into their practice. One participant (8%) reported they were somewhat likely to apply the strategies learned, one participant (8%) reported being moderately likely to apply the strategies, and eleven participants (85%) reported being very likely to apply the strategies learned. Therefore, the majority of participants reported to be very likely to apply the “SPIKES: A Six-Step Protocol for Delivering Bad News” strategies in their current practice.

**Objective 2:** The second objective was to evaluate participants’ confidence in initiating EOL conversations and making changes in their practice. Participants completed the End-of-Life Conversations: Quality Assurance in EOL Conversations Through Continuing Education post-survey and one participant (8%) reported feeling somewhat confident applying EOL strategies into their practice. Six participants (46%) felt moderately confident, and six participants (46%) reported feeling very confident applying EOL strategies into practice. There was an overall increase in confidence in participants in utilizing EOL strategies. Pre- and post-TS average scores decreased from 14.9 to 13.1, indicating a decrease in thanatophobia and uncertainty when working with dying patients. There was an overall increase in average PCSE

scores for each question, after completing the “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020) online module. This indicates an increase in confidence in working with and caring for dying patients and their family members. The improvement in both PCSE and TI scores indicate an improvement in knowledge and confidence in EOL strategies, skills, and application in practice.

### **Implications for Practice**

Since completing the EOL Conversations project, participants have new knowledge and skills on EOL conversations to utilize and incorporate in their practice as providers. Participants felt more confident and competent to engage in difficult conversations with patients and to manage the care of dying patients. Participants noted the importance of understanding the patient’s perspectives and setting time aside prior to initiating EOL conversations. Furthermore, participants noted to very likely apply the strategies learned into their current practice. This will greatly improve the quality of life and care of patients and families who either require palliative care or EOL care.

The “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020) online module is available online until June 2022 and allows providers to both gain new skills and review knowledge on EOL conversations. Participants have also requested to share the module with fellow colleagues, which is encouraging because it increases the knowledge and skillset of providers when it comes to initiating and engaging in difficult conversations.

The positive results of this project highlight the importance of teaching new providers EOL conversation skills as well as reviewing these essential concepts regularly to continue feeling comfortable and confident in one’s ability to have such conversations. Perhaps more programs can incorporate EOL conversation material in their curriculum to better prepare

providers for such situations and provide insight and experience on an inevitable topic. Difficult conversations do not have to be intimidating or avoided if one feels confident in their capabilities and approaches.

### **Project Strengths**

One of the strengths of this project was its accessibility. Because it was web-based, providers had the opportunity to access it on their own time and continue to have access to the “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020) online module. Furthermore, a larger population could have been utilized in the project because of its accessibility. More providers can continue to have access to the “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020) online module for future use given its user-friendliness and availability. Another strength of this project was the knowledge and confidence gained by participants. Participants remarked on how much they learned and how they will apply it to their current practices.

### **Project Limitations**

One of the limitations of this project was the small sample size of thirteen providers. Providers were contacted electronically via email and the project was reliant upon the participants’ internal motivation to complete the project. Although participants received 0.75 CME hours, there might have been a lack of incentive for participants’ time given to the project. Another possibility for the small sample size was the time constraints of participants, who may have had other tasks or responsibilities to complete during that particular six-week period in January and February.

### **Dissemination Plans**

The project findings should be shared with nursing and medical programs as well as resident programs to promote curriculum on EOL and difficult conversations. Sharing the

findings with participants and other providers in the County of Hawai'i would also be beneficial in highlighting the importance of EOL conversations and skillsets. The final manuscript for this project will be submitted to the University of Hawai'i at Hilo's Institutional Repository (HOKU), for future reference by the public.

### **Conclusion and Recommendations**

Death and dying is inevitable and providers play an essential role in ensuring one's wishes are met. Patient-centered care at the end of one's life is fundamental in ensuring increased quality of life during this time. Given the improvement in provider confidence and decrease in thanatophobia after completing the "SPIKES: A Six-Step Protocol for Delivering Bad News" (2020) education module, it is clear that education on this topic is imperative. One's death and dying experience is unique to each individual and engaging in EOL conversations with patients is one way to promote high quality of life at the end of one's life. EOL discussions are daunting and often uncomfortable to engage in. However, it is one's right to live and die with autonomy and dignity. This project has shown that with the use of an evidence-based education module, providers' confidence increased as well as the likelihood of utilizing EOL conversation strategies. Continuing to provide education to providers, both new and experienced, is essential in promoting high quality and patient centered EOL care.

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Appendix A  
**End-of-Life Conversations:  
 Quality Assurance in EOL Conversations Through Continuing Education**

Pre-Survey

1. What is your license type?
  - A. APRN
  - B. M.D.
  - C. D.O.
  - D. PA
  
2. How many years have you been practicing?
  - A. 0-4 years
  - B. 5-10 years
  - C. 11-15 years
  - D. 16 years and over
  
3. In the past 12 months, how many EOL conversations have you had with patients?
  - A. 0-5
  - B. 6-10
  - C. 11-15
  - D. 16 and over
  
4. On a scale from 1 to 5, where 1 is “very unapplicable” and 5 is “very applicable,” how applicable is end-of-life care knowledge and competence in your current practice?
 

1	2	3	4	5
Very unapplicable		Somewhat applicable		Very applicable
  
5. On a scale from 1 to 5, where 1 is “very unconfident” and 5 is “very confident,” how would you rate your confidence in applying end-of-life strategies into your practice?
 

1	2	3	4	5
Very unconfident		Somewhat confident		Very confident

Appendix B  
**Palliative Care Self-Efficacy (PCSE) Scale**

**Palliative care confidence**

Please rate your degree of confidence with the following patient / family interactions and patient management topics, by ticking the relevant box below

1 = Need further basic instruction	2 = Confident to perform with close supervision / coaching
3 = Confident to perform with minimal consultation	4 = Confident to perform independently

No	Patient/family interactions and clinical management	1	2	3	4
1	Answering patients' questions about the dying process				
2	Supporting the patient or family member when they become upset				
3	Informing people of the support services available				
4	Discussing different environmental options (eg hospital, home, family)				
5	Discussing patient's wishes for after their death				
6	Answering queries about the effects of certain medications				
7	Reacting to reports of pain from the patient				
8	Reacting to and coping with terminal delirium				
9	Reacting to and coping with terminal dyspnea (breathlessness)				
10	Reacting to and coping with nausea / vomiting				
11	Reacting to and coping with reports of constipation				
12	Reacting to and coping with limited patient decision-making capacity				

Phillips, J., Salamonson, Y., & Davidsons, D.M. (2011). An instrument to assess nurses' and care assistants' self-efficacy to provide a palliative care approach to older people in residential aged care: A validation study. *International Journal of Nursing Studies*, 48(9), 1096-1100.

Appendix C  
**Thanatophobia Instrument**

Please circle the number that corresponds to how strongly you agree or disagree with the following statements. Circle the number that correlates to how you think you would feel regarding the issues and situations presented below:

1. Dying patients make me feel unease

1	2	3	4	5	6	7
Strongly disagree			Somewhat agree			Strongly agree

2. I feel pretty helpless when I have terminal patients in my care

1	2	3	4	5	6	7
Strongly disagree			Somewhat agree			Strongly agree

3. It is frustrating to have to continue talking with relatives of patients who are not going to get better

1	2	3	4	5	6	7
Strongly disagree			Somewhat agree			Strongly agree

4. Managing dying patients traumatizes me

1	2	3	4	5	6	7
Strongly disagree			Somewhat agree			Strongly agree

5. It makes me uncomfortable when a dying patient wants to say goodbye to me

1	2	3	4	5	6	7
Strongly disagree			Somewhat agree			Strongly agree

6. I don't look forward to being the personal PCP of a dying patient

1	2	3	4	5	6	7
Strongly disagree			Somewhat agree			Strongly agree

7. When patients begin to discuss death, I feel uncomfortable

1	2	3	4	5	6	7
Strongly disagree			Somewhat agree			Strongly agree

Merrill, J., Lorimor, R., Thornby, J., Woods, A. (1998). Caring for terminally ill persons: comparative analysis of attitudes (thanatophobia) of practicing physicians, student nurses, and medical students. *Psychological Reports*, 83(1), 123-128.

According to the *Psychological Reports Journal/Sage* webpage on journal permissions, journal permission for reuse is not necessary for this PIP, since it will not be hosted on a commercial platform (<https://us.sagepub.com/en-us/nam/journals-permissions>).

Appendix D  
Recruitment Flyer



**END-OF-LIFE CONVERSATIONS**

**THE PURPOSE OF THIS STUDY IS TO IMPROVE PROVIDERS' CONFIDENCE AND COMPETENCE IN INITIATING DIFFICULT CONVERSATIONS THROUGH AN ONLINE EDUCATION MODULE.**

Paige Sumida, BSN, CMSRN, would like to invite you to participate in a practice inquiry project.

Participants will complete the following:

- A pre-survey to evaluate their confidence in initiating end-of-life conversations with patients and their families.
- A 45-minute online educational module with tools to equip them for these difficult conversations. This can be done at ones' own pace.
- A post-survey and evaluation of ones' confidence after the online modules to assess the impact of the educational tool.

\* All participants will receive 0.75 CME hours for completing the online module

Are you a practicing  
Primary Care Provider?

Are you confident in your  
ability to engage in  
difficult conversations?

Would you like to  
improve your skills in  
initiating end-of-life  
conversations with  
patients?

**IF YOU ARE INTERESTED  
IN THIS STUDY OR  
WOULD LIKE MORE  
INFORMATION, PLEASE  
CONTACT:**

Paige Sumida  
808-896-1224

## Appendix E

**End-of-Life Conversations:  
Quality Assurance in EOL Conversations Through Continuing Education**

Post-Survey

1. Did you complete the entire education module?
  - A. Yes
  - B. No
    - a. If you answered no, can you please explain why? \_\_\_\_\_
  
2. On a scale from 1 to 5, where 1 is “very unapplicable” and 5 is “very applicable,” how applicable is end-of-life care knowledge and competence in your current practice?
 

1	2	3	4	5
Very unapplicable		Somewhat applicable		Very applicable
  
3. After completing this module, on a scale from 1 to 5, where 1 is “very unconfident” and 5 is “very confident,” how would you rate your confidence in feel in applying end-of-life strategies into your practice?
 

1	2	3	4	5
Very unconfident		Somewhat confident		Very confident
  
4. On a scale from 1 to 5, were 1 is “very unlikely” and 5 is “very likely,” how likely are you to apply the strategies provided in the “SPIKES: A Six-Step Protocol for Delivering Bad News” (2020) educational module to your practice when discussing end-of-life care with your patients?
 

1	2	3	4	5
Very unlikely		Somewhat likely		Very likely



## Appendix F

### Permission to use PCSE Scale



Paige Sumida &lt;psumida@hawaii.edu&gt;

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**Re: Obtain permission request - Journal (1205118) [210921-007739]**

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Rights and Permissions (ELS) <Permissions@elsevier.com>  
Reply-To: "Rights and Permissions (ELS)" <Permissions@elsevier.com>  
To: psumida@hawaii.edu

Wed, Sep 22, 2021 at 2:06 AM

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## Appendix G



Completion Date 08-Mar-2021  
Expiration Date 07-Mar-2024  
Record ID 41527643

This is to certify that:

**Paige Sumida**

Has completed the following CITI Program course:

Not valid for renewal of certification  
through CME.

**Human Subjects Research (HSR)**

(Curriculum Group)

**Non-Exempt Social & Behavioral Sciences Researchers and Key Personnel**

(Course Learner Group)

**1 - Basic Course**

(Stage)

Under requirements set by:

**University of Hawaii**

**CITI**  
Collaborative Institutional Training Initiative

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## Appendix H



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SYSTEM

Office of Research Compliance  
Human Studies Program

**DATE:** November 04, 2021

**TO:** Van Hoose, Diane, PhD, MSN, BA,  
ADN, University of Hawaii at Hilo,  
School of Nursing  
Daub, Katharyn, University of Hawaii at  
Hilo, School of Nursing, Sumida, Paige,  
BSN, University of Hawaii at Hilo,  
School of Nursing

**FROM:** Rivera, Victoria, Dir, Ofc of Rsch  
Compliance, Social&Behav Exempt  
End-of-Life Conversations: Improving  
Providers ' Competence in EOL  
Conversations Through an Education  
Module

**PROTOCOL TITLE:**

**FUNDING SOURCE:** None

**PROTOCOL NUMBER:** 2021-00881

**APPROVAL DATE:** November 04, 2021

#### NOTICE OF APPROVAL FOR HUMAN RESEARCH

This letter is your record of the Human Studies Program approval of this study as exempt.

On November 04, 2021, the University of Hawaii (UH) Human Studies Program approved this study as exempt from federal regulations pertaining to the protection of human research participants. The authority for the exemption applicable to your study is documented in the Code of Federal Regulations at 45 CFR 46.104(d) 3.

Exempt studies are subject to the ethical principles articulated in The Belmont Report, found at the OHRP Website [www.hhs.gov/ohrp/humansubjects/guidance/belmont.html](http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html).

Exempt studies do not require regular continuing review by the Human Studies Program. However, if you propose to modify your study, you must receive approval from the Human Studies Program prior to implementing any changes. You can submit your proposed changes via the UH eProtocol application. The Human Studies Program may review the exempt status at that time and request an application for approval as non-exempt research.

In order to protect the confidentiality of research participants, we encourage you to destroy private information which can be linked to the identities of individuals as soon as it is reasonable to do so. Signed consent forms, as applicable to your study, should be maintained for at least the duration of your project.

2425 Campus Road, Sinclair 10  
Honolulu, HI 96822  
Telephone: (808) 956-5007 • Fax: (808) 956-9150  
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## Appendix I

## Consent to Participate in Practice Inquiry Project



**University of Hawai'i**  
**Consent to Participate in a Research Project**

Paige Sumida, Principal Investigator

*End-of-Life Conversations: Improving Providers' Competence in EOL Conversations Through an Online Education Module*

Aloha! My name is Paige Sumida, and you are invited to take part in a Practice Inquiry Project (PIP). I am a graduate student at the University of Hawai'i at Hilo School in the Doctor of Nursing Program. As part of the requirements for earning my graduate degree, I am doing a project inquiry.

***What am I being asked to do?***

If you participate in this project, you will be asked to complete a pre-survey to test your knowledge on end-of-life (EOL) care resources and conversations, complete a 45 minute online educational module, and complete a post-survey to assess your confidence, competence, and understanding of end-of-life care conversations.

***Taking part in this study is your choice.***

Your participation in this project is completely voluntary. You may stop participating at any time. If you stop being in the study, there will be no penalty or loss to you.

***Why is this study being done?***

The purpose of my project is to evaluate the effectiveness of EOL education modules on primary care providers' confidence and competence in EOL conversations.

***What will happen if I decide to take part in this study?***

The pre-survey will consist of 5 multiple choice questions. It will take 5 minutes to complete. The survey questions will include questions like, "What is your general practice type?", "What would you rate your confidence in EOL care as?" You will also complete a 12-question Palliative Care Self-Efficacy (PCSE) scale and 7-question Thanatophobia Instrument (TI). The "SPIKES: A Six-Step Protocol for Delivering Bad News" (2020) education module that will take approximately 45-minutes to complete online. It will provide EOL care education and strategies to implement in your practice. The post-survey will consist of 9 multiple choice, and open ended questions and will take 10 minutes to complete. It will include questions like, "What would you rate your current confidence in EOL conversations?" You will complete the PCSE and TI scales once again after completing the module.

***What are the risks and benefits of taking part in this study?***

I believe there is little risk to you for participating in this research project. You may become stressed or uncomfortable answering any of the survey questions. If you do become stressed or

uncomfortable, you can skip the question or take a break. You can also stop taking the survey or you can withdraw from the project altogether.

The direct benefit to you for participating in this survey may include increased knowledge in this topic and increased competence in EOL conversations. The results of this project may help improve your confidence and competence when engaging in EOL conversations with patients and their family members.

***Privacy and Confidentiality:***

I will not ask you for any personal or identifiable information, such as your name or address. Please do not include any personal information in your survey responses. I will keep all study data secure in an encrypted on a password protected computer. Only my University of Hawai'i advisor and I will have access to the information. Other agencies that have legal permission have the right to review research records. The University of Hawai'i Human Studies Program has the right to review research records for this study.

***Compensation:***

Participants will receive 0.75 CME hours upon completion of the online education module.

***Future Research Studies:***

Identifiers will be removed from your identifiable private information and after removal of identifiers, the data from this project will not be used for future research studies or distributed to another investigator for future research studies.

***Questions:***

If you have any questions about this study, please call or email me at (808) 932-7067 & [psumida@hawaii.edu](mailto:psumida@hawaii.edu). You may also contact my faculty advisor, Dr. Diane Van Hoose, at (808) 932-7067 & [diane@hawaii.edu](mailto:diane@hawaii.edu). You may contact the UH Human Studies Program at (808) 932-5007 or [uhirb@hawaii.edu](mailto:uhirb@hawaii.edu) to discuss problems, concerns, and questions, obtain information, or offer input with an informed individual who is unaffiliated with the specific research protocol. Please visit <http://go.hawaii.edu/jRd> for more information on your rights as a research participant.

Filling out the survey will be considered your consent to participate in this study.

Please keep a copy of the consent form for your records.

**Signature(s) for Consent:**

I give permission to join the project entitle, “*Provider Education on End-of-Life Discussions.*”

**Name of Participant (Print):** \_\_\_\_\_

**Participant’s Signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_

Mahalo!