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Descriptive, Comparative, and Correlational Study Related to End-of-Life Care Prior to the Covid-19 Pandemic Outbreak (Time 1) and 12 Months Following Lockdown (Time2)

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DESCRIPTIVE, COMPARATIVE, AND CORRELATIONAL STUDY RELATED TO END-OF-LIFE CARE PRIOR TO THE COVID-19 PANDEMIC OUTBREAK (TIME 1) AND 12 MONTHS FOLLOWING LOCKDOWN (TIME 2)

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The Barbara H. Hagan School of Nursing and Health Sciences

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In Partial Fulfillment of the Requirements

For the degree of

Doctor of Philosophy

by

Elizabeth Infante

Veronica D. Feeg, Dissertation Supervisor

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Molloy College

The dissertation committee of the Barbara H. Hagan School of Nursing has
examined the dissertation titled

DESCRIPTIVE COMPARATIVE AND CORRELATIONAL STUDY RELATED TO END-OF-LIFE CARE PRIOR TO THE COVID-19 PANDEMIC OUTBREAK (TIME 1) AND 12 MONTHS FOLLOWING LOCKDOWN (TIME 2)

Presented by ELIZABETH INFANTE

A candidate for the degree of Doctor of Philosophy

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Abstract

Background

Palliative care has grown in its acceptance nationally and formed the base of a growing number of programs to provide care in a way that recognizes the importance of supporting people with chronic, debilitating, and life-limiting illnesses by focusing on “care” rather than “cure.” This special care warrants an understanding by all nurses and requires education across specialties and disciplines.

Despite the increase of palliative care services in hospitals and other settings, long-term care and home care agencies continue to struggle with the education of staff and delivery of care to clients that incorporate the central tenets of what has been defined by the Guidelines for Quality Palliative Care developed by the National Consensus Project (National Coalition for Hospice & Palliative Care, 2018). Numerous educational programs have been developed to train physicians, nurses, and others to improve communication skills, reduce pain and manage symptoms, and foster an environment that supports patients nearing death and their families.

While there has been research on the education of health care providers on palliative care, little of this research has been done in the home health care setting. To incorporate palliative care into this setting, the health care providers on the home care team need to be adequately trained to increase their comfort with and knowledge of palliative care. Some of the providers’ understanding and confusion of palliative and hospice care may need resolving, and some of their personal beliefs about end-of-life (EOL) treatment and palliative care may be barriers to their readiness to participate in a change of treatment and care goals, which may include their own fear of death or personal negative experiences with dying loved ones.

Purpose

While palliative care services are underutilized under the best circumstances, the emergence of COVID-19 has further highlighted the importance of and vital need for palliative and EOL care. Already overburdened health care systems due to COVID-19 are faced with the challenge of administering safe and effective palliative and EOL care. For this study, two time periods were anchored by the two data collection points: pre- COVID-19, referred to as TIME 1: one year prior to the outbreak of COVID-19 in New York (January 2019) and TIME 2: approximately one year after the outbreak of COVID-19 in New York (February/March 2021) when home care services had been altered by emergency and EOL care needs due to the COVID-19 pandemic. The purpose of the study is to compare and determine if correlations exist related to palliative and EOL care between Time 1 and Time 2 involving health care providers' comfort with, attitudes toward, and fear of dying. Specifically, this study examines the interprofessional home care team in a large multi-hospital system to (a) describe professionals' characteristics, comfort with and attitudes about EOL treatment and palliative care, and their fear of death at Time 1 and (b) compare them with Time 2 characteristics, comfort, attitudes, and fear of death. It also includes an examination of the relationship of these characteristics with the home care staff's self-reported professional self-confidence in EOL caregiving.

Method

This study used a descriptive, pre- and post- comparative, and correlational design of multi-professional home care providers' comfort with, attitudes toward, and fear of dying before and after Time 1 and Time 2. The pre-survey (Time 1) was used prior to the pandemic to determine which characteristics of home care providers influence their comfort with and attitudes about palliative and EOL care, and fear of dying. The post-survey (Time 2) compares these previously recorded variables with their self-reported self-confidence in EOL caregiving, an educational assessment tool in the subscales of cultural and ethical values; patient and family- centered communication; and effective care delivery.

The study sample was recruited from the roster of all professional health care providers at a large, certified home health care agency (CHHA). Participants included registered nurses (RNs), physical therapists (PTs), occupational therapists (OTs), speech therapists (STs), and medical social workers (MSWs) (n = 601) who were employed at and made home visits for the CHHA with an average daily census of 3,000 patients. The Time 1 survey was distributed in January 2019. A total of 33% of the surveyed providers responded (n = 200). The Time 2 survey was distributed to the same agency roster in April 2021; due to some attrition and some newer employees in the organization, there was some expected variation in the Time 2 sample population. This survey yielded a suitable expected sample for the proposed analysis of >180 providers.

The measures include instruments developed for the study and pre-tested for reliability including items to measure comfort (Comfort in Providing Palliative Care [CPPC]); the Collett- Lester Fear of Death Scale with reported validity and reliability, which includes four subscales: Fear of Death, Fear of Dying, Fear of Others Death, Fear of Others Dying; and F-S Hospice Scale: Views on Hospice Care to measure attitude toward hospice (Attitude Toward Hospice Scale [ATHS]). The dependent measure of the Time 2 sample is the End-of-life Professional Caregiver Survey (EPCS) instrument used frequently to assess educational needs of staff in the clinical practice domains of palliative care. The subscales include (a) Cultural and Ethical Values (CEV) (8 items), Patient and Family Centered Communication (PFCC) (12 items), and Effective Care Delivery (ECD) (8 items).

Results

The results are a descriptive analysis of all measures related to home care providers' EOL comfort, attitudes, and fear of dying; a comparative analysis of EOL comfort, attitudes, and fear of dying before and after the onset of the COVID-19 pandemic; and a regression analysis of related variables with the educational needs identified in the self-reported EPCS subscales.

Summary and Recommendations

This study explored the relationship between home health care providers' personal characteristics and their comfort with and attitudes toward hospice and palliative care, and fear of death and dying of self and others. The findings of the study yielded significant results regarding staff level of comfort, attitudes, and fear of death and dying in relation to staff personal characteristics.

The study demonstrated changes in staff comfort and attitudes toward palliative and EOL care during the onset of the pandemic. Differences were seen between Time 1 and Time 2 in staff level of comfort in discussing the dying process, attitudes toward hospice related to pain control, feelings toward fear of death (self) in the measure of death and the shortness of life, feelings of fear about dying away from others, and feelings about the dying (others) as a reminder of their own death. The study results also identified certain predictors for staff self- reported EPCS in the domains of personal characteristics, level of comfort with, and attitudes about providing EOL and palliative care services.

Further research is needed to guide future policies and programs to improve access to family-centered palliative care during a global health crisis such as the COVID-19 pandemic need to be implemented. An investment in further research and the resultant policy changes from the study findings can further support home health care workers in caring for patients and families at end of life.

Dedication

This dissertation is dedicated to my father, William Patrick Wallace. You always have been and still are “the wind beneath my wings.”

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Chapter 1: Introduction

Palliative care has grown in its acceptance nationally and formed the base of a growing number of programs to provide care in a way that recognizes the importance of supporting people with chronic, debilitating, and life-limiting illnesses by focusing on “care” rather than “cure.” Providers who are devoted to special populations with palliative care needs have learned how to assess and treat pain along with other symptoms, facilitate patient-centered decision- making and interpersonal communication, and coordinate continuity across settings as the disease trajectory waxes and wanes. Palliative care has been shown to increase longevity of life and improve quality of life for patients and their caregivers. This special care warrants an understanding by all nurses and requires education across specialties and disciplines.

The National Hospice and Palliative Care Organization (2017) defines hospice care as a team-oriented approach to pain management, spiritual and emotional support, and expert medical care for those patients facing a life-limiting illness: “At the center of hospice and palliative care is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so” (National Hospice and Palliative Care Organization, 2017, para. 1). The American Nurses Association (ANA) released a position statement in 2016 outlining the roles and responsibilities of nurses in providing End-of-Life (EOL) care and support (Nursing World, n.d.). The ANA position statement refers to the 2015 Institute of Medicine (IOM) report and its findings, dying in America: Improving Quality and Honoring Individual Preferences Near the End-of-Life. The IOM report states that currently the U.S. health care system is ill-equipped and poorly designed for meeting the needs of patients and their families facing a life-limiting illness. The system focuses on providing curative, acute care and not the pain and symptom management preferred by patients facing the EOL (Nursing World, n.d.).

According to the National Palliative Care Registry, only 3.4% of patients admitted yearly to organizations that have palliative care teams receive palliative care services when the actual need is estimated to be 7.5-8% of the patient population. This translates to 1 to 1.8 million people admitted to hospitals each year who would benefit from palliative care services but do not receive them (National

Palliative Care Registry, n.d.).

End-of-Life and Palliative Care Movement in the U.S.

More than 40 years have passed since palliative care was introduced in the United States as a result of a movement to bring hospice care to the U.S. from the United Kingdom. This effort began in 1963 with the Dean of the School of Nursing at Yale, Florence Wald, inviting Dr. Cicely Saunders to the U.S. to lecture on hospice care (Connor, 2007). The 1969 publication of Elizabeth Kubler-Ross' book On Death and Dying attracted further attention to the issue of hospice care, outlining five stages that terminally ill patients experience during their EOL journey. Kubler-Ross testified before the U.S. Senate in 1972, offering her recommendations for EOL care (Lutz, 2011). These events ultimately resulted in the first U.S. hospice founded in 1973 in Branford, Connecticut (Connor, 2007). According to Connor (2007), some have stated that hospice originated in the U.S. as an anti-physician movement. However, this was not entirely accurate, as many physicians at the time, like their colleagues, expressed concern for how the health care system was providing, or as Connor (2007) offers, not providing care for the dying.

Connor (2007) described the next steps in the evolution of hospice and palliative care in the U.S., involving national meetings held in Connecticut in 1975, New Jersey in 1977, and California in 1978, which led to the development of the National Hospice Organization (NHO). The first NHO conference took place in Washington, D.C., in 1978, resulting in the publication of the first Standards of a Hospice Program of Care. While the hospice movement began to gain worldwide acceptance in the 1970s, it was political talks surrounding hospice in the U.S that transformed hospice from a volunteer-led movement to a full-blown medical specialty. Initially a bill stating hospice services should be covered by Medicare proposed in 1974 was rejected by the U.S. Congress. Following this rejection, a U.S. government task force was formed that ultimately concluded that hospice is a feasible concept that could decrease Medicare expenses while improving EOL care.

The development of the Medicare Hospice Benefit (MHB) greatly contributed to the growth of hospice in the U.S. With this growth, there also arose an increased number of programs delivering palliative care. These programs developed separately from hospices mainly due to the hospice eligibility limitations and the need to provide palliative care to those with serious illnesses, who were not yet terminal, but in need of pain and symptom management. In 1995, a study of EOL care in teaching hospitals across the U.S. was performed. The landmark Study to Understand Prognoses and Preferences for Outcomes and Risks Treatment (SUPPORT) study "revealed that hospitalized patients often had unmet needs for pain control and that treatment wishes were often unknown or ignored, even when useful information was readily accessible to physicians and specially trained nurses were available for patients and families" (Connor, 2007, p. 93). The results of this study were shocking to many and propelled palliative care to national attention. The SUPPORT intervention, proving to have failed, became a call to action and thus palliative care became an emerging field (Mathews & Nelson, 2017). To demonstrate the blending of traditional hospice care with palliative care in the U.S., the NHO changed its name in 1999 to the National Hospice and Palliative Care Organization (NHPCO) (Connor, 2007).

Another instrumental piece in the growth of palliative care in the U.S. was the release of three significant reports by the IOM. The health arm of the National Academy of Sciences, Engineering, and Medicine, the IOM was created in 1970. It was renamed in 2016 to emphasize its focus on not only medicine but also a broader range of health matters and is currently known as the Health and Medicine Division (HMD) (National Academies of Sciences Engineering and Medicine, 2020). The first report, Approaching Death: Improving Care at the End-of-Life was first released in 1997 and addressed the dying and deaths of American adults by outlining seven recommendations (Field, 1997). Meghani and Hinds (2015) described the recommendations in their policy brief.

In brief, the 1997 recommendations were that all persons with a potentially fatal illness and those close to them should be able to expect skilled and supportive care; that all health professionals commit to improving care for dying persons and effectively preventing symptoms; that all parties involved in health care should improve methods to measure quality of life and other outcomes of dying patients and those close to them; to improve methods for financing end-of-life care; that all levels of education should prepare health professionals to care well for dying patients; that palliative care should become a defined area of expertise if not a medical specialty; that the research establishment should implement priorities that would strengthen the knowledge underlying end-of-life care; and that a public discussion be created regarding dying including care options. (p. 543)

The 2003 report, When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families offered 12 recommendations summarized by Meghani and Hinds (2015): that all pediatric health professionals and systems of care need to collaborate on creating clinical practice guidelines for palliative, end-of-life, and bereavement care; funders of care expand benefits and eliminate certain restrictions related to palliative, hospice, and bereavement care; all pediatric health professionals and care systems promote the coordination and continuity of care among providers and develop regional information programs as resources for providers and families; all pediatric institutions develop policies and procedures for involving children in talking about and deciding about care; all health professional programs collaborate with professional associations to improve the care of seriously ill children; pediatric health professionals collaborate with experts in adult palliative care; the collection of descriptive data needed to guide palliative, end-of- life, and bereavement care be funded by public and private organizations; and research priorities related to pediatric palliative, end-of-life, and bereavement care be established by all funders of pediatric research. (pp. 543-544)

In 2012 the IOM appointed a panel of 21 members from various disciplines including doctors, nurses, lawyers, health care administrators, social workers, caregivers, chaplains, epidemiologists, financial analysts, and pediatric and geriatric specialists. This committee, named the Committee on Approaching Death, was charged with completing a consensus study on the state of care of persons approaching the EOL and create recommendations for needed changes in the care of these people. The committee’s final report was released in 2015 and called Dying in America: Improving Quality and Honoring Individual Preferences Near the End-of-Life. The report was comprised of six chapters and three commissioned papers and put forth five key recommendations. The first recommendation according to Meghani and Hinds (2015), had to do with delivery of care, stating that all care delivery programs, both government and private, should cover comprehensive care for those individuals with advanced illness approaching EOL. The second recommendation offered that standards of care should be established for clinician-patient communication and advance care planning that are evidence based and both measurable and actionable. The third recommendation focused on the importance of professional education and development, ensuring that clinicians caring for those with advanced disease receive appropriate training, certification, and/or licensure. The fourth recommendation of the IOM report stressed the need for legislation supporting policies and payment systems that align with the values, preferences, and patient-centered goals of those individuals nearing EOL. Finally, the fifth recommendation centered on the education and engagement of the public to embolden them to explore advanced care planning and informed decision making regarding EOL care (Meghani & Hinds, 2015). These three IOM reports and resultant recommendations were a catalyst for the advancement of the palliative care movement in the U.S.

To actualize the goals expressed by the IOM reports and other palliative care and hospice organizations, the Guidelines for Quality Palliative Care were created by the National Consensus Project for Quality Palliative Care (NCP). The NCP is a collaboration of The American Academy of Hospice and Palliative Medicine (AAHPM – the physician membership association), The Center to Advance Palliative Care (CAPC – a palliative care advocacy and information organization), The Hospice and Palliative Nurses Association (HPNA – the nursing membership association), Last Acts Partnership (a consumer organization now part of NHPCO), and the National Hospice and Palliative Care Organization (NHPCO) – the hospice membership organization (National Coalition for Hospice & Palliative Care, 2018). The NCP goal was simple and straightforward: to build national consensus around the definition, philosophy, and principles of palliative care. The process was more complex: to create voluntary palliative care clinical guidelines through an open and inclusive process that included the many professionals, providers, and consumers involved in and affected by palliative care. The endorsement of the guidelines by the National Quality Forum and numerous professional organizations paved the way for the development of efforts to change care for patients at EOL.

Education Efforts in EOL Care

Educating Nurses

City of Hope, founded in 1913, is a National Cancer Institute—designated comprehensive cancer center and has been instrumental in the development of EOL care education for providers. In 1998, the American Association of Colleges of Nursing (AACN) released the document, Peaceful Death: Recommended Competencies and Curricular Guidelines for End-of-Life Nursing Care, which offered guidelines to include EOL care to undergraduate nursing education (Ferrell, et al., 2015). Following this, The End-of-Life Nursing Education Consortium (ELNEC) project was launched in 2000 at City of Hope in collaboration with the AACN in response to research that revealed there was a significant lack of education and training surrounding EOL care. In 2014, the IOM recommended the advancement of palliative care across the disease trajectory and to all clinical areas. The 2014 IOM Report Dying in America included in one of its key recommendations the importance of the preparation of all future health professionals in the essentials of basic palliative care (Ferrell, et al., 2016). In response to this recommendation, Ferrell et al, (2016) offered that to accomplish the IOM recommendation of training healthcare professionals in palliative care across all clinical settings, palliative care education must be included in all undergraduate nursing programs. In February 2016, the AACN released the historic document Palliative Competencies and Recommendations for Educating undergraduate nursing Students (CARES), which was a revision of the 1998 AACN document Peaceful Death: Recommended Competencies and Curricular Guidelines for End-of-Life Nursing Care. This revised document described the history of palliative care nursing education and outlined 17 competencies that all undergraduate nursing students should master prior to graduation (Ferrell et al., 2016).

In 2019, the ELNEC project launched an interactive, online curriculum titled ELNEC Graduate for Master's and Doctor of Nursing Practice nursing students. This curriculum is designed to meet the recommendations and competencies of the 2019 AACN Graduate Competencies and Recommendations for Educating Nursing Students (G-CARES) document. The G-CARES document was built on the 2006 AACN CARES document for undergraduate nursing palliative care education. The foundation for the graduate competencies include: the AACN Master's and Doctor of Nursing Practice Essentials (2011 and 2006, respectively), the Institute of Medicine report, Dying in America Improving Quality and Honoring

Individual Preferences Near the End-of-Life (Dying in America, 2015), American Nurses Association (ANA) and Hospice and Palliative Nurses Association (HPNA) Call for Action: Nurses Lead and Transform Palliative Care (2017), and The National Consensus Project Clinical Practice Guidelines for Quality Palliative Care, 4th Edition (2018) (American Association of Colleges of Nursing, 2020).

In 2019, City of Hope's Division of Nursing Research and Education achieved an important milestone for nurses and patients worldwide. The ELNEC curricula became available in Bulgaria, marking the 100th country to share this important training and education. More than 24,000 health care professionals in all 50 states and as of 2019, and professionals in 100 countries have been trained since the ELNEC project began (City of Hope, 2020).

Generalist Level Palliative Care and Specialty Level Palliative Care

According to Etkind (2017), it is estimated that approximately 75% of people nearing EOL could benefit from palliative care. With the aging population and prevalence of chronic disease, the need for palliative care services will certainly increase in the future. To meet these needs, two levels of palliative care training have been promoted by experts in the field: generalist level of palliative care and specialty palliative care. Palliative care was recognized by the American Board of Medical Specialties as a subspecialty in 2006. Members of a palliative care team are usually comprised of professionals from a variety of disciplines, including medicine, nursing, and social work, along with added support from other professional disciplines such as pastoral care, rehabilitation, pharmacy, and dieticians (Quill & Abernethy, 2013).

The Institute of Medicine (IOM), now called The National Academy of Medicine (NAM), defines these two different levels of palliative care providers. Specialty palliative care is defined as "Palliative care that is delivered by health care professionals who are palliative care specialists, such as physicians who are board certified in this specialty; palliative-certified nurses; and palliative care-certified social workers, pharmacists, and chaplains" (National Consensus Project for Quality Palliative Care, 2018, p. ii). Primary palliative care (also known as generalist palliative care) is defined as:

> Palliative care that is delivered by health care professionals who are not palliative care specialists,

such as primary care clinicians; physicians who are disease-oriented specialists (such as oncologists and cardiologists); and nurses, social workers, pharmacists, chaplains, and others who care for this population but are not certified in palliative care" (National Consensus Project for Quality Palliative Care, 2018, p. ii).

Quill and Abernethy (2013) offered a care model that differentiates between primary specialist palliative care and palliative care skills or generalist palliative care skills that all clinicians should possess. This care model was developed with the hope that the two levels could exist side-by-side and support one another. According to Quill and Abernethy (2013), the number of people living longer with increased chronic disease burden will increase the need for palliative care services to levels greater than the palliative care that specialists alone can provide. It was their hope that with the demand for palliative care exceeding the supply of palliative care specialists, all disciplines would define a basic set of palliative care skills and incorporate these skills into their training.

Educating Other Professionals

Numerous educational programs have been developed to train physicians (Kogan, 2012), nurses (Gillett et al., 2016), and others to improve communication skills (Chung, et al., 2016), reduce pain and manage symptoms (Hinds, 2014), and foster an environment that is supportive for patients nearing death and their families (Fahlberg, 2015). While there has been research done on the education of health care providers on palliative care, not much research has been done in the home health care setting. To incorporate palliative care into this setting, the health care providers on the home care team need to be adequately trained to increase their comfort with and knowledge of palliative care. Some of the providers' understanding and confusion of palliative and hospice care may need resolving, and some of their personal beliefs about EOL treatment and palliative care may be barriers to their readiness to participate in a change of service, which may include their own fear of death or personal negative experiences with dying loved ones.

These variables need to be understood as a baseline before implementing a focused educational program. Providers' readiness to change their orientation of care to being patient- centered, from "curing" to “caring,” should be assessed. The baseline assessments needed include providers’ personal beliefs, attitudes, and confidence in providing quality palliative care as defined by the National Consensus Project (NCP) (National Coalition for Hospice & Palliative Care, 2018). Even less research has been done in the home health care setting. To incorporate palliative care into this setting, the health care providers on the home care team need to be adequately trained to increase their comfort with and knowledge of palliative care.

EOL/Palliative Care and COVID-19

According to the World Health Organization (WHO), the severe acute respiratory syndrome coronavirus 2 (SARS CoV-2) is part of a large family of viruses which that result in illness, known as COVID-19, in animals or humans. It is the most recently discovered coronavirus. The first laboratory-confirmed case of COVID-19 in the United States was confirmed on January 20, 2020, and subsequently reported to CDC on January 22, 2020.

The first case of COVID-19 in the state of New York during the pandemic was confirmed on March 1, 2020, and the state rapidly became an epicenter of the pandemic in the United States. COVID-19 has turned into a global pandemic affecting every aspect of life. Globally, as of April 5, 2022, there have been 489,779,062 confirmed cases of COVID-19, including 6,152,095 deaths, reported to the WHO. In the United States alone, as of April 5, 2022, there have been 79,414,511 confirmed cases of COVID-19 with 974,179 deaths (World Health Organization, 2022).

COVID-19 Timeline of Events in New York (A Timeline of COVID-19, 2020)

2020

January 9 — WHO announces mysterious Coronavirus-related pneumonia in Wuhan, China.

January 11— China reports first COVID-19 death.

January 21 — CDC confirms first US Coronavirus case, Chinese scientist confirms COVID-19 human transmission.

January 31 — WHO issues global health emergency.

February 3 — US declares public health emergency.

February 29 — First reported COVID-19 death in the U.S.

March 7 — NY Governor Andrew Cuomo declares a state of emergency.

March 13 — Trump declares COVID-19 a national emergency.

March 17 — Center for Medicare & Medicaid Services temporarily expands use of telehealth.

March 20 — State-wide stay-at-home order declared. All non-essential businesses were ordered to close. All non-essential gatherings canceled/postponed.

March 22 — NYS on Pause Program begins, all non-essential workers must stay home.

March 30 — FDA Authorizes Use of Hydroxychloroquine.

April 12th —Daily positivity rate number of persons 6337, 47 in 100,000, % positive = 37.8%.

April 15 — All state residents ordered to wear face masks/coverings in public places where social distancing is not possible.

May 14 — State of emergency for NYS extended to June 13 (Kerr, 2020).

May 28 — US COVID-19 deaths pass the 100,000 mark.

June 10 — US COVID-19 cases reach 2 million.

July 9 — WHO announces COVID-19 can be airborne.

August 17 — COVID-19 now the third-leading cause of death in the US.

August 28 — First known case of COVID-19 reinfection reported in the US.

September 23 — A new, more contagious strain of COVID-19 ss discovered.

September 28 — Global COVID-19 deaths surpass 1 million.

October 19 — Global cases top 40 million.

November 4 — US reports an unprecedented 100,000 cases in 1 day.

November 18 — Pfizer, BioNTech vaccine is 95% effective.

December 11 — FDA formally authorized use of the Pfizer vaccine.

December 14 —New York, the director of critical care at Long Island Jewish Medical Center (LIJ) in Queens has become the first person in the United States to receive the Pfizer COVID-19 vaccine. Sandra Lindsay RN was the first healthcare worker to receive the vaccine in the U.S. (Coronavirus News, 2020)

2021

January 7 — One year anniversary of CDC COVID-19 pandemic response.

February 27 — FDA approves emergency use authorization for Johnson & Johnson one-shot COVID-19 vaccine.

March — Delta variant first identified in New York.

June 1 — The Delta variant becomes the dominant variant in the U.S.

June 15 — Governor Cuomo lifts COVID restrictions.

August 22 — Governor Andrew Cuomo announced that New York health care workers would be required to be vaccinated against COVID-19.

October 29 — New CDC study provides evidence that COVID-19 vaccines offer higher protection than previous COVID-19 infection.

November 26 — WHO identifies new variant, Omicron.

2022

January 1 — Weekly positivity rate in New Your hits a pandemic high.

January 7 — Governor Hochul mandates booster for healthcare workers in New York.

January 14 — New Yorkers with 1 dose= 86%, fully vaccinated = 72.9%.

February — Omicron BA2 identified in New York.

February 10 — New York statewide mask mandate lifted.

February 18 — Booster mandate for healthcare workers lifted due to worry over healthcare worker shortages.

New York and COVID-19

The first case of COVID-19 in New York was identified on March 1st, 2020, and since that day, numerous changes were put in place to slow down the spread of the virus or what became known as “flattening the curve.” Cases in the state doubled overnight on March 5th and then doubled overnight on March 6th. The country’s first containment zone was created in New Rochelle, New York, on March 10th. New York’s first two coronavirus deaths were announced on March 14th. As New York State cases reached 3,437, Governor Cuomo signed an executive order requiring all nonessential businesses to reduce their workforce by 50% percent. By March 20th, statewide cases exceeded 8,300 and Governor Cuomo took the drastic step of closing all nonessential statewide businesses and suspending elective surgeries. On March 25th, the state issued a policy requiring nursing homes to accept COVID-19 positive patients discharged from hospitals. Cases in the state soared to 59,513 by March 29th with 965 deaths. In one month, New York went from 1 case to an unbelievable 83,000 cases and 2,300 deaths. Governor Cuomo announced that the state had 53,000 hospital beds and predicted that the number needed will reach 140,000 (Francescani, 2020). The impact of the pandemic on the health care system was enormous, overloading hospital bed capacity and depleting the supply of personal protective equipment (PPE) and much needed ventilators.

According to Francescani (2020), cases continued to increase in New York during April and May. Due to thousands of additional nursing home deaths, the state repealed the policy requiring nursing homes to accept COVID-19 positive patients discharged from hospitals. The number of cases in NYS peaked on May 20th at 354,370 cases and 22,230 deaths. On the hundredth day since the first case was confirmed in NYS, June 8th, the first phase to reopen NYS was implemented. The state slowly reopened in four different phases based on strict guidelines outlined by Governor Cuomo. Testing results and infection rates were closely monitored, and contract tracing was initiated to monitor the reopening phases and the impact that would have on the spread of the virus.

As of early October 2020, the number of COVID-19 cases in the U.S. reached a staggering number of 7.64 million, with 213,000 deaths nationwide. The virus continued to have a major impact on the United States, with vaccination variations nationally. However, there will most likely be additional layers of deferred or indirect influence of the virus resulting from delayed or canceled treatment or medical care, unknown health impact of COVID-19 survivors, the emotional and physical ramifications of sheltering in place, and the additional health consequences generated from an economic decline (Coe, et al., 2020). On December 10th, the Federal Drug Administration’s (FDA) vaccine advisory panel voted to recommend the authorization of the Pfizer vaccine, followed that same day with NYS’s independent

COVID-19 Clinical Advisory Task Force voting unanimously to approve the FDA panel's decision. On December 11th, the FDA formally authorized the use of the Pfizer vaccine. The first person to receive the vaccine in the U.S. was a New York nurse, Sandra Lindsay (Coronavirus News, 2020).

On December 10th, 2020, Governor Kathy Hochul announced a statewide indoor business mask-or-vaccine requirement, one of the most stringent requirements in the nation. During late 2020 and into early January 2021, a second surge of the virus was experienced in New York State. On January 11th, 2021, daily positivity rates in New York reached 19,942, 102 cases per 100,000, 6.1% positive (Department of Health, 2022.). The first New Yorkers became fully vaccinated on January 17, 2021. Vaccination efforts continued on a widespread scale in New York, including pop-up vaccine and testing sites. On August 22, 2021, Governor Cuomo announced that all New York healthcare workers would be required to be vaccinated. The Omicron variant was first confirmed in New York State on December 2, 2021. Hospitals and nursing homes began to modify visiting restrictions to allow for limited visitation as the vaccination rates rose and positivity rates decreased. As of January 14, 2022, the percentage of New Yorkers with the first dose of the COVID-19 vaccine was 86% and the percentage of fully vaccinated New Yorkers was 72.9%. (The Official Website of New York State, 2022, March 22).

Palliative Care Services Home Care Challenges During the COVID-19 Outbreak

Palliative care services are underutilized under normal conditions. According to the 2017 Lancet Commission on Palliative Care and Pain Relief, the universal lack of access to inexpensive and efficacious measures to reduce serious health-related suffering is a terrible injustice. Providing high-quality palliative care is a challenge that has been acknowledged and introducing COVID-19 into the equation makes this challenge even greater (Knaul, 2018). Community-based palliative care became more difficult to deliver safely, with healthcare workers and patients at heightened risk from COVID-19, PPE in limited supply, and healthcare systems overwhelmed. Guidelines have been issued by the WHO on how to preserve essential health care services during the COVID-19 pandemic. This guidance focused on emergency care, immunization, maternal care, and chronic illnesses. The health service overlooked by the WHO was palliative care which is actually in greater need during a pandemic where suffering is amplified

(Lancet, 2020).

According to Jennifer Moore Ballentine, the Executive Director of the California State University Shiley Institute for Palliative Care, palliative care strengths such as symptom management, communication, and advance care planning are in demand now more than ever as a result of the COVID-19 pandemic. The WHO reports the average death rate from COVID-19 as anywhere between 2% and 4% percent. However, the death rate among elderly patients is approximated at more like a staggering 15% to 22%. An infection with COVID-19 can thrust a person suffering from a serious or life-limiting disease into an imminent EOL situation. A valuable skill in palliative care is the ability to quickly reassess patients' needs and goals of care and align these with treatment options (CSU The California State University Shiley Haynes Institute for Palliative Care 2020).

Palliative care teams can face obstacles such as shortage of PPE, limited visitation for staff and patient caregivers, and an increased need for palliative care during the COVID-19 crisis. Adaptability, creativity, and innovation are key elements necessary to effectively meet the increased and specific palliative care needs of COVID-19 patients. Obtaining an adequate supply of PPE to protect staff and the ability to perform telehealth visits through a Medicare waiver during COVID-19 have afforded home care-based agencies the ability to continue to provide valuable and much-needed care to this vulnerable population (Holly, 2020).

Problem Statement

The problem addressed by this study emerged when the development of palliative care education for home health providers at Catholic Home Care was interrupted by the COVID-19 crisis. This certified home health agency (CHHA), like other healthcare entities, had to develop and adopt innovative and creative ways to administer healthcare to patients during the pandemic, while keeping both staff and patients safe. A program was created called "a virtual COVID-19 unit," which allowed patients to be discharged home from the hospital earlier in their course of illness to maximize in-patient hospital capacity. This program included installing telemonitoring equipment in the patient's home prior to hospital discharge as well as virtual physician and in- person home care staff visits. Initially, patients were screened for the type of home care visits needed to prioritize which disciplines would need to be visited in the first two weeks. This initiative was implemented to preserve PPE, which was limited in the early phase of the pandemic. Other changes made in response to COVID-19 included medical social workers performing telephonic visits to support patients. Behavioral health was provided to all COVID-19 cases to support the changing needs of the patient due to illness, required precautions, and impact of these precautions on the patient and their loved ones. The problem was that this initiative did not include the carefully planned organizational learning-needs assessment for comprehensive palliative and end-of-life care that had been previously planned prior at the onset of the pandemic. The needs of the CHHA staff were addressed in various ways by the agency at that time.

Innovation and creativity were also key in meeting the changing needs of the staff during the pandemic. It was important to the agency that the staff felt safe and had the necessary equipment to safely administer care to the patients they served. Agency leadership held multiple weekly conference calls open to all staff to keep them updated about emerging scientific knowledge about COVID-19, case volumes throughout the health system, changes to policies and procedures, availability of support resources, and an open forum for questions. Drop shipment of supplies, the normal mechanism used to get needed supplies to staff prior to

COVID-19 was unable to continue during this unprecedented time. To limit the exposure of staff, management would drive to staff homes to deliver this important safety equipment. To address both the emotional and physical toll of providing care during a pandemic, the health system provided workshops to foster staff resilience. Finally, education was provided to the multidisciplinary team regarding how to care for these patients safely and the correct use of PPE necessary to administer this care.

Prior to COVID-19, the organization began planning an agency-wide palliative care educational program. A survey was administered, and data were collected on an anonymous sample of the home care team to determine baseline knowledge, comfort, attitudes, and fear of dying to plan the delivery of an educational intervention. Unfortunately, the educational plan was postponed due to the restrictions and urgent clinical care needs created by the COVID-19 pandemic. These data collected in preparation for an educational intervention comprise the Time 1 measure of the organization's readiness to implement palliative care. They form the baseline for assessing the impact of the COVID-19 pandemic on staff's comfort with, attitudes toward, and fear of dying.

Purpose of Study

The purpose of this study is to compare and determine if correlations exist between Time 1 and Time 2 in the domains of health care providers' comfort with and attitudes toward EOL and palliative care, and their fear of dying. Specifically, this study examines the interprofessional home care team in a large multi-hospital system to (a) describe pre-Time 1 professionals' personal characteristics, comfort with and attitudes about EOL treatment and palliative care, and their fear of death; and (b) compare them with Time 2 personal characteristics, comfort, attitudes, and fear of death. It also includes an examination of the relationship of these elements with staff's self-reported professional self-confidence in EOL caregiving. For the purpose of this study, the members of the interprofessional home care team are considered to be generalist-level palliative care providers.

Research Questions

The study uses the previously collected baseline data (Time 1) with a second sample (Time 2) of interprofessional home care staff's comfort with and attitudes toward EOL treatment and palliative care to answer the questions: For this study, two time periods anchored the two data- collection points:

TIME 1: One year prior to the outbreak of COVID-19 in New York (January 2019) when planning palliative care initiative (baseline data).

TIME 2: Approximately one year after the outbreak of COVID-19 in New York (February/March 2021) when home care services had been altered by emergency and EOL care had to meet the needs of the time.

1. At Time 1, what was the staff's level of comfort with providing EOL and palliative care services? What were their attitudes toward EOL and palliative care? How fearful were they about death and dying? Was there a relationship between their personal characteristics such as level/type of

education, marital status, age, or having children with their comfort, attitudes and fears about death and dying?

2. Is there a difference in staff level of comfort with and attitudes about providing EOL and palliative care services between Time 1 and Time 2? Does fear of death and/or fear of dying change between Time 1 and Time 2?
3. Is there a relationship between staff level personal characteristics, comfort and attitudes about providing EOL and palliative care services with their self-reported EPCS scores? Does their fear of death or fear of dying predict their EPCS results?
4. Do comfort, attitudes, or fear of death/fear of dying predict staff self-reported End-of-Life Professional Caregiver Survey (EPCS) results?

Significance

Since the literature shows the need for the interprofessional education of palliative care teams, it is clear that changes to incorporate palliative care for a home care service of a large multi-hospital system would take preparation and planning. Understanding the staff pre-training characteristics that include their own attitudes about palliative care and personal discomfort about caring for the dying or fear of death itself would be important to assess. EOL communication and introduction to hospice and palliative care programs are important aspects of caring for patients and families at EOL. The social, spiritual, physical, and psychological well-being of patients and their families can be negatively impacted by untimely referral or lack of referral to these valuable programs. There is a gap in the literature between identifying barriers to referral and identifying the best ways to overcome these barriers that would be most useful for developing and executing this palliative care program. A nurse-led EOL communication and palliative/hospice care educational intervention would benefit the entire interprofessional staff and establish nursing as the head of an organization-wide training model for the interdisciplinary healthcare team. Understanding their characteristics at baseline and related to the pandemic is necessary to plan any intervention.

Definition of Terms

For this study, two time periods anchored the two data-collection points:

TIME 1*:* One year prior to the outbreak of COVID-19 in New York (January 2019; baseline data).

TIME 2: Approximately one year after the outbreak of COVID-19 in New York (February/ March 2021) when home care services had been altered by emergency and EOL care needs of the time.

Palliative Care

Palliative care is defined as medical care administered by an interdisciplinary team to patients facing serious, life-limiting illnesses and their caregivers. This care focuses on providing the best quality of life for these patients through pain and symptom management (National Coalition for Hospice & Palliative Care, 2018). Palliative care addresses the physical, emotional, and spiritual needs of patients and their caregivers. Unlike hospice care, palliative care can be administered concurrently with curative and disease-focused treatments (Meghani & Hinds, 2015). For the purpose of this study, palliative care was also referred to as symptom management and supportive care, and the terms have been used interchangeably.

Health Care Providers

Providers are defined in this study as members of the home care team in a large suburban home care agency. The National Hospice and Palliative Care Organization (2017) defines hospice care as a team-oriented approach to pain management, spiritual and emotional support, and expert medical care for those patients facing a life-limiting illness. Therefore, it is important for all members of the team to be included in the study such as nurses, social workers, physical therapists, speech therapists, occupational therapists, and chaplains (Wittenberg, et al., 2016).

Personal Characteristics

Personal characteristics, for the purpose of this study, are defined as providers' select demographics, including marital status, children, and previous experience with caring for a dying loved one. For this study, these demographics were captured on the Time 1 survey to describe the sample and at Time 2 to assess the similarities of the two samples.

Comfort with Providing Palliative Care (CPPC)

Comfort is addressed as the self-perceived level of ease or freedom from stress that a provider reports on discussing palliative care as an option to his or her patients (Merriam-Webster, n.d.). For this study, it is measured with five survey items in which respondents self-report their level of comfort with providing palliative care. Reliability and construct validity on this measure was conducted in a Phase 1 pilot study done by the investigator. Cronbach's alpha for CPPC = .85 (Infante, 2019).

Attitudes About Palliative/End-of-Life Care

Attitudes are feelings or emotions toward something or a mental position about something (Merriam-Webster, n.d.). For the purpose of this study, the Feeg-Stewart instrument (F-S Hospice Scale: Views of Hospice Care) as a measure of Attitude Toward Hospice Scale (ATHS) was developed for a previously reported study (Feeg & Stewart, 2000) and was used in the pilot study done by the investigator with a reported Cronbach's alpha = .87 (Infante, 2019).

Fear of Death/Dying

For the purpose of this study, fear of death will address the four elements described by Collett and Lester in The Collett/Lester Fear of Death Scale: "death of self, dying of self, death of others, and dying of others" (Lester & Abdel-Khalek, 2003, p. 81). Validity and reliability are reported in the literature by Kolawole and Olusegun (2008) with Cronbach's alpha range of .80 to .89. In the pilot study of Phase 1 done by the investigator, Cronbach's alpha ranged from .79 to .89 (Infante, 2019).

COVID-19 Pandemic

The COVID-19 pandemic is an ongoing global pandemic of coronavirus disease 2019 (COVID-19) caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). The novel virus was first identified from an outbreak in Wuhan, China, in December 2019. The virus was unable to be contained there and spread worldwide. The WHO declared a Public Health Emergency of International Concern on January 30, 2020, and a pandemic on March 11, 2020.

Professional Self-Reported Confidence in End-of-Life Caregiving

Professional Self-Reported Confidence in End-of-Life Caregiving is the extent to which one self-reports his or her ability to provide competent EOL care. In this study, it is measured by the End-of-Life Professional Caregiver Survey (EPCS), administered approximately one year after the onset of the pandemic. This tool is often used for pre-assessment for educational programs with reported validity and reliability in the literature. It includes three subscales: an 8- item Cultural and Ethical Values (CEV), 12-item Patient and Family Centered Communication (PFCC), and an 8- item ECD.

Summary

This study compared identified variables between Time 1 and Time 2 concerning health care providers' comfort with and attitudes toward EOL and palliative care, and their fear of dying. It examined the interprofessional home care team in a large multi-hospital system to describe Time 1 professionals' characteristics, comfort with and attitudes about EOL treatment and palliative care, and their fear of death; and compared them with Time 2 characteristics, comfort, attitudes and fear of death. It then tested if staff characteristics and these variables predict the staff's self-reported confidence in EOL caregiving in three areas in particular: cultural and ethical values, patient-and-family centered communication, and effective care delivery.

Chapter 2: Review of Literature

According to the Center to Advance Palliative Care (2019), “Palliative care sees the person beyond the disease. It is a fundamental shift in health care delivery” (para. 1). This is a powerful statement and emphasizes the fact that the focus of palliative care is to improve the quality of life for those persons with serious illnesses through pain and symptom management. Palliative care also improves the quality of life for those who care for these patients. Ferrell et al., 2015 offered that for over 30 years, the WHO has acknowledged the need and advocated for the improvement of palliative care worldwide. The WHO stresses that palliative care not only benefits the patient but also those taking care of these patients. The belief that the benefit of palliative care extends to caregivers as well is apparent in the definition of palliative care given by the WHO: “Palliative care is an approach to care which improves QOL of patients and their families facing life-threatening illness, through the prevention, assessment and treatment of pain and other physical, psychological and spiritual problems” (Ferrell et al., 2015, p. 62). This specialized care can be provided at any age or stage of illness and can be provided concurrently with curative treatment (Center to Advance Palliative Care, 2019).

Studies on Knowledge Deficits Related to Palliative Care

Several studies have documented the lack of knowledge and need for training of professionals about palliative care. A study done by Devader and Jeanmonod (2012) explored how physicians’ lack of knowledge can be a barrier in hospice and palliative care referrals. The study’s objectives were to determine the residents’ knowledge base regarding key concepts in hospice and palliative care as well as the residents’ level of comfort in handling EOL discussions and managing EOL care. The study also looked at the effect educational intervention would have on improving the residents’ knowledge and comfort level in dealing with EOL issues (Devader & Jeanmonod, 2012).

According to Devader and Jeanmonod (2012), the results demonstrated a previously unidentified gap in emergency medicine residents’ knowledge base regarding qualifying hospice diagnosis and symptom management at EOL. The authors stated that this gap is correctable with minimal education and if maintained for at least six months. EOL discussions and hospice referrals increased after education and perceived barriers decreased. Some limitations of the study were identified. This study used survey data, which can be subject to recall bias. The study was also a single center study, so the findings cannot be generalized to all emergency medicine residents nationally. Inadequacies in the electronic medical record made the tracking of referrals difficult. Future research could include a broader sample of multiple residency sites. Better tracking tools for referrals would also aid in achieving more reliable results.

Another study done by Schlairet (2009) looked at formal EOL education and continuing education on EOL care and if this education impacted scores of those participating in this education in areas of EOL attitude/belief, desire for education, knowledge competence, and workplace appropriateness. Schlairet (2009) offered that few surveys exist that examine the needs of practicing nurses for EOL education. The End-of-Life Care-Educational Needs Survey was developed and looked at six domains: nurses' attitudes and beliefs, competence, opinions on workplace suitability, core content for EOL nursing, knowledge/skill, and education aspiration.

The survey was initially tested in a population of graduate nursing students, nurses with EOL experience, and nurse generalists in four healthcare settings. Internal consistency, with Cronbach's alpha score of .70, was supported for nurses' attitudes toward knowledge and care. The survey was then administered to 51,000 nurses in a southeastern state with a return of 567 surveys. Findings indicated that nurses' attitudes were unmistakably positive; however, there were sweeping knowledge deficits and correlating self-competency ratings spanning 23 areas of EOL topics. This pointed to a huge "gap in the level of EOL care RNs want to deliver and their actual abilities" (Schlairet, 2009, p. 174).

Regarding workplace appropriateness and desire for education, findings suggested there is a need for EOL nursing care education to be developed and dispersed to all RNs in all care settings in addition to the palliative care team members. The results of the study supported the hypothesis that undergraduate and graduate nursing education does not adequately prepare nursing students with the appropriate tools and skills to deliver quality EOL care. Limitations of the study included a threat to external validity due to low response rate and selection bias. For future consideration, Schlairet (2009) emphasized the need for nurse educators to constantly assess the educational needs associated with providing high-quality EOL care and continually evaluating outcomes of EOL education initiatives.

Educational Interventions

A study done by Harden and Galunas (2017) utilized a pre/post-test design to assess baseline knowledge, attitudes, and behaviors of nurses prior to an educational intervention and then again one-month post-intervention. Fifty-four nurses working on an oncology unit were given palliative care education, a modified curriculum derived from the ELNEC, in a four-hour class. Results demonstrated significant increases in overall mean scores from before and after the intervention for knowledge, behavior, and attitudes. The researchers reported that the biggest obstacle of the initiative was the uncertainty if the educational program would be sustainable.

Limitations of the study included lack of generalizability due to the population consisting of RNs on one oncology unit. Selection bias could also be a limitation, considering the population was strictly oncology nurses who showed an interest in palliative care. Recommendations for future research arising from this study suggest the need to include all members of the health care team in palliative care education (Harden & Galunas, 2017). They eloquently summarized the need for all stakeholders to be included in the provision of palliative care: “When each facet of the care team and family understands his or her role in palliative care, conversations will be early, deep, and meaningful and will be focused on the patient’s goals, values, and preferences” (p. E237).

Moir, et al., (2015) utilized a non-experimental survey design in their study to explore the comfort and educational needs of nurses. The End-of Life Professional Caregiver Survey (EPCS) was used to determine if there were differences in educational needs of nurses concerning patient discussion of palliative care and EOL care based on age, years of experience, and type of unit the nurse worked on. The EPCS looks at three domains: delivery of effective care, ethical and cultural values, and communication with patients and caregivers. The survey was given to 60 nurses working on three different units in a hospital. MANOVA was used and demonstrated that there was no significant difference in any of the domains based on age; however, level of experience and unit did play a role. Unit played a significant role in the domain of patient and family-centered communication (PFCC).

Significantly higher levels of comfort with PFCC were reported by oncology nurses (Moir et al, 2015).

The researchers concluded that a smoother transition from curative to palliative care is the optimal goal and this depends on the communication that patients and their caregivers receive from the healthcare team. Some limitations of the study include a relatively small sample, which may indicate the results are not generalizable. There was also a data-collection flaw that could be another area of limitation. The experience range choices were 2-5 years and 5-10 years, which presented an overlap that could have prevented differences in those age groups to be revealed. Implications for nursing practice from this study emphasize the need for palliative care and EOL care education for nurses to improve comfort and knowledge level in communicating with patients and caregivers, thus making the transition from curative to palliative care smoother. Recommendations for future research posed by the authors include assessing home health nurses' level of comfort with palliative care patients receiving home care (Moir et al., 2015).

The type of educational intervention utilized in palliative and EOL care training can play a major role in the success of the training. This was explored in a study by Selman (2016). The researchers used a mixed-methods design comprised of a before and after questionnaire made up of 14 self-assessment questions. A qualitative component was included in the design, which involved free text responses analyzed for thematic content. The population consisted of 236 participants inclusive of nurses, nurse managers, general practitioners, health and social care assistants, and nursing and medical students. The educational intervention consisted of a 2-day Transforming End-of-Life Care course with the goal of improving EOL care confidence and competence (Selman, 2016).

Results of the study demonstrated that after the educational intervention, there was a significant improvement in all 14 self-assessment questions. The qualitative data results indicated increased knowledge and confidence in EOL care. Overall, the participants stated they would recommend this course and it would impact their practice. Some limitations with the study included a small sample size, which could affect t test reliability and self-assessment bias. In addition to these limitations, participants self-selected to the course that could affect the results due to their increased motivation and responsiveness (Selman, 2016).

Advance Directives Studies

A study by Hong et al. (2016), Adopting Advance Directives Reinforces Patients Participation in End of-Life Care Discussion, explored the barriers to having EOL discussions with patients and possible ways to overcome these barriers. This study was a retrospective review of medical records of 106 hospice patients during the period between July 2012 and February 2013 at one hospice center. The objective of the study was to examine the proportion of patients that participated in EOL discussions with healthcare personnel after the introduction of advance directives upon admission.

The population of the study by Hong et al. (2016) consisted of 106 patients admitted to St. Vincent’s Hospital Center between July 6, 2012, and February 28, 2013. During the years 2003 through 2012, advance directives and do-not-resuscitate (DNR) forms were discussed upon admission. After evaluating patient records, it was demonstrated that EOL discussions increased from 30% to 51% after advance directives were part of a patient’s admission process. Barriers to having EOL discussions were identified. These barriers were divided into four areas: patient, provider, family, and systemic barriers. The most common reasons identified for patients not participating in EOL discussions were concern by family members regarding the distress level of the patient and the poor physical condition of the patient. The authors stated the study demonstrated “that adopting advance directives can increase patient participation in EOL discussions, which could enhance their autonomy” (Hong et al., 2016, p. 756).

Limitations of the study were identified. The study consisted of a retrospective review of medical records. As a result of this, not all EOL discussions may have been captured. Patients that were involved in EOL discussions but did not sign for themselves may have been missing. The authors assumed that a signed advance directive meant participation in EOL discussions; however, further research such as a prospective observational study would be indicated to confirm this relationship. Research to further study barriers to and content of EOL discussions is needed (Hong et al., 2016).

Recommendations for Training Models

According to the Clinical Practice Guidelines for Quality Palliative Care, members of the palliative care team should receive continuous development of team building and communication skills to ensure they have the necessary tools and skills for effective collaboration (Wittenberg et al., 2016). However, most palliative care training and team building does not incorporate all members of the health care team. According to The National Hospice and Palliative Care Organization (2022), the palliative care team should include a team of specialists typically made up of physicians, nurses, including nurse practitioners, social workers, and spiritual care workers. In addition to these specialties, some palliative care teams also include physical therapists, speech therapists, dieticians, pharmacists, and specially trained volunteers. These specialists are all trained to provide care for patients and their families during one of the most difficult times in their lives. Wittenberg et al. (2016) focused on this important need in their study, evaluating the effectiveness of a two-day communication training course for all members of a palliative care team. The population of the study was made up of 58 palliative care professionals including nurses, social workers, physicians, chaplains, and a psychologist. The previously tested online learning tool Communication, Orientation and options, Mindful communication, Family, Openings, Relating, Team (COMFORT) Communication for Palliative Care Teams curriculum was utilized. Research method included a pre-course survey, the implementation of the education intervention, and post-course surveys at six and nine months.

After the initial training, the participants brought the curriculum back to their respective institutions and attempted a train the trainer process, as the COMFORT training was developed as a statewide initiative. The participants reported considerable obstacles when they ventured to train others at their respective institutions. The support, leadership, and dedication necessary to guarantee the success of the COMFORT program was lacking at some institutions. While the need for palliative care–trained team members is increasing, there is a lack of access to quality palliative care training programs that meet the mandates of the National Consensus Project. There is a lack of research regarding high-quality, tested training tools for palliative care team building and communication across disciplines (Wittenberg et al., 2016). This is an area for future research.

The increase in demand for palliative care service that will be needed for our aging population was a topic of research for Levine (2017). With the baby boomers coming of age, patients with serious illness are expected to double in the next 25 years (National Palliative Care Registry, n.d.). According to Levine (2017), this increase in demand will coincide with a shortage of hospice and palliative care physicians, producing the need to train all members of the health care team on providing quality palliative and EOL care. The research methods included 30 nurse and physician fellows from throughout the Chicago area who participated in a two-year palliative care training program. The course design included online learning, live conferences, mentorship and development, integration, and evaluation of a practice improvement project. The evaluation of participant knowledge was done prior to implementation and 18 months after.

The results of the study demonstrated positive results in areas of knowledge, confidence, and performance of palliative care skills. Qualitative results indicated high satisfaction from participants. A major limitation to this study was the lengthy time requirements for participants and financial backing. Additionally, a comprehensive evaluation of the program was not completed to ascertain the overall impact of the components of the program. Recommendations for further research include incorporating other disciplines in the program such as social workers and chaplains.

According to Abdelaziz, et al., (2011), over the past two decades, there has been rapid growth and developments of information and communication technology that have had a significant influence on nursing education. E-learning can be defined as delivering instruction electronically via the internet, intranets, or other various multimedia modalities. The study by Abdelaziz et al. (2011) revealed that there was a highly statistically significant difference between two groups of nursing students: one receiving cardiac disease education via the e-learning method and the other taught via standard lecture method. The study confirmed that e-learning is an effective instructional tool for nursing education that may be suitable for a wide delivery of palliative care education across all settings or disciplines. The recommendation from the results of the study, however, suggest that the best form of an educational method is a blended-learning environment that incorporates the strengths of both lecture and e-learning in creating a nursing education intervention.

Another study done by Moattari, et al., (2014) also supported the use of web-based education in delivering training to nurses. The study involved designing a learning management system consisting of an electronic module, interactive tests, learning activities, and a forum for delivering diabetes education as continuing nursing education. The outcome of the study demonstrated that the implementation of a web-based education intervention is possible and results in increased competency and knowledge of nurses. The efficiency of web-based education may also be a desirable method of delivering EOL and palliative care education. The authors reported that, although web-based learning proved to be effective as an education method to provide Certified Nursing Educator training to the participants, only half of the volunteers agreed to participate. This was attributed to the extensiveness of the module and therefore the authors suggested that future research involve design of the e-learning modules to encourage participation (Moattari et al., 2014). Customizing an education program should also be based on an understanding of participants' characteristics at baseline related to their personal attitudes and comfort with providing EOL care.

Research has been done looking at virtual versus traditional teaching methods in a variety of disciplines by Moazami, et al., (2014) that involved comparing two methods of education, virtual versus traditional, in the training of undergraduate dental students. The dental students were divided into two groups, with one receiving the e-learning module and the other traditional lecture format. The results of the study demonstrated that when comparing the mean knowledge scores of both groups, virtual learning proved more effective than the traditional method. The limitations discussed include that the design of the study was post test only with the control group as a quasi-experimental design. The authors recommended further research using more rigorous designs and a larger sample size to be able to generalize the findings (Moazami et al., 2014).

Summary

Palliative care is an approach to care that has been proven to increase the quality of life for both patients and their caregivers facing life-threatening illnesses, in the U.S. and globally. Although palliative care services in hospitals and other settings have increased, long-term care and home care agencies continue to struggle with the education of staff and delivery of care to clients that incorporate the central tenets of what has been defined by the Guidelines for Quality Palliative Care developed by NCP (National Coalition for Hospice & Palliative Care, 2018). While many educational programs have been designed to train physicians and nurses in palliative care, there is disagreement as to the best design and implementation for this education. In addition to this, there is a paucity of research regarding the preparation of multidisciplinary staff in home care services whose general practice is not focused on palliative care. This study assesses the personal characteristics, comfort with and attitudes toward palliative care rather than just knowledge to identify predictors of their confidence in providing care before undertaking a systemwide educational intervention.

Chapter 3: Methods

Chapter 3 summarizes the research design, population of the study, methods, sampling, procedure, instruments, and ethical considerations.

Research Design

This research consists of a descriptive comparative and correlational study of health care providers' comfort with, attitudes toward, and fear of dying between Time 1 and Time 2. A survey was designed to determine which characteristics of health care providers influence their reported comfort with and attitudes toward palliative and EOL care, and fear of dying at Time 1, and compared these variables to a subsequent survey at Time 2. The study recruited health care providers from a large CHHA in the metropolitan New York area. Participants included registered nurses (RNs), physical therapists (PTs), occupational therapists (OTs), speech therapists (STs), and medical social workers (MSWs) (n = 601) who are employed at and make home visits for the CHHA that has an average daily census of 3,000 patients. These patients were referred from six large hospitals that are part of the same health care system as well as other local hospitals outside the health system.

Methods

This research used a survey implemented prior to the pandemic to determine which characteristics of home care providers influence their comfort with and attitudes about palliative and EOL care, and fear of dying. The Time 2 survey compared these previously recorded variables with their Self-Reported Confidence in EOL caregiving. Hypotheses are stated in the null.

Research Questions

1. At Time 1, what was the staff's level of comfort with providing EOL and palliative care services? What were their attitudes toward EOL and palliative care? How fearful were they about death and dying? Was there a relationship between their personal characteristics such as level/type of education, marital status, age, having children or experience caring for a dying person with their comfort, attitudes and fears about death and dying?
   a. Describe the personal characteristics of the staff at Time 1 (age, education, marital status, having

children, experience caring for a dying loved one).

b. Describe staff level of comfort providing EOL and palliative care services; their attitudes toward EOL and palliative care. Describe how fearful staff are about death and dying for themselves and for others.

c. Hypothesis: There is a relationship between personal characteristics and level of comfort, attitudes toward EOL, and fear of death/dying (self/others):

H0: There is no relationship between the personal characteristics of staff and their level of comfort providing EOL and palliative care services.

H01: There is no relationship between personal characteristics of staff and their attitudes toward EOL and palliative care.

H02: There is no relationship between personal characteristics and their (a) fear of death for themselves; (b) fear of dying for themselves; (c) fear of death of others; (d) fear of dying others.

2. Is there a difference in staff level of comfort with providing EOL and palliative care services, attitudes toward EOL and palliative care services between Time 1 and Time 2? Does fear of death and/or fear of dying change between Time 1 and Time 2?

   a. Describe level of comfort, attitudes about providing EOL and palliative care, and fear of death/fear of dying at Time 1 and Time 2.

   b. Hypotheses: There are differences in the Time 1(pre-COVID) and Time 2 (during-COVID) mean scores of levels of comfort with providing EOL care, attitudes toward EOL care, and fear of death/dying (self/others).

      H03: There is no difference in the mean scores for level of comfort with providing EOL care between Time 1 and Time 2.

      H04: There is no difference in the mean scores for attitudes toward EOL care between Time 1 and Time 2.

      H05: There is no difference in the mean scores for fear of death (self) between Time 1 and Time 2.

H06: There is no difference in the mean scores for fear of dying (self) between Time 1 and Time 2.

H07: There is no difference in the mean scores for fear of death (other) between Time 1 and Time 2.

H08: There is no difference in the mean scores for fear of dying (other) between Time 1 and Time 2.

3. Is there a relationship between staff level personal characteristics, comfort and attitudes about providing EOL and palliative care services with their self-reported EPCS results? Does their fear of death or fear of dying predict their EPCS scores?
    a. Describe correlations between personal characteristics, comfort, attitudes, and EPCS results (all 3 subscales) at Time 2.
    b. Hypotheses: Personal characteristics predict EPCS scores (3 subscales).

       H09: There is no relationship between personal characteristics and any of the 3 EPCS subscales.

       H010: There is no relationship between comfort with providing EOL services and any of the 3 EPCS subscales.

       H011: There is no relationship between attitudes toward EOL services and any of the 3 EPCS subscales.

       H012: Any scores of fears of death/fear of dying (self/others) predict EPCS (the 3 EPCS subscales).

4. Does comfort, attitudes, or fear of death/fear of dying predict staff self-reported End-of-Life Professional Caregiver Survey (EPCS)?
    a. Describe a model to predict EPCS subscales using level of comfort with providing EOL care, attitudes toward EOL care, and any of the fear of death variables (if any are correlated, these will go into three multiple regression models using EPCS subscales as outcomes of comfort, attitudes and fears).

       H013: EPCS Patient- and Family-Centered Communication Score can be predicted by comfort, attitudes and/or fears.

H014: EPCS Cultural and Ethical Values Score can be predicted by comfort, attitudes and/or fears.

H015: EPCS Effective Care Delivery Score can be predicted by comfort, attitudes and/or fears.

Population/Sample

The sample was recruited from the list of all professional health care providers from a large CHHA. Participants included registered nurses (RNs), physical therapists (PTs), occupational therapists (OTs), speech therapists (STs), and medical social workers (MSWs) (n = 601) who are employed at and make home visits for a CHHA with an average daily census of 3,000 patients. The Time 1 survey was distributed in January 2019. At that time, a total of 33% of the surveyed providers responded (n = 200). The Time 2 survey was distributed to the agency's employee roster in February/March 2021; due to attrition and new employees in the organization, the population sample for Time 2 contains some different providers.

Nonetheless, the Time 2 population yielded a suitable sample for the proposed analysis of >180. A priori power analysis was conducted using G*Power version 3.1.9.7 (Faul, et al., (2002) for sample size estimation for the planned correlational and regression analyses. For the correlation, the effect size chosen was considered to be medium (0.3) according to Cohen's (1988) criteria. With a significant criterion of $\alpha = .05$ and power = .95, the minimum sample size needed with this effect size is N = 111 for the bivariate correlation. For the regression, the effect size chosen was small (0.25) according to Cohen's (1988) criteria. With a significant criterion of $\alpha = .05$ and power = .95, the minimum sample size needed with this effect size is N = 60 for the repeated measures regression upon 11 variables. Thus, the obtained sample size of N =180 is more than adequate to test the study hypotheses using correlation and egression.

Procedure

The procedures for this study followed the Time 1 survey process for data collection. Home care providers employed at the CHHA where the study took were contacted via email through home care team email distribution lists. The web-based surveys were anonymous, and responses were voluntary, with an incentive of a chance to win a 100-dollar Amazon gift card drawing for participants who submitted the completed survey. All data were separated from the email addresses to assure anonymity. A description of the study was presented in the email and consent was indicated by their completion of the survey. The measures included a combination of established tools and one new measure developed by the investigator to assess a general simple self-reported comfort providing palliative care (Infante, 2019).

When participants submitted their responses, they were directed to a site where they could provide their email address to be contacted if they were selected to win one of the five 100-dollar Amazon gift cards. SurveyMonkey® provides an email "cover letter" that allows the investigators to inform the participants what the survey is about and what is expected. This was on the cover letter of the survey "collector." Subjects' identity was protected automatically via a SurveyMonkey® option that was selected. Because the 100-dollar incentive required contacting subjects, the survey was designed so that when the participants completed the survey, they were directed to a separate site that recorded their email for having submitted the survey. This was clear on the instructions, so participants were able to make an informed decision to participate voluntarily.

Instrumentation/Measures

The measures included instruments developed for the study and pre-tested for reliability, including items to measure comfort, attitudes, and the Collett-Lester Scale on Fear of Death with reported validity and reliability, which includes four subscales: Fear of Death, Fear of Dying, Fear of Others Death, Fear of Others Dying and the Attitude Toward Hospice Scale. The Time 2 survey included the EPCS instrument used to assess professional competence in palliative care for educational assessments.

Variables of Interest

Independent variables. The investigator used web-based survey instruments found in Appendix G and H that included a combination of measures as self-report scales. The previous instrument at Time 1 combined demographics and several measures related to health care providers' comfort with providing the core elements of palliative care with their attitudes about hospice, palliative care, and fear of death/fear of dying (Appendix G). The survey tool specifically includes items to measure several variables including:

- Demographics (age, gender, ethnicity, highest level of education, type of provider, marital status, children, and prior palliative care training, personal experience with death of a loved one) see demographic instrument.
- Comfort with providing palliative care (Level of Comfort)
- Attitude towards hospice care
- Personal fear of death (Lester & Abdel-Khalek, 2003)

Dependent variables. The new instrument (Time 2) added the measure of confidence in providing palliative care (Level of Comfort) as the dependent variable (Appendix H). The dependent measure of the Time 2 sample was the EPCS instrument used frequently to assess educational needs of staff on the identified clinical practice domains of palliative care. The EPCS, developed by Lazenby et al. (2011), is an instrument used to assess the palliative and EOL care educational needs of multidisciplinary health care professionals. Lazenby, et al., (2011) reviewed the literature for instruments that measured educational needs of health care professionals who provide palliative and EOL care. From the review of literature, they identified six domains: (1) scientific and clinical knowledge/technical skills; (2) communication/interpersonal skills with patients, family members, and other clinicians; (3) spiritual and cultural issues; (4) ethical, professional, and legal principles; (5) organizational skills; and (6) attitudes, values, and feelings of health care professionals (Lazenby et al., 2014, p. 427).

The developers of the EPCS sought to create a tool that would cover all eight domains of clinical practice guidelines identified by the NCP in 2004. These domains include:

- Domain 1: Structure and Processes of Care
- Domain 2: Physical Aspects of Care
- Domain 3: Psychological and Psychiatric Aspects of Care
- Domain 4: Social Aspects of Care
- Domain 5: Spiritual, Religious, and Existential Aspects of Care

- Domain 6: Cultural Aspects of Care
- Domain 7: Care of the Imminently Dying
- Domain 8: Ethical and Legal Aspects of Care

The EPCS is a 28-item scale with each item scored on a 5-point Likert-type scale that ranges from 1 (lowest skill level) to 5 (greatest skill level). The EPCS has a strong internal consistency (alpha = .96). It is comprised of three subscales: an 8-item Cultural and Ethical Values (CEV), 12-item Patient and Family Centered Communication (PFCC), and an 8-item ECD.

The subscales are:

Cultural and Ethical Values (8 items)

1. I am comfortable dealing with ethical issues related to end-of-life/hospice/palliative care.
2. I am able to deal with my feelings related to working with dying patients.
3. I am able to be present with dying patients.
4. I can address spiritual issues with patients and their families.
5. I am comfortable dealing with patients' and families' religious and cultural perspectives.
6. I am comfortable providing grief counseling for families.
7. I am comfortable providing grief counseling for staff.
8. I am knowledgeable about cultural factors influencing end-of-life care.

Patient and Family Centered Communication (12 items)

1. I am comfortable helping families to accept a poor prognosis.
2. I am able to set goals for care with patients and families.
3. I am comfortable talking to patients and families about personal choice and self- determination.
4. I am comfortable starting and participating in discussions about code status.
5. I can assist family members and others through the grieving process.
6. I am able to document the needs and interventions of my patients.

7. I am comfortable talking with other health care professionals about the care of dying patients.
8. I am comfortable helping to resolve difficult family conflicts about end-of-life care.
9. I can recognize impending death (physiologic changes).
10. I know how to use nondrug therapies in the management of patients' symptoms.
11. I am able to address patients' and family members' fears of getting addicted to pain medications.
12. I encourage patients and families to complete advance care planning.

Effective Care Delivery (8 items)

1. I can recognize when patients are appropriate for referral to hospice.
2. I am familiar with palliative care principles and national guidelines.
3. I am effective at helping patients and families navigate the health care system.
4. I am familiar with the services hospice provides.
5. I am effective at helping to maintain continuity across care settings.
6. I feel confident addressing requests for assisted suicide.
7. I have personal resources to help meet my needs when working with dying patients and families.
8. I feel that my workplace provides resources to support staff who care for dying patients.

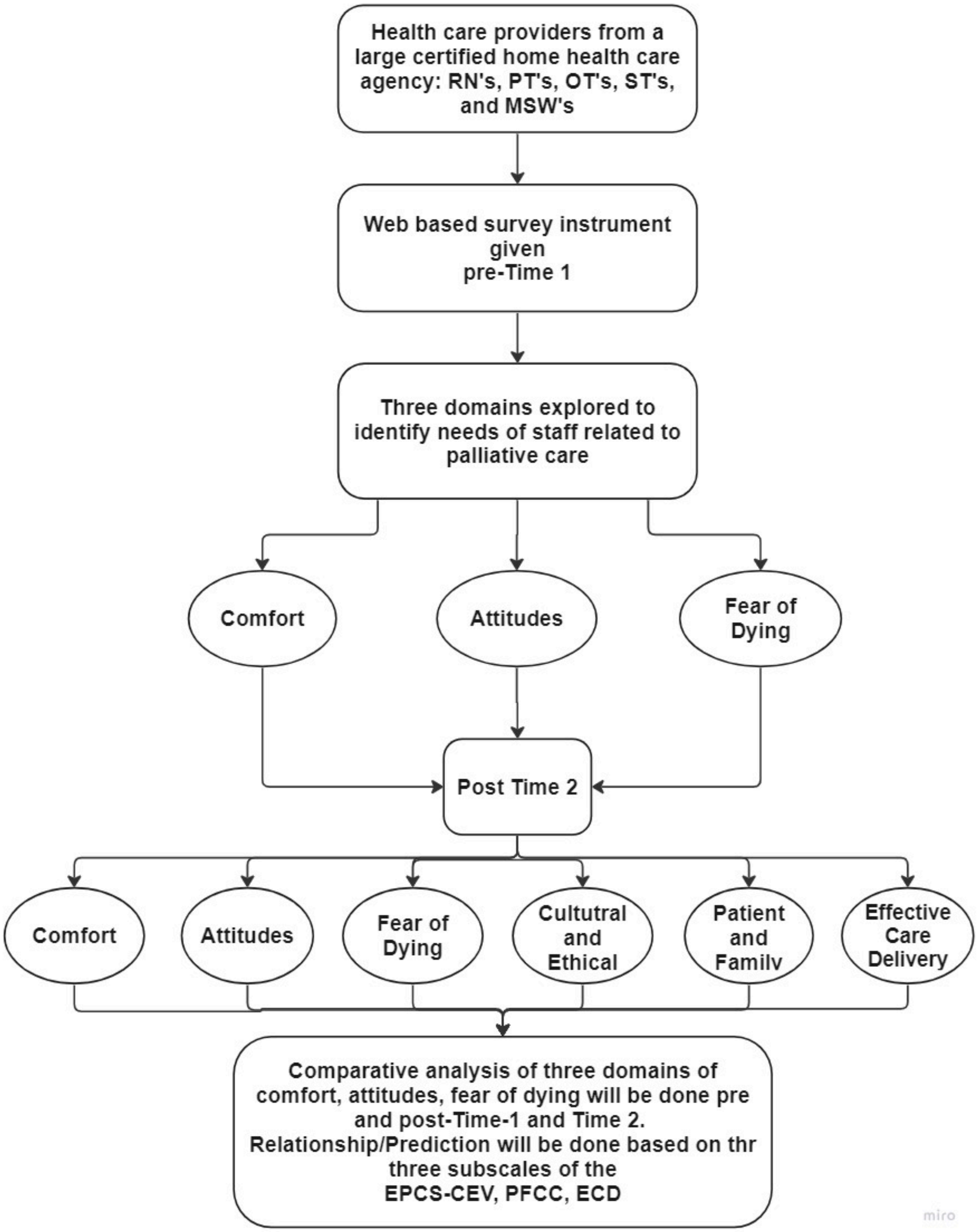
Ethical Considerations/Institutional Review Board

A research proposal was submitted to the Molloy College Institutional Review Board for both surveys, with written support from the home health care organization, and was approved. No risk was anticipated, so an exempt status was requested. Participants were recruited via emailed web-based survey. The consent form was embedded in the survey. Responses to the survey were anonymous. Participation was voluntary. The confidentiality and anonymity of the research participants were respected, and participants were reassured that they could drop out of the study at any time. Eligibility for $100 gift cards drawn at random were offered as an incentive. Data was collected from the web-based survey separate from the emails requested for the drawing and stored in double-password–protected computer systems.

Planned Analysis

The study used a combination of planned statistical analyses that considered both Time 1 and Time 2 surveys. The Time 1 survey was analyzed descriptively using SPSS-23 to identify relationships among the variables of interest. Those variables provided a baseline of data that serves as the Time 1 measures to compare with the Time 2 measures collected. Analysis included t-test and ANOVA for comparisons, correlation, and regression for relationship and prediction. Appropriate independent measures were added to the regression to predict the dependent variables (three subscales) of the EPCS.

Figure 1: Planned Analysis of Time 1 and Time 2 Data-Collection



Summary

This chapter illustrated the methods of this descriptive comparative and correlational study of health care providers' comfort with, attitudes toward, and fear of dying between Time 1 and Time 2. A web-based survey was emailed to all participants to determine which characteristics of health care providers influence their reported comfort with and attitudes toward palliative and EOL care, and fear of dying at Time 1, and compared these variables to a subsequent survey at Time 2. Those variables provided a baseline of data that serves as the Time 1 measures to compare with the Time 2 measures collected. The analysis included t-test and ANOVA for comparisons, correlation and regression for relationship and prediction. Appropriate independent measures were added to the regression to predict the dependent variables (three subscales) of the EPCS.

Chapter 4: Results

This chapter includes the presentation and analysis of the data collected for this research study. The presentation in this chapter consists of demographic data that was used to collect personal characteristics of each participant. In addition to the demographic questions, this chapter presents a descriptive summary of the general responses and psychometric properties of the instruments used to address the research questions and findings of the hypotheses.

Population/Sample

As previously described, the study participants were recruited from the list of all professional health care providers from a large CHHA. The Time 1 survey yielded 33% of the provider population (n = 200) distributed in January 2019.

The Time 2 survey was distributed to the agency's employee roster in April 2021. A total of 188 survey responses were returned by the Time 2 group (n =188). Preliminary analysis of the returned surveys resulted in the removal of 21 respondents from the first survey, leaving 188, and 23 respondents from the second survey leaving 165, because respondents did not answer an acceptable number of the questions in the survey.

Data Analysis

All data analysis was performed on the latest version of IBM SPSS Statistics 27 software.

Questionnaire Psychometrics

Each scale utilized for this study was measured for reliability of internal consistency with Cronbach's alpha coefficient, one of the most used indicators of internal consistency. According to Pallant (2020), Cronbach's alpha levels of 0.7 and above are considered acceptable for pilot testing, and values of .8 and greater are viewed acceptable for existing instruments. For this study, an alpha coefficient of > .70 was considered an acceptable value of instrument reliability.

Research Questions

TIME 1: One year prior to the outbreak of COVID-19 in New York (January 2019)

TIME 2: Approximately one year after the outbreak of COVID-19 in New York (February/March 2021)

Research Question 1

1. At Time 1, what was the staff's level of comfort with providing EOL and palliative care services? What were their attitudes toward EOL and palliative care? How fearful were they about death and dying? Was there a relationship between their personal characteristics such as level/type of education, marital status, age, having children or experience caring for a dying person with their comfort, attitudes and fears about death and dying?
    a. Describe the personal characteristics of the staff at Time 1 (age, education, marital status, having children, experience caring for a dying loved one; see Tables 1-4).

Characteristics and Demographics

The characteristic and demographic data present the findings from both survey groups. The demographic data collected in the surveys included these categories age, gender, ethnicity, highest level of education, type of provider, relationship status, children, prior palliative care training, and personal experience with death of a loved one.

Personal and demographic characteristics are summarized in Table 1. The respondent population contained 188 providers (n =188): the gender composition was 87.8% female (n =165) and 11.7% male (n =22), with one response missing. To encourage response rates for age reporting, the survey requested age information in ranges, rather than exact age numbers. The age range data were as follows: 21-34 years of age (n =8, 4.3%), 35-44 years of age (n =25, 13.3%), 45-54 years of age (n =55, 29.3%), 55-64 years of age (n =82, 43.6%), 65-74 years of age (n =17, 9.0%), and 75 years of age or older (n =1, 0.5%). Respondents were mostly female and there was a preponderance of providers over the age of 55 in the sample. For some analyses in the study, age was consolidated as younger (<45) and older (> or = to 45).

The relationship status of the sample Time 1 was: married n =139 (73.9%), widowed n =4 (2.1%), divorced n =23 (12.2%, separated n =2 (1.1%), single, but cohabitating with a significant other n =9 (4.8%), single, never married n =8 (4.3%), with 3 respondents not answering the relationship status question. The survey also asked if the respondents had children. Time 1 answered as follows: those who have children n =165 (87.8%), and those who do not have children n =20 (10.6%). There were three respondents who did not answer this question. Respondents were asked if they have personally cared for a dying loved one. Time 1 answered as follows: those who answered yes n =127 (61.2%) and those who have not cared for a dying loved one were n =61 (38.2%). In summary, most respondents were married and had children; a majority had cared for a dying loved one. For the purpose of hypothesis testing, marital status was recoded as Married (including those in a domestic partnership/civil union) = 1, Single = 2.

Table 1: Time 1 Sample Demographics: Personal Characteristics

	n	%
Gender		
Female	165	87.8
Male	22	11.7
Missing	1	0.6
Total	188	100
Age		
21 to 34	8	4.3
35 to 44	25	13.3
45 to 54	55	29.3
55 to 64	82	43.6
65 to 74	17	9.0
75 or older	1	0.5
Total	188	100
Relationship Status		
Married	139	73.9
Widowed	4	2.1
Divorced	23	12.2
Separated	2	1.1
Single, but cohabiting with a significant other	9	4.8
Single Never Married	8	4.3
Missing	3	1.6
Total	188	100
Children		

Yes	165	87.8%
No	20	10.6
Missing	3	1.6
Total	188	100
Personally cared for a dying loved one		
Yes	127	61.2
No	61	38.2
Total	188	100

The personal and demographic characteristics of the Time 2 sample are summarized in Table 2. The gender composition of the Time 2 sample consisted of 85.5% female (n =141) and 13.9% male (n =23) with one missing answer. To encourage response rates for age reporting, the survey requested age information in ranges, rather than exact age numbers. The age ranges of the Time 2 survey were as follows: 21-34 years of age n =5 (3.0%), 35-44 years of age n =22 (13.3%), 45-54 years of age n =49 (29.7%), 55-64 years of age n =72 (43.6%), 65-74 years of age n =17 (9.0%), and 75 years of age or older n =1 (0.5%). The relationship status of the sample was obtained with Time 2 as follows: married n =116 (70.3%), widowed n =3 (1.8%), divorced n =30 (18.2% , separated n =1 (0.6%), in a domestic partnership or civil union n =2 (1.2%), single but cohabitating with a significant other n =4 (2.4%), single, never married n =9 (5.5%); three respondents did not answer the relationship status question. The survey also asked if the respondents had children. Time 2 answered as follows: those who have children n =147 (89.1%), and they do not have children n =18 (10.9%). There were three respondents who did not answer this question. The respondents were asked if they have personally cared for a dying loved one; those who answered yes n =101 (61.2%), and those who have not cared for a dying loved one n =63 (38.2%), with one respondent not answering this question (see Table 2).

The demographic samples for both Time 1 and Time 2 demonstrated similar results indicating that although the survey did not capture the same individuals by design, respondents represented the same population of healthcare workers in the organization at two points in time.

Table 2: Time 2 Sample Demographics: Personal Characteristics

		n	%
Gender	Female	141	85.5%
	Male	23	13.9%
	Missing	1	0.6
	Total	165	100%
Age			
	21 to 34	5	3.0%
	35 to 44	22	13.3%
	45 to 54	49	29.7%
	55 to 64	72	43.6%
	65 to 74	17	10.3%
	75 or older	0	0.0%
	Total	165	100.0%
Relationship Status			
	Married	116	70.3%
	Widowed	3	1.8%
	Divorced	30	18.2%
	Separated	2	0.6%
	Single, but cohabiting with a significant other	4	2.4%
	Single, never married	9	5.5%
	In a domestic partnership or civil union	2	1.2%
	Total	166	100.0%
Children	Yes	147	89.1%
	No	18	10.9%
Personally cared for a dying loved one	Yes	101	61.2%
	No	63	38.2%
	Total	164	100.0%

Academic Degree, Type of Provider, Work Experience. The academic degree, type of provider, and work experience are displayed for the Time 1 sample in Table 3. For type of degree, master's and bachelor's were the most frequently reported with master's n =49 (26.1%) and bachelor's n =81 (43.1%). Those with an associate's degree were n =36 (19.1%), doctoral degree n =10 (5.3%), and both the diploma degree and licensed practical nurse degree holders were n =6 (3.2%). The types of providers who responded to the survey included advance practice nurses n =2 (1.1%), clinical home care nurse-RNs n =113 (60.1%), clinical home care nurse-LPNs n =8 (4.3%), physical therapists n =40 (21.3%), occupational therapists n =6 (3.2%), speech therapists n =3 (1.6%), social workers n =12 (6.4%), with n =2 (1.1%) that were missing the answer for the type of provider. Palliative care experience as it relates to this study was determined by how the respondents answered the question: Have you received any formal palliative care or hospice care training? The number of respondents who reported some type of palliative or hospice training was n =78 (41.5%). Those who answered no to prior training were n =101 (53.7%).

Table 3: Time 1 Sample Academic Degree, Type of Provider, Work Experience

		N	Percent
Highest Degree Level of Education	Doctoral Degree	10	5.3%
	Master's Degree Bachelor's Degree	49	26.1%
		81	43.1%
	Associate's Degree Diploma Degree	36	19.1%
	Licensed Practical Nursing Degree	6	3.2%
		6	3.2%
	Missing	0	0%.
	Total	188	100%
Type of Provider	Other (please explain if no choice above)	2	1.1%
	Advance Practice Nursing	2	1.1%
	Clinical Home Care Nurse - RN	113	60.1%
	Clinical Home Care Nurse - LPN	8	4.3%
	Physical Therapist	40	21.3%
	Occupational Therapist Speech Therapist	6	3.2%
	Social Work	3	1.6%
	Missing	12	6.4%
		2	1.1%
	Total	188	100.0%
Prior Palliative Care Training	Other (please write here if the choices are not sufficient about your prior training).	9	4.8%
	Yes	78	41.5%
	No Missing Total	101	53.7%
		0	0%
		188	100.0%

The academic degree, type of provider, and work experience are displayed for the Time 2 sample in Table 4. For type of degree, master's and bachelor's were the most frequently reported with master's n =34 (20.6%) and bachelor's n =81 (49.1%). Those with an associate's degree were n =23 (13.9%), doctoral degree n =16 (9.7%), diploma degree n =3 (1.8%), and licensed practical nurse degree holders were n =7 (4.2%). One respondent did not answer with n =1 (0.6%). The types of providers who responded to the survey included advance practice nurses n =3 (1.8%), clinical home care nurse-RNs n =99 (60.0%), clinical home care nurse-LPNs n =8 (4.8%), physical therapists n =39 (23.6%), occupational therapists n =4 (2.4%), speech therapists n =2 (1.2%), social worker n =6 (3.6%), with n =4 (2.4%) that were missing the answer for the type of provider. Palliative care experience as it relates to this study was determined by how the respondents answered the question: Have you received any formal palliative care or hospice care training? The number of respondents who reported some type of palliative or hospice training was n =93 (56.4%). Those who answered no to prior training were n =65 (39.4%). Although most of these results were comparable for the Time 1 and Time 2 samples, the Time 2 sample indicated that they had more palliative care or hospice training than the Time 1 sample (56.4% vs. 41.5%), which could be expected.

For the purpose of hypothesis testing, several demographic characteristics were consolidated. For age, the participants were coded as less than age 45 =1 and greater than or equal to age 45 =2. For the highest level of education, the participants were coded as above bachelors =1, bachelors=2, below bachelors=3. For the discipline of providers, the participants were coded as “nurses” = 1 and “non-nurses” = 2. For married/relationship status, the participants were coded as married (including those in a domestic partnership/civil union) =1 and single (including widowed, divorced, separated, single, but cohabitating with a significant other, and single, never married) = 2.

Table 4: Time 2 Sample Academic Degree, Type of Provider, Work Experience

		N	Percent
Highest Degree Level of Education	Doctoral Degree	16	9.7%
	Master's Degree	34	20.6%
	Bachelor's Degree	81	49.1%
	Associate's Degree	23	13.9%
	Diploma Degree	3	1.8%
	Licensed Practical Nursing Degree	7	4.2%
	Missing	1	.6%
	Total	165	100%
Type of Provider	Advance Practice Nursing	3	1.8%
	Clinical Home Care Nurse - RN	99	60.0%
	Clinical Home Care Nurse - LPN	8	4.8%
	Physical Therapist	39	23.6%
	Occupational Therapist Speech Therapist	4	2.4%
	Social Work	2	1.2%
	Missing	6	3.6%
		3	1.8%
	Other	1	.6%
	Total	165	100.0%
Prior Palliative Care Training	Other (please write here if the choices are not sufficient about your prior training).	6	3.6%
	Yes	93	56.4%
	No Missing Total	65	39.4%
		1	0.6%
		165	100.0%

Describe the home care staff's level of comfort providing EOL and palliative care services and their attitudes toward EOL and palliative care. Describe how fearful staff are about death and dying for themselves and for others.

Descriptive analyses were performed on the measures used in the study including level of comfort (Comfort Composite Score— including all five comfort variables), attitudes toward EOL (Attitude Composite Score— including all attitude variables), and Fear of Death and Dying (Fear of Death and Dying Composite Score— including all fear variables) with its four subscales (Fear of Death Own Self; Fear of Dying Self; Fear of Death Others; and Fear of Dying Others). The means and standard deviations of all measures are listed in Table 5 with associated Cronbach's Alpha scores that demonstrated reliability >.70.

Table 5: Means and Standard Deviations of all Measures.

	Times	N	Mean	Std. Deviation	Cronbach's Alpha
Attitude Composite Score	1	188	4.20	.44	.760
	2	165	4.13	.46	.753
Comfort Composite Score	1	188	3.68	.83	.888
	2	165	3.54	.90	.879
Fear Death and Dying Composite Score	1	186	3.19	.69	.933
	2	165	3.27	.72	.927
Fear of Death Own Self	1	186	2.80	.93	.839
	2	165	2.93	.98	.838
Fear of Dying Self Score	1	186	3.40	.89	.874
	2	165	3.53	.92	.878
Fear of Death of Others Score	1	186	3.40	.73	.761
	2	165	3.33	.76	.764
Fear of Dying of Others Score	1	186	3.13	.81	.834
	2	165	3.22	.79	.819

Hypothesis: There is a relationship between personal characteristics and level of comfort, attitudes toward EOL, and fear of death/dying (self/others) for respondents from Time 1 (see Tables 6-12) stated in the null:

H0: There is no relationship between the personal characteristics of staff and their level of comfort providing EOL and palliative care services.

The hypothesis about the personal characteristics of staff and their level of comfort yields significant results for some personal characteristics. The personal characteristic of staff discipline was recoded to indicate those who were nurses (1) and those who were not nurses (2). The correlation for staff discipline was r = - .273, p<.001, for staff reporting any formal palliative care or hospice care training, r =

.151, p < .01, and for the staff characteristic of personally having cared for a dying loved one r = .294, p<.001. The null hypothesis is rejected. Personal characteristics are significantly related to staff level of comfort providing EOL and palliative care services. For non-nurses versus nurses, there was a lower level (negative) of comfort with providing EOL care. There is a positive relationship between staff having received any formal palliative care or hospice care training with their level of comfort with EOL and palliative care services. There is also a positive relationship for the staff characteristic of having personally cared for a dying loved one and their comfort level with EOL and palliative care services.

H01: There is no relationship between personal characteristics of staff and their attitudes toward EOL and palliative care.

Most personal characteristics of staff did not yield clinically significant results on attitudes of staff toward providing EOL and palliative care, but with the correlation for having personally cared for a dying loved one being r = .221, p< .001, the null hypothesis is rejected for prior personal experience only. Staff attitudes toward providing EOL and palliative care is significantly related positively to whether they have personally cared for a dying loved one.

H02: There is no relationship between personal characteristics and their (a) fear of death for themselves; (b) fear of dying for themselves; (c) fear of death of others; (d) fear of dying others.

The hypothesis about to the relationship of personal characteristics and staff fear of death and dying of self and others yields significant results. With Pearson Correlation (Fear of Dying Self Score with gender r = -.169, p = .002) and (Fear of Death of Others Composite Score with age r = -.158, p = .003), the null hypothesis is rejected. There is a relationship between staff age and gender and their fear of death and dying. The results showed that women were more likely to have a fear of dying. Younger staff were more likely to fear the death of others.

Table 6: Time 1 Statistics: Gender

	Gender	N	Mean	Std. Deviation	t Test
Attitude Composite Score	Female	165	4.21	.46	-.063
	Male	22	4.21	.33	
Comfort Composite Score	Female	165	3.67	.83	.199
	Male	22	3.64	.78	
Fear Death and Dying Composite Score	Female	163	3.23	.66	1.889
	Male	22	2.94	.82	
Fear of Death Own Self	Female	163	2.84	.92	1.455
	Male	22	2.53	.99	
Fear of Dying Self Score	Female	163	3.44	.87	2.037*
	Male	22	3.03	1.02	
Fear of Death of Others Composite Score	Female	163	3.42	.71	.391
	Male	22	3.28	.87	
Fear of Dying of Others Composite Score	Female	163	3.1671	.78	.116
	Male	22	2.8788	.93	

*p<.05.

Table 7: Time 1 Statistics: Age Recoded

	Age Recoded	N	Mean	Std. Deviation	t Test
Attitude Composite Score	44 and under	33	4.28	.41	.986
	45 and older	155	4.19	.45	
Comfort Composite Score	44 and under	33	3.67	.85	-.017
	45 and older	155	3.68	.83	
Fear Death and Dying Composite Score	44 and under	32	3.31	.79	1.113
	45 and older	154	3.17	.66	
Fear of Death Own Self	44 and under	32	2.99	.89	1.254
	45 and older	154	2.76	.93	

Fear of Dying Self Score	44 and under	32	3.35	.90	184
	45 and older	154	3.41	.89	
Fear of Death of Others Composite Score	44 and under	32	3.63	.83	1.992*
	45 and older	154	3.35	.70	
Fear of Dying of Others Composite Score	44 and under	32	3.25	1.14	.708
	45 and older	154	3.10	.73	

*p<.05.

Table 8: Group Statistics: Discipline Recoded

	Discipline Recoded	N	Mean	Std. Deviation	T-Test
Attitude Composite Score	Nurses	123	4.22	.46	.519
	Non-Nurses	61	4.18	.42	
Comfort Composite Score	Nurses	123	3.83	.78	3.837**
	Non-Nurses	61	3.34	.85	
Fear Death and Dying Composite Score	Nurses	121	3.19	.68	-.198
	Non-Nurses	61	3.21	.69	
Fear of Death Own Self	Nurses	121	2.84	.89	.886
	Non-Nurses	61	2.72	.97	
Fear of Dying Self Score	Nurses	121	3.40	.85	.217
	Non-Nurses	61	3.37	.99	
Fear of Death of Others Composite Score	Nurses	121	3.38	.75	-.833
Fear of Dying of Others Composite Score	Nurses	121	3.08	82	-1.032

**p<.01.

Table 9: Group Statistics: Marital Status

	Marital Status Recoded	N	Mean	Std. Deviation	T-Test
Attitude Composite Score	Married	139	4.19	.42	-1.103
	Single	46	4.28	.49	
Comfort Composite Score	Married	139	3.65	.80	-.583
	Single	46	3.73	.93	
Fear Death and Dying Composite Score	Married	138	3.22	.71	.617
	Single	45	3.14	.63	
Fear of Death Own Self-Composite Score	Married	138	2.84	.95	.897
	Single	45	2.70	.87	
Fear of Dying Self Composite Score	Married	138	3.42	.90	.383
	Single	45	3.36	.87	
Fear of Death of Others Composite Score	Married	138	3.43	.76	.726
	Single	45	3.34	.65	
Fear of Dying of Others Composite Score	Married	138	3.13	.87	.069
	Single	45	3.12	.64	

Table 10: Group Statistics: Children

Any children?	N	Mean	Std. Deviation		t Test
	Yes	165	4.21	.45	.077
Attitude Composite Score	No	20	4.20	.42	
Comfort Composite Score	Yes	165	3.69	.82	.989
	No	20	3.50	.92	
Fear Death and Dying Composite Score	Yes	163	3.21	.69	.962
	No	20	3.06	.61	
Fear of Death Own Self	Yes	163	2.84	.93	1.540
	No	20	2.51	.82	
Fear of Dying Self Score	Yes	163	3.44	.90	1.835
	No	20	3.05	.74	
Fear of Death of Others Composite Score	Yes	163	3.40	.74	-.074
	No	20	3.41	.71	
Fear of Dying of Others Composite Score	Yes	163	3.12	.81	-.256
	No	20	3.17	.84	

Table 11: Prior Formal Palliative Care or Hospice Care Training

	Have you received any formal palliative care or hospice care training?	N	Mean	Std. Deviation	t Test
Attitude Composite Score	No	101	4.16	.43	-1.524
	Yes	78	4.26	.46	
Comfort Composite Score	No	101	3.55	.79	-2.495*
	Yes	78	3.86	.86	
Fear Death and Dying Composite Score	No	100	3.22	.73	.647
	Yes	78	3.15	.64	
Fear of Death Own Self	No	100	2.82	1.02	.156
	Yes	78	2.79	.84888	
Fear of Dying Self Score	No	100	3.44	.93	.943
	Yes	78	3.31	.85	
Fear of Death of Others Composite Score	No	100	3.44	.76	.790
	Yes	78	3.35	.69	
Fear of Dying of Others Composite Score	No	100	3.13	.81	.287
	Yes	78	3.10	.81	

*p<.05

Table 12: Group Statistics: Personally Cared for a Dying Loved One

	Have you personally cared for a dying loved one?	N	Mean	Std. Deviation	t Test
Attitude Composite Score	No	61	4.09	.41	-2.697**
	Yes	127	4.27	.45	
Comfort Composite Score	No	61	3.36	.90	-3.470**
	Yes	127	3.82	.75	
Fear Death and Dying Composite Score	No	60	3.20	.58	.097
	Yes	126	3.19	.73	
Fear of Death Own Self	No	60	2.80	.82	-.027
	Yes	126	2.80	.98	
Fear of Dying Self Score	No	60	3.27	.83	-1.349
	Yes	126	3.46	.91833	
Fear of Death of Others Composite Score	No	60	3.46	.65	.719
	Yes	126	3.38	.77	
Fear of Dying of Others Composite Score	No	60	23	8	1.189
	Yes	126	3.08	.86	

**p<.01

Research Question 2

1. Is there a difference in staff level of comfort with providing EOL and palliative care services, attitudes toward EOL and palliative care services between Time 1 and Time 2? Does fear of death and/or fear of dying change between Time 1 and Time 2?
    a. Describe level of level of comfort, attitudes about providing EOL and palliative care, and fear of death/fear of dying at Time 1 and Time

Hypotheses: There are differences in the Time 1 and Time 2 mean scores of levels of comfort with providing EOL care, attitudes toward EOL care, and fear of death/dying (self/others) stated in the null:

H03: There is no difference in the mean scores for level of comfort with providing EOL care between Time 1 and Time 2 (see Table 13).

An independent-samples t Test was conducted to compare the Level of Comfort Providing EOL Care Scores for Time 1 and Time 2. There was no significant difference in overall scores for Time 1 (M = 3.68, SD = .06) and Time 2 (M = 3.54, SD = .06; t (351) = 1.5, p = .13). The magnitude of the difference in the means (mean difference = .14, 95% CI [-.04, .32]) was very small. There was a significant trend in the difference between caregivers' level of comfort between Time 1 and Time 2 seen in the question of "Discussing the Dying Process" (p = .085), with comfort decreasing from 3.61 before the pandemic to 3.41 one year into the pandemic but did not reach significance at α <.05.

Table 13: Sample T-Test Comparisons of Level of Comfort for Caregivers Time 1 and Time 2

	(N=188)		Time 2 (N=165)		
	M	SD	M	SD	t Test
EOL-Convo	3.66	.99	3.50	1.03	.139
Discussing Dying Process	3.61	1.01	3.41	1.10	1.73*
Religious Spiritual Needs	3.73	0.92	3.67	0.91	0.58
Discussing Palliative Care	3.74	.93	3.70	0.99	0.42
Discussing Life-Limiting Illness	3.69	.88	3.54	0.96	1.48

*p < .10

Levene's Test indicated equal variances.

Note. M = Mean. SD = Standard Deviation. All variables range from 1 (Strongly Disagree) to 5 (Strongly Agree)

H04: There is no difference in the mean scores for attitudes toward Hospice care between Time 1 and Time 2 (see Table 14).

An independent-samples t-test was conducted to compare the Attitude Toward Hospice Scores for Time 1 and Time 2. There was no significant difference in scores for Time 1 (M = 4.21, SD =.44) and Time 2 (M = 4.13, SD = .46). The magnitude of the differences in the means (mean difference = .08, 95% CI [- .02, .17]) was very small. The only significant difference between caregivers' attitudes toward hospice before the pandemic and one year into the pandemic was seen in the measure of "Attitude toward pain control" (Item "If I were dying, I would want my pain controlled even if it meant hastening my death") and this was significant at the α = .05 level, with attitude toward hospice pain control decreasing from 4.38 before the pandemic to 4.21 one year into the pandemic.

Table 14: Sample Descriptives of Attitudes Toward Hospice Time 1 and Time 2

	Time 1 (N=188)		Time 2 (N=164)		
	M	SD	M	SD	t Test
Value Supportive Care of Hospice	4.62	0.51	4.54	0.61	1.25
Attitude Toward Pain Control	4.38	0.75	4.21	0.86	2.04**
Personal Past Experience Negative	4.07	.99	4.00	1.05	0.624
Hospice as Living Well Until We Die	4.07	0.84	3.96	0.96	1.347
Would Not Want Relative to Receive Hospice	4.47	0.84	4.40	0.93	0.685
Hospice Close to Dying Service	2.80	1.04	2.91	1.13	-0.990
Past Personal Experience Positive	3.68	1.06	3.78	0.97	0.685
Hospice Care Appeals to Me	3.80	0.99	3.70	0.97	0.960
Making Living Will Smart	4.43	0.69	4.38	0.69	0.674
Comfortable with Issues of Death and Dying	3.80	0.89	3.73	0.93	0.722
Do Not Like to Talk About Death, Dying, Hospice	3.83	0.95	3.74	0.93	0.881
Hospice Decision Made by Irrational People	4.65	0.61	4.60	0.63	0.746

People Should Be Allowed to Die in Pe at Home	4.54	0.60	4.58	0.71	-0.523

**p < .05.
Levene’s Test indicated equal variances.
Note. M = Mean. SD = Standard Deviation. All variables range from 1 (Strongly Disagree) to 5 (Strongly Agree)

H05: There is no difference in the mean scores for fear of death (self) between Time 1 and Time 2. (see Table 15)

An independent-samples t-test was conducted to compare the Fear of Death Self for Time 1 and Time 2. There was no significant difference in overall scores for Time 1 (M = 2.80, SD = .93) and Time 2 (M = 2.93, SD = .98). The magnitude of the differences in the means (mean difference = -.13, 95% CI [-.33, .07]) was very small. There was a significant difference between caregivers’ feelings toward fear of death self before the pandemic and one year into the pandemic. This was on “Death and the shortness of life” with mean increasing from 3.07 before the pandemic to 3.32 one year into the pandemic. This difference was significant at the α = .05 level.

Table 15: Sample T-Test Comparisons of Feeling Towards Death and Dying Self Time 1 and Time 2

	Time 1 (N=188)		Time 2 N=164)		
	M	SD	M	SD	t-test
Death, Shortness of Life	3.07	1.05	3.32	1.12	-2.16**
Death Dying Young	3.55	1.27	3.60	1.36	-0.37
Death – Missing out After You Die	3.17	1.34	3.30	1.37	-0.90
Death How Will It Feel to Be Dead	2.39	1.31	2.45	1.41	-0.47
Death- Never Thinking of Experiencing	2.52	1.25	2.67	1.31	-1.09
Death- Disintegration of Body	2.09	1.30	2.21	1.33	-0.84
Death- Physical Degeneration	3.06	1.30	3.16	1.32	-0.71
Death- Pain of Dying	3.55	1.17	3.55	1.12	0.027
Death- Intellectual Degeneration of Old Age	3.60	0.97	3.71	1.09	-0.92

Death- Dying Limited Abilities	3.54	1.19	3.67	1.19	-0.99
Death- Uncertainty of Braveness	3.23	1.19	3.38	1.21	-1.18
Death- Lack of Control	3.33	0.61	3.52	1.15	-1.47
Death- Dying in Hospital Away from Ot	3.44	1.33	3.74	1.20	-2.19**

**p<.05
Levene's Test indicated equal variances.
Note. M = Mean. SD = Standard Deviation. All variables range from 1 (Strongly Disagree) to 5 (Strongly Agree)

H06: There is no difference in the mean scores for fear of dying (self) between Time 1 and Time 2 (see Table 15).

An independent-samples t-test was conducted to compare the Fear of Dying Self for Time 1 and Time 2. There was no significant difference in overall scores for Time 1 (M = 3.40, SD = .89) and Time 2 (M = 3.53, SD = .92). The magnitude of the differences in the means (mean difference = -.14, 95% CI [-.33, .05]) was very small. There was a significant difference between caregivers' feelings toward fear of dying self before the pandemic and one year into the pandemic. This was on "Death- Dying in Hospital Away from Others" with the mean increasing from pre-pandemic at 3.44 to 3.74 one year into the pandemic. This difference was significant at the α = .05 level.

H07: There is no difference in the mean scores for fear of death (others) between Time 1 and Time 2. (See Table 16)

An independent-samples t-test was conducted to compare the Fear of Death (Others) for Time 1 and Time 2. There was no significant difference in scores for Time 1 (M = 3.40, SD =.73) and Time 2 (M = 3.32, SD = .76). The magnitude of the differences in the means (mean difference = .07, 95% CI [- .08, .23]) was very small.

Table 16: Sample T-Test Comparisons of Feeling Towards Death and Dying of Others Time 1 and Time 2

	Time 1 (N=185)		Time 2 (N=165)		
	M	SD	M	SD	t-test
Death, Losing Someone Close	4.323	0.92	4.32	0.94	0.03
Death of Others Seeing Dead Body	2.63	1.35	2.59	1.35	0.30
Death of Others-Never Communicating Again	4.20	1.02	4.13	1.17	0.64
Death of Others-Regrets	2.60	1.23	2.44	1.32	1.37
Death of Others- Growing Old Alone	3.93	1.11	3.84	1.13	0.73
Death of Others- Guilt Relieved That They are Dead	2.16	1.17	2.21	1.18	0.37
Death of Others- Feeling Lonely	3.98	1.00	3.88	1.06	0.91
Dying of Others Being with the Dying	2.45	1.26	2.47	1.21	-0.14
Dying of Others- Talking About Death	2.22	1.21	2.22	1.16	-0.01
Dying of Others- Watching Their Suffering	4.19	0.98	4.27	1.06	-0.77
Dying of Others-Seeing Physical Degeneration	3.36	1.09	3.51	1.21	-1.24
Dying of Others- Not Knowing What To Do About Grief When with Them	3.09	1.11	3.15	1.08	-0.46
Dying of Others- Watching Their Mental Deterioration	3.55	1.06	3.67	1.01	-1.08
Dying of Others Reminder of Own Death	3.02	1.21	3.27	1.15	-1.98**

**p < .05
Levene's Test indicated equal variances.
Note. M = Mean. SD = Standard Deviation. All variables range from 1 (Strongly Disagree) to 5 (Strongly Agree)

H08: There is no difference in the mean scores for fear of dying (others) between Time 1 and Time 2. (See Table 16)

An independent-samples t-test was conducted to compare the Fear of Dying Others for Time 1 and Time 2. There was no significant difference in overall scores for Time 1 (M = 3.13, SD = .81) and Time 2 (M = 3.22, SD = .79). The magnitude of the differences in the means (mean difference = -.10, 95% CI [- .27, .07]) was very small. There was a significant difference between caregivers' feelings about dying of others before the pandemic and one year into the pandemic was seen in the measure of "Dying of others- reminder of own death" and this was significant at the $\alpha = .05$ level, with feelings of concern increasing from 3.02 before the pandemic, and to 3.27 one year into the pandemic (see Table 16).

A summary of the non-significant mean scores for all composite measures is in Table 17.

Table 17: Sample T-Test Comparisons of Comfort, Attitudes, and Fear of Death and Dying Toward Hospice Time 1 and Time 2

	Time 1 (N=185)		Time 2 (N=165)		
	M	SD	M	SD	t-test
Attitude Hospice Score	4.21	0.44	4.13	0.46	0.11
Comfort Hospice Score	3.68	0.83	3.54	0.90	0.33
Fear of Death Dying Score	3.19	0.69	3.26	0.72	0.34
Fear of Death Own Self Score	2.80	0.93	2.93	0.98	-1.263
Fear of Dying Self Score	3.40	0.89	3.53	0.92	-1.410
Fear of Death Others Score	3.40	0.73	3.32	0.76	0.929
Fear of Dying Others Score	3.13	0.81	3.22	0.79	-1.137

**p < .05 (all in this table)

Levene's Test indicated equal variances.
Note. M = Mean. SD = Standard Deviation. All variables range from 1 (Strongly Disagree) to 5 (Strongly Agree)

Research Question 3

3. Is there a relationship between staff level personal characteristics, comfort and attitudes about

providing EOL and palliative care services with their self-reported End-of-Life Professional Caregiver Survey (EPCS) scores? Does their fear of death or fear of dying predict their EPCS scores?

a. Describe correlations between personal characteristics, comfort, attitudes, and EPCS (all 3 subscales) at Time 2 EPCS Results

The relationship between EPCS values for the subscale of CEV and Personal Characteristics was investigated using a Pearson product-moment correlation coefficient. Preliminary analyses were performed to ensure no violation of the assumptions of normality and linearity unless otherwise noted. There was a positive correlation between EPCS-CEV subscale results and those participants who reported formal training in hospice and palliative care, r = .24, n = 153, p < .01, with higher values associated with reported formal training in hospice and palliative care. There was also a positive correlation for the EPCS-CEV subscale results and those participants who had personally cared for a dying loved one, r = .22, n =153, p < .01. Respondents who had personally cared for a dying loved one had higher scores on EPCS-CEV. The data demonstrated a negative correlation between EPCS-CEV subscale scores and participants' discipline, r = -.37, n = 153, p < .001. Those participants who were not nurses as coded in the analysis scored lower on the EPCS- CEV than nurses (see Table 18).

Table 18: Correlations between EPCS_ CEV and Personal Characteristics

		EPCS_CEV
What is your gender?	Pearson Correlation	-.122
	Sig. (2-tailed)	.135
	N	152
Do you have any children?	Pearson Correlation	.104
	Sig. (2-tailed)	.202
	N	153
Marital Status Recoded	Pearson Correlation	.183
	Sig. (2-tailed)	.023*
	N	153
Education Recoded	Pearson Correlation	.028
	Sig. (2-tailed)	.729
	N	152
Discipline Recoded	Pearson Correlation	-.371
	Sig. (2-tailed)	.000**

	N	149
Received formal palliative care/hospice training	Pearson Correlation	.239**
	Sig. (2-tailed)	.003
	N	150
Personally cared for dying loved one	Pearson Correlation	.224**
	Sig. (2-tailed)	.006
	N	150

The relationship between EPCS values for the full scale and three subscales of CEV and EOL Comfort Variables was investigated using a Pearson product-moment correlation coefficient. There was a statistically significant relationship for the composite Comfort Scale and all three subscales (r = .683, p<.001 [PFCC]; r = .568, p<.001 [CEV] and r = .572, p<.001 [ECD]. There was a moderate positive relationship between EPCS-CEV subscale results and all five EOL Comfort Variables (see Table 19).

Table 19: Correlations between EPCS CEV and EOL Comfort Variables

		EPCS_CEV
Comfort Initiating EOL Conversations	Pearson Correlation	.538
	Sig. (2-tailed)	.000**
	N	153
Comfort Discussing Dying Process	Pearson Correlation	.591
	Sig. (2-tailed)	.000**
	N	153
Comfort Discussing Religious Needs	Pearson Correlation	.507
	Sig. (2-tailed)	.000**
	N	153
Comfort Initiating PC Discussions	Pearson Correlation	.390
	Sig. (2-tailed)	.000**
	N	153

Comfort Discussing Life-Limiting DX	Pearson Correlation	.549
	Sig. (2-tailed)	.000**
	N	153

**p < .001 All significant at α = .01

The relationship between EPCS values for the subscale of CEV and Attitudes toward Hospice was investigated using a Pearson product-moment correlation coefficient. There was a moderate positive correlation between the EPCS-CEV and Attitudes toward Hospice for three of the attitude variables Hospice care appeals to me, Comfortable with issues with death and dying, and don't like talking about death, dying, or hospice care. Those participants who demonstrated agreement with these statements scored higher values on EPCS-CEV (see Table 20).

Table 20: Correlations between EPCS Cultural and Ethical Values (CEV)and Attitudes towards Hospice

		EPCS_CEV
Value Supportive Care Hospice Provides	Pearson Correlation	.090
	Sig. (2-tailed)	.272
	N	152
Attitude Toward Pain Control	Pearson Correlation	.172
	Sig. (2-tailed)	.034*
	N	153
Personal Past Experience Negative	Pearson Correlation	.035
	Sig. (2-tailed)	.667
	N	150
Hospice as Living Well Until We Die	Pearson Correlation	.133
	Sig. (2-tailed)	.100
	N	153
Don't Want Terminally Ill Relative to Receive Hospice	Pearson Correlation	-.075
	Sig. (2-tailed)	.360
	N	152
Hospice Close to Dying Service	Pearson Correlation	.176
	Sig. (2-tailed)	.031*

	N	150
Past Personal Experience Positive	Pearson Correlation	.150
	Sig. (2-tailed)	.064
	N	153
Hospice care Appeals to Me	Pearson Correlation	.230
	Sig. (2-tailed)	.004**
	N	152
Making Living Will Smart	Pearson Correlation	.108
	Sig. (2-tailed)	.184
	N	153
Comfortable with Issues of Death and Dying	Pearson Correlation	.543
	Sig. (2-tailed)	.000**
	N	152
Don’t like talking About Death, Dying, Hospice	Pearson Correlation	.495
	Sig. (2-tailed)	.000**
	N	153
Hospice Decision made By Irrational People	Pearson Correlation	.140
	Sig. (2-tailed)	.086
	N	152
Should be Allowed to Die in Peace at Home	Pearson Correlation	.135
	Sig. (2-tailed)	.097
	N	153

*$p < .05$ Significant at $\alpha = .05$ level (2-tailed)**$p < .01$ Significant at $\alpha = .01$ level (2-tailed)

The relationship between EPCS values for the subscale of CEV and Fear of Death and Dying was investigated using a Pearson product-moment correlation coefficient. There was no significant correlation between EPCS, CEV values, and Fear of Death and Dying (see Table 21).

EPCS_CEV Correlations

Table 21: Correlations between EPCS CEV and Fear of Death and Dying

		EPCS_CEV
Fear of Death Own Self	Pearson Correlation	.080
	Sig. (2-tailed)	.324
	N	153
Fear of Dying Self Score	Pearson Correlation	.084
	Sig. (2-tailed)	.301
	N	153
Fear of Death of Others Composite Score	Pearson Correlation	-.009
	Sig. (2-tailed)	.916
	N	153
Fear of Dying of Others Composite Score	Pearson Correlation	-.057
	Sig. (2-tailed)	.483
	N	153

No Significance.

The relationship between EPCS values for the subscale of PFCC and Personal Characteristics was investigated using a Pearson product-moment correlation coefficient. There was a positive correlation between EPCS-PFCC scores and participants' marital status r = .25, n = 153, p < .01. Those participants who were not married or in a relationship scored higher on EPCS-PFCC. A negative correlation exists between EPCS-PFCC scores and participants' discipline, r = -.39, n = 153, p < .01. Those participants who were not nurses scored lower on EPCS-PFCC subscale. There was a positive correlation between EPCS-PFCC scores and those participants who personally cared for a dying loved one, r = .23, n = 153, p < .01. These participants scored higher on EPCS-PFCC. There was also a positive correlation between EPCS- PFCC scores and those participants who reported formal training in hospice and palliative care, r= .19, n = 153, p < .05, with those reporting training having higher EPCS-PFCC scores (see Table 22).

Table 22: Correlations between EPCS_ PFCC and Personal Characteristics

		EPCS_PFCC
What is your gender?	Pearson Correlation	-.053
	Sig. (2-tailed)	.514
	N	152
Do you have any children?	Pearson Correlation	.127
	Sig. (2-tailed)	.117
	N	153
Marital Status Recoded	Pearson Correlation	.254
	Sig. (2-tailed)	.002**
	N	153
Education Recoded	Pearson Correlation	.134
	Sig. (2-tailed)	.099
	N	152
Discipline Recoded	Pearson Correlation	-.388
	Sig. (2-tailed)	.000**
	N	149
Received formal palliative care/hospice training	Pearson Correlation	.186**
	Sig. (2-tailed)	.021
	N	153
Personally cared for dying loved one	Pearson Correlation	.229**
	Sig. (2-tailed)	.005
	N	152

The relationship between EPCS values for the subscale of PFCC and EOL Comfort Variables was investigated using a Pearson product-moment correlation coefficient. All comfort variables showed a moderate positive correlation for participants’ comfort level and EPCS-PFCC scores (see Table 23).

Table 23: Correlations between EPCS PFCC and EOL Comfort Variables

		EPCS_PFCC
Comfort Initiating EOL Conversations	Pearson Correlation	.613
	Sig. (2-tailed)	.000**
	N	153
Comfort Discussing Dying Process	Pearson Correlation	.635
	Sig. (2-tailed)	.000**
	N	153
Comfort Discussing Religious Needs	Pearson Correlation	.417
	Sig. (2-tailed)	.000**
	N	153
Comfort Initiating PC Discussions	Pearson Correlation	.527
	Sig. (2-tailed)	.000**
	N	153
Comfort Discussing Life-Limiting DX	Pearson Correlation	.601
	Sig. (2-tailed)	.000**
	N	153

**p < .001 All significant at α = .01 level (2-tailed)

The relationship between EPCS values for the subscale of PFCC and Attitudes toward Hospice Care was investigated using a Pearson product-moment correlation coefficient. A positive correlation exists between EPCS-PFCC scores and Attitudes toward Hospice Care for ten of the attitude variables. Those participants who scored higher for positive attitude toward hospice care scored higher values on between EPCS-PFCC. There was no correlation for the following attitude variables: Personal Past Negative Experience, Do Not Want Terminally Ill Relative to Receive Hospice, and Hospice Decision made by Irrational People (see Table 24).

Table 24: Correlations between EPCS PFCC and Attitudes about EOL

		EPCS_PFCC
Value Supportive Care Hospice Provides	Pearson Correlation	.194
	Sig. (2-tailed)	.017*
	N	152
Attitude Toward Pain Control	Pearson Correlation	.219
	Sig. (2-tailed)	.006**
	N	153
Personal Past Experience Negative	Pearson Correlation	.101
	Sig. (2-tailed)	.217
	N	151
Hospice as Living Well Until We Die	Pearson Correlation	.253
	Sig. (2-tailed)	.002**
	N	153
Don’t Want Terminally Ill Relative to Receive Hospice	Pearson Correlation	-.042
	Sig. (2-tailed)	.605
	N	152
Hospice Close to Dying Service	Pearson Correlation	.223
	Sig. (2-tailed)	.006**
	N	149
Past Personal Experience Positive	Pearson Correlation	.197
	Sig. (2-tailed)	.014**
	N	153

Hospice Care Appeals to Me	Pearson Correlation	.292
	Sig. (2-tailed)	.000**
	N	152
Making Living Will Smart	Pearson Correlation	.178
	Sig. (2-tailed)	.028*
	N	153
Comfortable with Issues of Death and Dying	Pearson Correlation	.543
	Sig. (2-tailed)	.000**
	N	152
Don’t like talking About Death, Dying, Hospice	Pearson Correlation	.479
	Sig. (2-tailed)	.000**
	N	153
Hospice Decision made By Irrational People	Pearson Correlation	.136
	Sig. (2-tailed)	.095
	N	152
Should be Allowed to Die in Peace at Home	Pearson Correlation	.168
	Sig. (2-tailed)	.037*
	N	153

*p < .05 Significant at α = .05 level (2-tailed), **p < .01 Significant at α = .01 level (2-tailed)

The relationship between EPCS values for the subscale of PFCC and Fear of Death and Dying Scale was investigated using a Pearson product-moment correlation coefficient. There was no significant correlation between EPCS-PFCC scores and participants’ Fear of Death and Dying (see Table 25).

Table 25: Correlations between EPCS PFCC and Fear of Death and Dying

		EPCS_PFCC
Fear of Death Own Self	Pearson Correlation	.083
	Sig. (2-tailed)	.305
	N	153
Fear of Dying Self Score	Pearson Correlation	.142
	Sig. (2-tailed)	.081
	N	153
Fear of Death of Others Composite Score	Pearson Correlation	.035
	Sig. (2-tailed)	.665
	N	153
Fear of Dying of Others Composite Score	Pearson Correlation	-.044
	Sig. (2-tailed)	.587
	N	153

No Significance.

The relationship between EPCS values for the subscale of ECD and Personal Characteristics was investigated using a Pearson product-moment correlation coefficient. There was a positive correlation between EPCS-ECD scores participants' relationship status, r = .25, n = 153, p < .01. Those participants who were not in a relationship scored higher on the EPCS-ECD subscale. There was a negative correlation between EPCS-ECD scores and participants' discipline, r = -.36, n = 153, p < .01. Participants who were non-nurses scored lower on the EPCS-ECD subscale. There was a positive correlation between EPCS-ECD scores and those participants who had cared for a dying loved one, r = .17, n = 153, p < .05, with those participants who had personally cared for a dying loved one scoring higher on the EPCS-ECD. There was also a positive correlation between the EPCS-ECD scores and those participants who reported formal hospice and palliative care training, r = .30, n = 153, p < .01. Those participants reporting training had higher EPCS-ECD scores (see Table 26).

Table 26: Correlations between EPCS_ ECD and Personal Characteristics

		EPCS_ECD
What is your gender?	Pearson Correlation	-.021
	Sig. (2-tailed)	.798
	N	150
Do you have any children?	Pearson Correlation	.128
	Sig. (2-tailed)	.118
	N	151
Marital Status Recoded	Pearson Correlation	.252
	Sig. (2-tailed)	.002**
	N	153
Education Recoded	Pearson Correlation	.048
	Sig. (2-tailed)	150
	N	-.358
Discipline Recoded	Pearson Correlation	.000**
	Sig. (2-tailed)	149
	N	
Received formal palliative care/hospice training	Pearson Correlation	.304**
	Sig. (2-tailed)	.000
	N	153
Personally cared for dying loved one	Pearson Correlation	.173*
	Sig. (2-tailed)	.035
	N	153

The relationship between EPCS values for the subscale of ECD and EOL Comfort Variables was investigated using a Pearson product-moment correlation coefficient. All comfort variables showed a moderate positive correlation for participants' comfort level and EPCS-ECD scores. The higher the participants' comfort level with palliative and EOL care, the higher the score on the EPCS-ECD scores (see Table 27).

Table 27: Correlations between EPCS ECD and EOL Comfort Variables

		EPCS_ECD
Comfort Initiating EOL Conversations	Pearson Correlation	.513
	Sig. (2-tailed)	.000**
	N	153

Comfort Discussing Dying Process	Pearson Correlation	.559
	Sig. (2-tailed)	.000**
	N	151
Comfort Discussing Religious Needs	Pearson Correlation	.333
	Sig. (2-tailed)	.000**
	N	153
Comfort Initiating PC Discussions	Pearson Correlation	.501
	Sig. (2-tailed)	.000**
	N	153
Comfort Discussing Life-Limiting DX	Pearson Correlation	.405
	Sig. (2-tailed)	.000**
	N	153

**p < .001. All significant at α = .01 level (2-tailed).

The relationship between EPCS values for the subscale of ECD and Attitudes about EOL was investigated using a Pearson product-moment correlation coefficient. Preliminary analyses were performed to ensure no violation of the assumptions of normality and linearity. A positive correlation exists between the EPCS-ECD and the following attitude toward hospice variables: Attitude Toward Pain Control, r = .20, p < .05, Hospice as Living Well Until We Die, r = .16, p < .05, Hospice Close to Dying Service, r = .17, p < .05, Past Personal Experience Positive, r = .17, p < .05, Hospice Care Appeals to Me, r = .23, n = 150, p < .01, Comfortable with Issues of Death and Dying, r = .40, n = 151, p < .01, Don’t Like Talking About Death, Dying, Hospice, r = .41, n = 151, p < .01. Those participants who scored higher for a positive attitude for these variables scored higher on the EPCS values for the subscale of ECD (see Table 28).

Table 28: Correlations between EPCS ECD and Attitudes about EOL

		EPCS_ECD
Value Supportive Care Hospice Provides	Pearson Correlation	.129
	Sig. (2-tailed)	.115
	N	151
Attitude Toward Pain Control	Pearson Correlation	.196
	Sig. (2-tailed)	.016*
	N	151
Personal Past Experience Negative	Pearson Correlation	.059
	Sig. (2-tailed)	.480
	N	148
Hospice as Living Well Until We Die	Pearson Correlation	.164
	Sig. (2-tailed)	.044*
	N	151
Don’t Want Terminally Ill Relative to Receive Hospice	Pearson Correlation	-.142
	Sig. (2-tailed)	.083
	N	151
Hospice Close to Dying Service	Pearson Correlation	.166
	Sig. (2-tailed)	.044*
	N	147
Past Personal Experience Positive	Pearson Correlation	.168
	Sig. (2-tailed)	.039*
	N	151
Hospice Care Appeals to Me	Pearson Correlation	.234
	Sig. (2-tailed)	.004**
	N	150
Making Living Will Smart	Pearson Correlation	.149
	Sig. (2-tailed)	.057
	N	151
Comfortable with Issues of Death and Dying	Pearson Correlation	.402
	Sig. (2-tailed)	.000**
	N	151
Don’t like talking About Death, Dying, Hospice	Pearson Correlation	.412
	Sig. (2-tailed)	.000**
	N	151
Hospice Decisions made By Irrational	Pearson Correlation	.117

People		
	Sig. (2-tailed)	.154
	N	150
Should be Allowed to Die in Peace at Home	Pearson Correlation	.102
	Sig. (2-tailed)	.214
	N	151

*p < .05 Significant at α = .05 level (2-tailed)**p < .01 Significant at α = .01 level (2-tailed).

The relationship between EPCS values for the subscale of ECD and the Fear of Death and Dying Scale was investigated using a Pearson product-moment correlation coefficient. There was no significant correlation between EPCS-ECD and Fear of Death and Dying (see Table 29).

Table 29: Correlations between EPCS ECD and Fear of Death and Dying

		EPCS_ECD
Fear of Death Own Self	Pearson Correlation	-.001
	Sig. (2-tailed)	.988
	N	151
Fear of Dying Self Score	Pearson Correlation	.085
	Sig. (2-tailed)	.302
	N	151
Fear of Death of Others Composite Score	Pearson Correlation	-.037
	Sig. (2-tailed)	.656
	N	151
Fear of Dying of Others Composite Score	Pearson Correlation	-.006
	Sig. (2-tailed)	.938
	N	151

No Significance.

Hypotheses: Personal characteristics predict EPCS scores (3 subscales) stated in the null:

H09: There is no relationship between personal characteristics and any of the 3 EPCS subscales.

Multiple linear regression was used to determine if gender, age, past experience, professional role, and previous palliative care training were significant predictors of the End-of- Life Professional Caregiver Survey (EPCS) three subscales: CEV (8 items), PFCC (12 items), and ECD (8 items).

For the EPCS subscale CEV (8 items), this significant (F [5,140]) = 5.186, p<.001) linear regression model explained 15.6% of the variability in the sum of CEV items that ranged from 8-40 for the 8 questions scored with a Likert scale of 1-5. Two significant predictors were found: having reported palliative care training (1-no training, 2-training), (β = 2.687, p =.001) and staff discipline (1-nursing group, 2-non-nursing group), (β = -.936, p = .013). CEV was lower by .936 among non-nurses and higher by 2.687 among those who had reported palliative care training.

For the EPCS subscale PFCC (12 items), this significant (F ([5,140]) = 9.34, p=.002) multiple linear regression model explained 12.1% of the variability in the sum of PFCC items which ranged from 17-60 for the 12 questions scored with a Likert scale of 1-5. Two significant predictors were found: staff discipline (1-nurses, 2- non-nurses), (β = -1.512, p = .011) and having cared for a dying loved one (1-no, 2-yes), (β = 4.056, p = .014). PFCC was lower by 1.512 among non-nurses and higher by 4.056 among those who cared for a dying loved one.

For the EPCS subscale ECD (8 items), this significant (F ([5,140]) = 4.133, p = .002) linear regression model explained 12.7% of the variability in the sum of ECD items that ranged from 8-40 for the 8 questions scored with a Likert scale of 1-5. Three significant predictors were found: having reported palliative care training (1-no training, 2-training), (β = 2.169, p = .029), staff discipline (1-nurses, 2-non-nurses), (β = -.936, p = .022), and having cared for a dying loved one (1-no, 2-yes), (β = 2.361, p = .045). ECD was lower by .936 among non- nurses and higher by 2.169 among those who had reported palliative care training and also higher by 2.361 among those who had cared for a dying loved one.

H010: There is no relationship between comfort with providing EOL services and any of the 3 EPCS subscales.

Multiple linear regression was used to determine if comfort with providing EOL services was a significant predictor of the EPCS instrument three subscales: CEV (8 items), PFCC (12 items), and ECD (8 items).

Multiple linear regression was used to determine if comfort levels with EOL services were significant predictors of the EPCS-CEV (8 items). The overall regression was statistically significant with R2 = .422. The results indicated that the model was a significant predictor of EPCS-CEV Scores, F [5,144] = 21.013, p < .001. The statements regarding “Comfort discussing the dying process” (β = 1.745, p = .027) and “Comfort Discussing Religious and Spiritual Needs” (β = 2.181, p < .001) were significant predictors of EPCS-CEV Scores (see Table 30).

Table 30: EPCS_CEV Comfort Regression – All Assumptions Met for Regression

Model Summary[b]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.712[a]	.422	.402	5.28529

a. Predictors: (Constant), Comfort Initiating PC Discussions, Comfort Discussing Religious and Spiritual needs, Comfort Discussing Life-limiting Dx, Comfort Discussing Dying Process, Comfort Initiating EOL Conversations

b. b. Dependent Variable: EPCS_CEV

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	3487.904	5	498.272	20.114	.000[b]
	Residual	3393.862	144	24.773		
	Total	6881.766	149			

Coefficients[a]

		Unstandardized Coefficient		Standardized Coefficients		
Model		B	Std. Error	Beta	t	Sig.
1	(Constant)	6.981	2.868		3.165	0.000
	Comfort Initiating EOL Conversations	0.683	0.853	0.101	0.832	0.407
	Comfort Discussing Dying Process	1.745	0.743	0.264	2.228	0.027

	Comfort Discussing Religious and Spiritual Needs	2.181	0.548	0.259	3.920	0.000
	Comfort Initiating PC Discussions	-0.515	0.584	-0.073	-0.882	0.379
a. Dependent Variable: EPCS_CEV_Sum						

EPCS_PFCC_SUM:

Multiple linear regression was used to determine if comfort levels with EOL services were significant predictors of EPCS subscale PFCC (12 items). The overall regression was statistically significant with R2 = .455. The results indicated that the model was a significant predictor of EPCS-PFCC scores, F [5,144] = 24.256, p < .001. It was found that "Comfort discussing the dying process" (β = 2.132, p = .043) was a significant predictor of EPCS-PFCC (see Table 31).

Table 31: EPCS_PFCC Comfort Regression – All Assumptions Met for Regression

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.675a	.455	.437	7.21757

a. Predictors: (Constant), Comfort Initiating PC Discussions, Comfortable with Issues of Death and Dying, Comfort Discussing Life-limiting Dx, Comfort Discussing Dying Process, Comfort Initiating EOL Conversations

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	6317.948	5	1263.616	24.256	.000[b]
	Residual	7553.522	145	52.093		
	Total	13592.473	150			

a. Dependent Variable: EPCS_PFCC
b. Predictors: (Constant), Comfort Initiating PC Discussions, Comfortable with Issues of Death and Dying, Comfort Discussing Life-limiting Dx, Comfort Discussing Dying Process, Comfort Initiating EOL Conversations

Coefficients[a]

Model		Unstandardized Coefficients B	Std. Error	Standardized Coefficients Beta	t	Sig.
1	(Constant)	15.044	2.950		5.100	0.000
	Comfort Initiating EOL Conversations	1.338	1.107	0.141	1.209	0.229
	Comfort Discussing Dying Process	2.132	1.043	0.242	2.045	0.043
	Comfort Initiating PC Discussions	1.287	0.807	0.134	1.595	0.113
	Comfort Discussing Life-limiting Dx	1.726	1.058	0.169	1.632	0.105

a. Dependent Variable: EPCS_PFCC

Multiple linear regression was used to determine if comfort levels with EOL services were significant predictors of EPCS values for the subscale of ECD (8 items). The overall regression was statistically significant with R2 = .358. The results indicated that the model was a significant predictor of EPCS-ECD, (F [5,142]) = 15.825, p < .001. The statements regarding “Comfort discussing the dying process” (β = 2.997, p = .003) and “Comfort Initiating PC Discussions” (β = 1.388, p = .007) were significant predictors of EPCS-ECD scores (see Table 32).

Table 32: EPCS_ECD Comfort Regression – All Assumptions Met for Regression

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.598[a]	.358	.335	4.60486

c. Predictors: (Constant), Comfort Initiating PC Discussions, Comfortable with Issues of Death and Dying, Comfort Discussing Dying Process, Comfort Initiating EOL Conversations

d. b. Dependent Variable: EPCS_ECD

ANOVA[a]						
Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	2188.448	6	364.741	19.734	.000[b]
	Residual	2532.191	137	18.483		
	Total	4720.639	143			

a. Dependent Variable: EPCS_ECD
b. Predictors: (Constant), Comfort Discussing Life-limiting DX Comfort Initiating PC Discussions, Comfortable with Comfort Discussing Religious and Spiritual Needs, Comfort Discussing Dying Process, Comfort Initiating EOL Conversations

Coefficients[a]						
		Unstandardized Coefficients		Standardized Coefficients		
Model		B	Std. Error	Beta	t	Sig.
1	(Constant)	12.494	1.913		6.530	0.000
	Comfort Initiating EOL Conversations	0.652	0.696	0.044	0.934	0.352
	Comfort Discussing Dying Process	2.021	0.674	0.395	2.997	0.003
	Comfort Initiating PC Discussions	1.388	0.505	0.245	2.747	0.007
	Comfort Discussing Life- limiting Dx	-1.099	0.670	-.1089	-1.641	0.103
	Comfort Discussing Religious and Spiritual needs	.696	0.499	0.110	1.393	0.166
b. Dependent Variable: EPCS_ECD						

H011: There is no relationship between attitudes toward EOL services and any of the 3 EPCS subscales.

Multiple linear regression was used to determine if attitudes toward EOL services were significant predictors of EPCS subscale CEV (8 items). The overall regression was statistically significant with R2 = .385. The results indicated that the model was a significant predictor of EPCS-CEV scores, (F [11,136] = 7.749, p < .001). The statements "Do not like to talk about death, dying and hospice" (β= 1.611, p < .001) and "Comfortable with issues of death and dying" (β = 4.171, p < .001) were significant predictors of EPCS-CEV scores (see Table 33).

Table 33: EPCS_CEV Attitude Regression – All Assumptions Met for Regression

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.621[a]	.385	.336	5.66512

a. Predictors: (Constant), People should be allowed to die in peace at home, Hospice care appeals to me, Would not want terminally ill relative to receive hospice, Do not like to talk about death and dying, Hospice decision made by irrational people, Past personal experience positive, Value support care hospice provides, Concept of hospice as living well until we die, Attitude toward pain control, Making living will smart, Comfortable with issues of death and dying

b. Dependent Variable: EPCS_CEV

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	2735.540	11	248.685	7.749	.000[b]
	Residual	4364.730	136	32.094		

	Total	7100.270	147

a. Dependent Variable: EPCS_CEV

b. Predictors: (Constant), People should be allowed to die in peace at home, Hospice care appeals to me, Would not want terminally ill relative to receive hospice, Do not like to talk about death and dying, Hospice decision made by irrational people, Past personal experience positive, Value support care hospice provides, Concept of hospice as living well until we die, Attitude toward pain control, Making living will smart, Comfortable with issues of death and dying

Coefficients[a]

		Unstandardized Coefficients		Standardized Coefficients		
Model		B	Std. Error	Beta	t	Sig.
1	(Constant)	14.238	5.138		2.771	0.006
	Value supportive care hospice provides	-.943	.931	-.084	-1.013	.313
	Attitude toward pain control	.291	.613	.037	.475	.636
	Concept of hospice as living well until we die	-.686	.556	-.098	-.233	.220
	Would not want terminally ill relative to receive hospice	-.901	.517	-.125	-1.743	.084
	Past personal experience positive	-.672	.556	-.094	-1.208	.229
	Hospice care appeals to me	.585	.637	.079	.919	.360
	Do not like to talk about issues of death, dying. hospice	1.611	.670	.217	2.405	.000
	Making living will smart	-.826	.804	-.084	-.026	.307
	Comfortable with issues of death and dying	4.170	1.150	.406	3.626	.000
	Hospice decision made by irrational people	.937	.804	.087	1.165	.246

People should be allowed to die in peace at home	.443	.699	46	.633	.528

Multiple linear regression was used to determine if attitudes toward EOL services were significant predictors of EPCS subscale PFCC (12 items). The overall regression was statistically significant with R2 = .352. The results indicated that the model was a significant predictor of EPCS-PFCC scores, F (11,136) = 6.704, p < .001. The statements "Do not like to talk about death, dying and hospice (β = 2.112, p = .032) and "Comfortable with issues of death and dying" (β = 4.170, p < .001) were significant predictors of EPCS-PFCC scores (see Table 34).

Table 34: EPCS_PFCC Attitude Regression – All Assumptions Met for Regression

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.593^a	.352	.299	8.17377

a. Predictors: (Constant), People should be allowed to die in peace at home, Hospice care appeals to me, Would not want terminally ill relative to receive hospice, Do not like to talk about death and dying, Hospice decision made by irrational people, Past personal experience positive, Value support care hospice provides, Concept of hospice as living well until we die, Attitude toward pain control, Making living will smart, Comfortable with issues of death and dying

b. Dependent Variable: EPCS_PFCC

ANOVA^a

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	4926.669	11	104.739	6.704	.000^b
	Residual	9086.223	136	26.728		
	Total	14012.892	147			

a. Dependent Variable: EPCS_PFCC

b. Predictors: (Constant), People should be allowed to die in peace at home, Hospice care appeals to me, Would not want terminally ill relative to receive hospice, Do not like to talk about death and dying, Hospice decision made by irrational people, Past personal experience positive, Value support care hospice provides, Concept of hospice as living well until we die, Attitude toward pain control, Making living will smart, Comfortable with issues of death and dying

Coefficients^{a}

Model		Unstandardized Coefficients		Standardized Coefficients		
		B	Std. Error	Beta	t	Sig.
1	(Constant)	18.402	7.388		2.491	0.014
	Value supportive care hospice provides	.007	1.374	.000	.005	.996
	Attitude toward pain control	.456	.912	.040	.500	.618
	Concept of hospice as living well until we die	-.513	.866	-.050	-.592	.555
	Would not want terminally ill relative to receive hospice	-.954	.742	-.094	-1.285	.201
	Past personal experience positive	-.495	.787	-.050	-.629	530
	Hospice care appeals to me	1.270	.931	.123	1.364	.175
	Do not like to talk about issues of death, dying. hospice	2.112	.972	.200	2.172	.032
	Making living will smart	-.905	1.159	-.066	-.781	.436
	Comfortable with issues of death and dying	4.170	1.150	.406	3.626	.000
	Hospice decision made by irrational people	.198	1.164	.013	.170	.865
	People should be allowed to die in peace at home	1.103	1.020	.081	1.082	.281

Multiple linear regression was used to determine if attitudes toward EOL services were significant predictors of EPCS values for the subscale of ECD (8 items). The overall regression was statistically significant with R2 = .242. The results indicated that the model was a significant predictor of EPCS-ECD scores, F (11,135) = 3.919, p < .001. The statement “Would not want terminally ill relative to receive hospice” (β = -1.100, p = .022) was a significant predictor of EPCS-ECD scores (see Table 35).

Table 35: EPCS_ECD Attitude Regression – All Assumptions Met for Regression

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.492[a]	.242	.180	5.16988

a. Predictors: (Constant), People should be allowed to die in peace at home, Hospice care appeals to me, Would not want terminally ill relative to receive hospice, Do not like to talk about death and dying, Hospice decision made by irrational people, Past personal experience positive, Value support care hospice provides, Concept of hospice as living well until we die, Attitude toward pain control, Making living will smart, Comfortable with issues of death and dying

b. Dependent Variable: EPCS_ECD

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	1152.134	11	104.739	3.919	.000[b]
	Residual	3608.233	135	26.728		
	Total	4760.367	146			

a. Dependent Variable: EPCS_ECD

Predictors: (Constant), People should be allowed to die in peace at home, Hospice care appeals to me, Would not want terminally ill relative to receive hospice, Do not like to talk about death and dying, Hospice decision made by irrational people, Past personal experience positive, Value support care hospice provides, Concept of hospice as living well until we die, Attitude toward pain control, Making living will smart, Comfortable with issues of death and dying

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients		
		B	Std. Error	Beta	t	Sig.
1	(Constant)	0.210	14.816		6.411	0.000

Value supportive care hospice provides	-.112	.872	-.012	-.128	0.898
Attitude toward pain control	.479	.595	.073	.806	.422
Concept of hospice as living well until we die	-.349	.547	-.057	-.638	.525
Would not want terminally ill relative to receive hospice	-1.100	.473	-.187	-2.326	.022
Past personal experience positive	-.010	.507	-.002	-.019	.985
Hospice care appeals to me	.284	.592	.047	.480	.632
Making living will smart	-.073	.737	-.009	-.099	.921
Comfortable with issues of death and dying	1.401	.735	.234	1.907	.059
Hospital decision made by irrational people	.549	.730	.062	.752	.453
People should be allowed to die in peace at home .590	.344	.637	.044	.540	

H012: Any scores of fears of death/fear of dying (self/others) predict EPCS (the 3 EPCS subscales).

EPCS with Fear of Death and Dying – these are non-significant, problematic models. One major problem with the model is that all the variables are highly correlated with one another, (problem of multi-collinearity) and additionally not correlated with any of the three EPCS outcome variables. Therefore, it did not meet the assumptions for regression in this model. The significance of the three models were: for EPCS values for the subscale of ECD (8 items) (F = .702, p = .592), for EPCS subscale PFCC (12 items) (F = 1.060, p = .305), and EPCS subscale CEV (8 items). (F = 1.141, p = .339) (see Table 36).

Table 36: EPCS_ECD Fear Did Not Meet Assumptions for Regression

Model Summary[b]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.225[a]	.050	.025	9.55785

e. Predictors: (Constant), Fear of Dying of Others Composite, Fear of Death Own Self, Fear of Dying Self, Fear of Death of Others

f. b. Dependent Variable: EPCS_PFCC

Summary of All Results

There are four areas of statistically significant findings to summarize that focus on (1) before the COVID-19 “lock-down” personal characteristics with EOL variables (comfort, attitudes, fear of death/dying), (2) the comparisons of before and after the COVID-19 “lock- down” variables; (3) relationships among participants’ three outcome variables of end-of-life professional competency scores for Culture and Ethical Values (CEV), Patient and Family Centered Communication (PFCC) and ECD and personal characteristics/EOL variables; and (4) using the personal characteristics/EOL variables to predict these three competency variables (CEV, PFCC and ECD).

Before COVID-19 “Lock Down”: Personal Characteristics of Staff

Level of Comfort

For non-nurses versus nurses, there was a lower level (negative) of comfort with providing EOL care. There is a positive relationship between staff having reported any formal palliative care or hospice care training with their level of comfort with EOL and palliative care services.

There is also a positive relationship for the staff characteristic of having personally cared for a dying loved one and their comfort level with EOL and palliative care services.

Attitudes

Staff attitudes toward providing EOL and palliative care is significantly related positively to whether they have personally cared for a dying loved one.

Fear of Death and Dying (Self and Others)

There is a relationship between staff age and gender and their fear of death and dying. The results showed that women were more likely to have a fear of dying. Younger staff were more likely to fear the death of others.

TIME 1 and TIME 2 Differences

The only notable difference between caregivers' level of comfort between Time 1 and Time 2 was seen in the measure of "Discussing the Dying Process" and this was only clinically significant at $\alpha = .10$, with comfort decreasing from 3.61 before the pandemic to 3.41 one year into the pandemic. Although not statistically significant at $p<.05$, the comfort change in discussing the dying process warrants further investigation.

The only significant difference between caregivers' attitudes toward hospice before the pandemic and one year into the pandemic was seen in the measure of "Attitude toward pain control" and this was significant at the $\alpha = .05$ level, with attitude toward hospice pain control decreasing from 4.38 before the pandemic to 4.21 one year into the pandemic. This difference is significant and worth exploring further related to the COVID deaths occurring and challenges that nurses experienced in providing care to the dying.

There was one significant difference between caregivers' feelings toward fear of death self before the pandemic and one year into the pandemic. This was on "Death and the shortness of life" with mean scores increasing from 3.07 before the pandemic to 3.32 one year into the pandemic. This difference was significant at the $\alpha = .05$ level.

There was one significant difference between caregivers' feelings toward fear of dying self before the pandemic and one year into the pandemic. This was on "Dying in Hospital Away from Others" with mean scores increasing from pre-pandemic at 3.44 to 3.74 one year into the pandemic. This difference was significant at the $\alpha = .05$ level.

Difference in Mean Scores Between Time 1 and Time 2	**Measure**
Level of Comfort	Discussing the Dying Process Decrease in Comfort at Time 2
Attitudes	Attitude toward pain control Decrease in Attitude at Time 2
Fear of Death (self)	Death and the shortness of life Increase at Time 2
Fear of Dying (self)	Death- Dying Away from Others Increase at Time 2
Fear of Death (others)	No difference
Fear of Dying (others)	Dying of others- reminder of own death Increase at Time 2

The only significant difference between caregivers' feelings about fear of dying of others before the pandemic and one year into the pandemic was seen in the measure of "Dying of others- reminder of own death" and this was significant at the $\alpha = .05$ level, with feelings of concern increasing from 3.02 before the pandemic, and to 3.27 one year into the pandemic.

a. Relationship between outcome variables EOL professional confidence (End-of-Life Professional Caregiver Survey [EPCS]) subscale values for the subscale of Cultural and Ethical Values (CEV) Comfort Variables. There were significant correlations for the composite and all five comfort variables with the subscale of Cultural and Ethical Values (CEV): Comfort Initiating EOL Conversations; Comfort Discussing Dying Process; Comfort Discussing Religious Needs; Comfort Initiating PC Discussions; Comfort Discussing Life-Limiting Disease.

Personal Characteristics. There were significant relationships for personal characteristics of staff with the subscale of Cultural and Ethical Values (CEV): staff who reported formal training; had personally cared for a dying loved one; marital status; and non-nurses compared to nurses.

Attitudes. There were significant relationships with 5 items of the attitudes scale with the subscale of Cultural and Ethical Values (CEV): Attitude Toward Pain Control; Hospice Close to Dying Service; Hospice Care Appeals to Me; Comfortable with Issues of Death and Dying; Don't Like

Talking about Death Dying or Hospice Care.

Subscale	Variable	Correlation
Cultural and Ethical Values (CEV)	Fear of Death and Dying	No significant correlation
Cultural and Ethical Values (CEV)	Comfort	Significant for all five variables Higher the level of comfort the higher the score on subscale
Cultural and Ethical Values (CEV)	Personal Characteristics	Positive correlation for staff who received formal training in hospice and palliative care, personally cared for a dying lived one scoring higher on subscale; marital status (those not married); negative correlation for non-nurses vs. nurses.
Cultural and Ethical Values (CEV)	Attitudes	Positive correlation for those who scored higher on “Attitude Toward Pain Control”, “Hospice care appeals to me”, “Hospice Close to Dying Service,” “Comfortable with issues with death and dying”, and “Don’t like talking about death, dying, or hospice care” scored higher on subscale

Relationship between outcome variables EOL professional confidence (End-of-Life Professional Caregiver Survey [EPCS]) subscale values for the subscale of Patient and Family Centered Communication (PFCC).

Comfort Variables. The composite comfort score and all comfort variables showed a moderate positive correlation for participants’ comfort level and the subscale of Patient and Family Centered Communication (PFCC): Comfort Initiating EOL Conversations; Comfort Discussing Dying Process; Comfort Discussing Religious Needs; Comfort Initiating Palliative Care Discussion; Comfort Discussing Life-Limiting Diagnosis. The higher the participants’ comfort level the higher the score on the EPCS values for the subscale of Patient and Family Centered Communication (PFCC).

Personal Characteristics. There were significant relationships for personal characteristics of staff with the subscale of Patient and Family Centered Communication (PFCC): marital status; staff who personally cared for a dying loved one or received some form of formal training in hospice and palliative care; non-nurses vs nurses.

Attitudes. There were significant relationships for ten attitudes variables with the subscale of Patient and Family Centered Communication (PFCC): Value Supportive Care Hospice Provides; Attitude Toward Pain Control; Hospice as Living Well Until We Die; Hospice Close to Dying Service; Past Personal Experience Positive; Hospice Care Appeals To Me; Making Living Will Smart; Comfortable with Issues of Death and Dying; Don't like talking About Death, Dying, Hospice; Should be Allowed to Die in Peace at Home. Those participants who scored higher for positive attitude toward hospice care scored higher on the subscale of Patient and Family Centered Communication (PFCC).

Subscale	**Variable**	**Correlation**
Patient and Family Centered Communication (PFCC)	Fear of Death and Dying	No significant correlation
Patient and Family Centered Communication (PFCC)	Comfort	Significant for all five variables Higher the level of comfort the higher the score on subscale
Patient and Family Centered Communication (PFCC)	Personal Characteristics	Positive correlation- marital status (those not married), those who personally cared for a dying loved one, those having received some formal training in hospice and palliative care. All scored higher on the subscale Negative correlation for discipline- Those participants who were not nurses scored lower.
Patient and Family Centered Communication (PFCC)	Attitudes	Positive Correlation-Value Supportive Care Hospice Provides, Attitude Toward pain Control, Hospice as Living Well Until We Die, Hospice Close to Dying Service, Past Personal Experience with Hospice Positive, Hospice Care Appeals to Me, Making Living Will Smart, Comfortable with Issues of Death and Dying, Should Be Allowed to Die in Peace at Home all scored higher on the subscale.

Relationship between outcome variables EOL professional confidence (End-of-Life Professional Caregiver Survey [EPCS]) subscale values for the subscale of ECD.

Comfort Variables. All comfort variables and the composite comfort score showed a moderate positive correlation for participants' comfort level and EPCS values for the subscale of ECD: Comfort Initiating EOL Conversations; Comfort Discussing Dying Process; Comfort Discussing Religious Needs; Comfort Initiating Palliative Care Discussion; Comfort Discussing Life-Limiting Diagnosis. The higher the participants' comfort level the higher the score on the EPCS values for the subscale of Effective Care Delivery.

Personal Characteristics. There were significant relationships for personal characteristics of staff with the subscale of ECD: positive relationship for staff who personally cared for a dying loved one or received some form of formal training in hospice and palliative care. Those participants who were not in a relationship scored higher on the subscale of ECD; participants who were non-nursing scored lower on the subscale of ECD.

Attitudes. There were significant positive relationships for seven attitude variables with the subscale of ECD: Attitude Toward Pain Control, Hospice as Living Well Until We Die, Hospice Close to Dying Service, Past Personal Experience Positive, Hospice Care Appeals to Me, Comfortable with Issues of Death and Dying, Don't Like Talking About Death, Dying, Hospice. Those participants who scored higher for a positive attitude for these variables scored higher on the EPCS values for the subscale of ECD.

Subscale	**Variable**	**Correlation**
Effective Care Delivery (ECD)	Fear of Death and Dying	No significant correlation
Effective Care Delivery (ECD)	Comfort	Significant for all five variables Higher the level of comfort the higher the score on subscale
Effective Care Delivery (ECD)	Personal Characteristics	Positive correlation- marital status (those not married), those who personally cared for a dying loved one, those having received some formal training in hospice and palliative care. All scored higher on the subscale

		Negative correlation for discipline- Those participants who were not nurses scored lower.
Effective Care Delivery (ECD)	Attitudes	Positive correlation- Attitude Toward Pain Control, Hospice as Living Well Until We Die, Hospice Close to Dying Service, Past Personal Experience Positive, Hospice Care Appeals to Me, Comfortable with Issues of Death and Dying, Don't Like Talking About Death, Dying, Hospice all scored higher on subscale

4 a. Personal Characteristics That Predict EPCS Subscale Scores

Outcome Variables (Subscales)	Predictor Variables
Cultural and Ethical Values (CEV)	Formal Palliative Care Training, Staff Group
Patient and Family Centered Communication (PFCC)	Having Cared for a Dying Loved One, Staff Group
Effective Care Delivery (ECD)	Formal Palliative Care Training, Having Cared for a Dying Loved One, Staff Group

4. b. Comfort Levels That Predict EPCS Subscale Scores

Outcome Variables (Subscales)	Predictor Variables
Cultural and Ethical Values (CEV)	Comfort discussing the dying process, Comfort Discussing Religious and Spiritual Needs
Patient and Family Centered Communication (PFCC)	Comfort discussing the dying process
Effective Care Delivery (ECD)	Comfort discussing the dying process, Comfort Initiating PC Discussions

4. c. Attitudes That Predict EPCS Subscale Scores

Outcome Variables (Subscales)	Predictor Variables
Cultural and Ethical Values (CEV)	Do not like to talk about death, dying and hospice, Comfortable with issues of death and dying
Patient and Family Centered Communication (PFCC)	Do not like to talk about death, dying and hospice, Comfortable with issues of death and dying
Effective Care Delivery (ECD)	Would not want terminally ill relative to receive hospice

4. d. Fear of Death and Dying Variables That Predict EPCS Subscale Scores

These are non-significant, problematic models. One major problem with the model is that all the variables are highly correlated with one another (problem of multi-collinearity) and additionally not correlated with any of the 3 EPCS outcome variables. Therefore, it did not meet the assumptions for regression in this model.

Chapter 5: Discussion and Recommendations

While palliative care services are underutilized under the best circumstances, the emergence of COVID-19 has further highlighted the importance of and vital need for palliative and EOL care. Already overburdened health care systems due to COVID-19 are faced with the challenge of administering safe and effective palliative and EOL care and ensuring that staff are well prepared to deliver this care is increasingly important.

This chapter presents the findings, implications, recommendations, and limitations of this descriptive, pre- and post-comparative, and correlational design study. The purpose of this study was to compare and determine if correlations exist related to palliative and EOL care between Time 1 and Time 2 in health care providers' comfort with, attitudes toward, and fear of dying.

This study examined the interprofessional home care team in a large multi-hospital system. Its results provide an opportunity to create an educational plan for the multidisciplinary home healthcare team taking into consideration the staff's level of comfort with and attitudes toward palliative and EOL care along with fear of death and dying. In addition, the data demonstrate how a global health crisis can impact staff's level of comfort with and attitudes toward palliative and EOL care along with the fear of death and dying.

Synthesis of Findings

Staff Level of Comfort with, Attitudes Toward EOL and Palliative Care Services and Relationship of Personal Characteristics Time 1

The findings of the study yielded significant results regarding staff level of comfort, attitudes, and fear of death and dying in relation to staff personal characteristics. For comfort level, the findings demonstrated there was a lower level of comfort with providing EOL care for those staff who were non-nurses compared to that of those who were nurses. The results demonstrated that there was a significant positive relationship between staff having reported any formal palliative care or hospice care training with their level of comfort with EOL and palliative care services. These results agree with the results of a study done by Dehghani and colleagues (2020) that palliative care education has the potential to improve nurses perceived self-efficacy. The authors also offered that this education is needed for the entire interprofessional team (Dehghani et al., 2020). This underscores the importance of all staff feeling comfortable working in this area and perhaps the possibility of improving their comfort with knowledge provided in formal training.

The findings also demonstrate a positive relationship for the staff characteristic of having personally cared for a dying loved one and their comfort level with EOL and palliative care services. Those staff who had personally cared for a dying loved one had a higher level of comfort. These findings agree with that of Slater et al., (2021) in whose study interprofessional healthcare team members reported that reflecting on one’s own experience with death can result in improved confidence and ability to provide supportive palliative care and compassionate communication to patients and their families. This is relevant when preparing any educational interventions that include discussion and sharing of personal experiences in a supportive session.

The current study results regarding attitudes of staff toward EOL care and personal characteristics demonstrated that staff who had personally cared for a dying loved one had a more positive attitude toward providing EOL and palliative care. Regarding personal characteristics and staff fear of death and dying of self and others, this study showed that women were more likely to have a fear of dying, and younger staff (under the age of 45) were more likely to fear the death of others. These results align with the results of a study published in 2019 that looked at attitudes toward death and dying in nurses working in an acute care setting. The findings of the study revealed that there is an inverse relationship between the attitudes of nurses caring for dying patients and the anxiety of those nurses toward death. The authors of this study also found that the relationship between death anxiety and attitude was impacted by personal characteristics such as age, amount of experience, and education level related to palliative care (Cheong et al., 2019). There are quite a few studies in the literature looking at the relationship of personal characteristics, attitude, comfort, and fear of staff, but these only address medical and nursing staff. There is a paucity of research related to the interprofessional home care team.

Difference Between Time 1 and Time 2 in Comfort with Providing Palliative Care, Attitudes Toward Hospice and Palliative Care Services and Fear of Death and Dying

There was a significant difference between caregivers' level of comfort between Time 1 and Time 2 seen in the measure of "Discussing the Dying Process" with a decrease in comfort from before the start of the pandemic and one year into the pandemic. There was a significant difference between caregivers' attitudes toward hospice before the pandemic and one year into the pandemic in the measure of "Attitude toward pain control" measured by the item on the original scale. This may be artifact due to the potentially outdated question ("If I were dying, I would want my pain relieved even if it hastens my death") in an age of concern related to opioid sparing changes. In fact, the score on this item related to attitude toward hospice pain control decreased significantly in Time 2 one year into the pandemic. This difference may be due to a combination of participants' responses at the time of taking the survey or due to the lived experiences they have had in caring for COVID-dying patients.

The study findings demonstrated one significant difference between caregivers' feelings toward fear of death of self before the pandemic and one year into the pandemic. This was on "Death and the shortness of life" level of fear increasing from before the pandemic to one year into the pandemic. There was one significant difference between caregivers' feelings toward fear of dying self before the pandemic and one year into the pandemic. This was on "Death— Dying Away from Others" with fear increasing for "Death and Dying Away from Others" one year into the pandemic. While there was no significant difference in scores for fear of death (others) between Time 1 and Time 2, the only significant difference between caregivers' feelings about dying of others before the pandemic and one year into the pandemic was seen in the measure of "Dying of others reminder of own death" with fear score increasing one year into the pandemic. The two fears are relevant to how hospital staff were faced with unprecedented number of dying of patients who were alone and often young. As of the date of this study, there were no other studies found in the literature comparing healthcare staff comfort with and attitudes toward EOL and palliative care services and fear of death and dying. The results of this study, demonstrating how professionals may have changed in their fears about death and dying, suggest an interesting domain for future studies that is often overlooked.

Relationship Between Staff Personal Characteristics, Level of Comfort with and Attitudes about Providing EOL and Palliative Care Services, and Fear of Death and Dying of Self and Others with their Self-Reported End-Of-Life Professional Caregiver Survey (EPCS)

The dependent measure of the study was the EPCS instrument, used frequently to assess educational needs of staff on the identified clinical practice domains of palliative care. The subscales include: (a) Cultural and Ethical Values (CEV), Patient and Family Centered Communication (PFCC), and Effective Care Delivery (ECD). This study explored whether relationships exist between staff personal characteristics, comfort with and attitudes about providing EOL and palliative care services, and fear of death and dying of self and others on these practice domains. Each subscale score was looked at for each of the domains of staff personal characteristics, level of comfort with and attitudes about providing EOL and palliative care services, and fear of death and dying of self and others. The following areas have relevance to planning palliative care education in the future, especially related to non-nursing staff.

Personal Characteristics

The relationship between the subscale of CEV and Personal Characteristics was positive for staff who received formal training in hospice and palliative care, and those who had personally cared for a dying loved one; those who had formal training in EOL and palliative care and those who had personally cared for a dying loved one scored higher on the Cultural and Ethical Values domain.

For discipline, nurses scored higher than non-nurses. This is clear evidence that professional education specifically focused on nursing and/or education in a formal training program will influence the confidence of staff providing palliative or EOL care. In fact, those with personal experiences may also bring their insights that are not only formal education to the caregiving they provide to patients but also ought to be understood whether it was a negative experience or positive one. This may be possible through sensitive palliative care education.

The relationship between EPCS values for the subscale of PFCC and personal characteristics were explored in the study that may be influential in predicting those outcomes that participants demonstrated in the patient and family communication area of practice. There were three positive correlations in the findings: marital status (relationship), those participants who had personally cared for a dying loved one, and those participants who had reported formal training in hospice and palliative care. Those participants who were not married or in a relationship, had any formal training, or had personally cared for a dying loved one scored higher in patient and family communication. Once again, nurses scored higher than staff who were not nurses. These all support the need for formal training that includes the kind of interactive discussions about staff experiences prior to working in palliative care. It is difficult to account for the marital status findings other than, perhaps, the way the groups were consolidated, including widows and singles together. This needs further refinement.

Several of these characteristics also influenced participants’ confidence in ECD in the same direction, including those who were not in a relationship, experience in caring for a dying loved one, and formal training. As subscales of an instrument used in educational programs, these findings support the underlying characteristics that should be taken into account if the instrument is used to assess two of the three practice domains.

Comfort

Comfort played a central influence on all of the participants’ self-reported confidence in providing palliative care as evidenced in all three subscales of the EPCS. There was a significant positive relationship between the values for CEV, PFCC and ECD with participants’ level of comfort in general, and all five comfort variables (Comfort Initiating EOL Conversations, Comfort Discussing Dying Process, Comfort Discussing Religious Needs, Comfort Initiating Palliative Care Discussion, Comfort Discussing Life–Limiting Diagnosis). It is important to consider that anyone working in EOL care should be comfortable in the type of work that is essential. It is also true that a professional who chooses to work in palliative care should be comfortable in communicating with patients and families. This may be one of the most important findings of the study. It suggests that a professional working with dying patients at the end of their lives should be comfortable in the elements of the work that is central to end-of-life professional care. Although it may be an artifact of the items themselves, it cannot be understated. Perhaps more importantly, all aspects of comfort with palliative care suggest a necessary prerequisite of all professionals who work in the area of palliative care – that they need to be comfortable in this intense and deeply emotional area of practice.

Attitudes

The findings revealed a positive relationship between EPCS values for the subscale of CEV and Attitudes. Those participants who scored higher for attitude for “Hospice care appeals to me,” “Comfortable with issues with death and dying,” and “Don’t like talking about death, dying, or hospice care” scored higher values on EPCS values for the subscale of Cultural and Ethical Values (CEV). These are important underlying views to be understood in developing palliative care education, and even more importantly, in the recruitment of staff and professional personnel.

There was also a positive relationship between participants’ patient and family communication (PFCC) and several of the items from the attitudes measure: Value Supportive Care Hospice Provides, Attitude Toward Pain Control, Hospice as Living Well Until We Die, Hospice Close to Dying Service, Past Personal Experience with Hospice Positive, Hospice Care Appeals to Me, Making Living Will Smart, Comfortable with Issues of Death and Dying, Should Be Allowed to Die in Peace at Home. Those participants who reported more positively on these items as they relate to hospice care suggest an underlying personal set of views that can be helpful in developing in others through education and discussion. Similar findings existed for participants’ ECD.

It is important to know that underlying views about hospice care might directly influence one’s ability to deliver effective care delivery and should be part of the discussions in planned educational programs. Honest discussion would be essential to have an impact on these underlying predictors to improve the outcome of effective care delivery.

Fear of Death and Dying

The study findings revealed no significant correlation between EPCS values for any of the subscales and Fear of Death and Dying. It is good to know that one’s fears are not influencing one’s confidence in the end-of-life practice domains.

Predictors of Staff Self-Reported End-of-Life Professional Caregiver Survey (EPCS)

The study results identified certain predictors for staff self-reported EPCS in the domains of personal characteristics, level of comfort with, and attitudes about providing EOL and palliative care services.

Personal Characteristics Predict EPCS Scores

The predictors identified from the results of the study for EPCS values for the subscale of CEV and personal characteristics were those staff who had formal EOL and palliative care training and staff discipline. The predictors identified for EPCS values for the subscale of PFCC and personal characteristics were staff discipline and those staff who personally cared for a dying loved one. The predictors identified for the EPCS values for the subscale of ECD and personal characteristics were those staff who had formal EOL and palliative care training, staff discipline and those staff who had personally cared for a dying loved one. These are all important characteristics to consider in developing palliative care education, although these particular predictors are fixed and not changeable. These positive predictors are important to know when recruiting and hiring staff who have had personal experiences or formal training, knowing that their personal characteristics may suggest their sensitive understanding and ability to communicate with family.

Comfort Level Predicts EPCS Scores

The predictors identified from the study for the EPCS values for the subscale of CEV and comfort with EOL care were comfort discussing the dying process and comfort discussing religious and spiritual needs. The predictor identified for EPCS values for the subscale of PFCC and comfort was comfort discussing the dying process. The predictors identified for the EPCS values for the subscale of

ECD and comfort were comfort discussing the dying process and comfort initiating palliative care discussions. Clearly, one’s comfort with EOL caring for patients is essential for one’s ability to practice effectively.

Attitudes Predict EPCS Scores

The predictors identified from the study for the EPCS values for the subscale of CEV and attitudes toward EOL and palliative care were the attitude variables of “do not like to talk about death, dying and hospice” and “comfortable with issues of death and dying.” These are particularly poignant issues during the months of pandemic care delivery and suggest areas to consider more deeply in how these might be integrated into palliative care education. The predictors identified for End- of-Life Professional Caregiver Survey (EPCS) values for the subscale of PFCC and attitudes toward EOL and palliative care were the attitude variables of do not like to talk about death, dying and hospice and comfortable with issues of death and dying. The predictor identified for the EPCS values for the subscale of ECD and attitudes toward EOL and palliative care was the attitude variable of “Would not want terminally ill relative to receive hospice.” This also suggests an area to consider in educational programs if it is discussed with open and honest understanding of the hospice and palliative care.

Some of the results for predictors of staff self-reported EPCS scores are similar to a study done by Huang, Tung, and Lin (2019). This study looked at the associations among knowledge, attitudes, and practices of medical and nursing staff in Taiwan towards a palliative care consultation service (PCCS). The results of that study demonstrated that formal training, attitudes toward the PCCS, and experiencing the death of a family member or friend were main predictors of the healthcare team members’ practices toward PCCS. The healthcare team in this study was comprised of nurses and physicians only. Another study also had some similar findings and looked at Mongolian oncology nurses and their attitudes toward death and dying, formal training in palliative care, and predictors of self- efficacy. This study identified palliative care knowledge and nursing experience as an oncology nurse as significant predictors of self-efficacy toward palliative care. The authors of this study found that attitudes toward EOL care, with this being defined as attitudes, feelings, thoughts, and level of comfort towards caring for a dying patient and their family, were a significant predictor of self-efficacy (Kim et al., 2020).

Implications of Nursing

Practice

Although there has been substantial research done on the education of health care providers on palliative care, relatively little research on this topic has been done in the home health care setting. To incorporate palliative care into this setting, the health care providers on the home care team need to be adequately trained to increase their comfort with and knowledge of palliative care. Implications for nursing practice from this study emphasize the need to consider staff personal characteristics, comfort with and attitudes toward EOL and palliative care, and staff fear of death and dying of self and others for palliative care and EOL care when creating education on EOL and palliative care for nurses as well as other members of the interdisciplinary team. Data from this study points to the importance of surveying staff in regard to personal characteristics such as caring for a dying loved one, to design education to address staff needs. Understanding the predictors for EPCS can identify areas to focus on when creating an educational intervention for training staff. Nurses, as case managers for the home healthcare team, need to take the role of leader in recognizing how staff personal characteristics, comfort with and attitudes toward EOL and palliative care, and staff fear of death and dying of self and others impact the entire interprofessional home care team and develop education with these subscales in mind.

The COVID-19 global health crisis placed even more emphasis on the need for EOL and palliative care and emphasized the need for education of the interprofessional home healthcare team who were faced with patients needing these valuable services in a time of uncertainty. Findings from this study reveal how COVID-19 impacted home care staff attitudes and comfort levels. It is important for this to be considered in the future education of not only nurses but non-nurses as well. Kamal et al. (2020) emphasized a clear lesson learned upon reflecting on the implications of the COVID-19 health crisis: “In times of uncertainty and complexity, palliative care should stand shoulder-to-shoulder with patients, caregivers, clinicians, and health systems to contribute to hoping for the best and planning for the rest” (p. 2326).

Research

Further research could be done, including a larger population sample of multiple home care agencies across the country to improve the generalizability of findings. While the need for palliative care–trained team members is increasing, there is a lack of access to quality palliative care training programs that meet the mandates of the National Consensus Project. There is a lack of research regarding high-quality, tested training tools for palliative care team building and communication across disciplines (Wittenberg et al., 2016). Understanding the impacts of home health care staff personal characteristics, comfort with and attitudes toward hospice and palliative care, as well as fear of death and dying can help guide future education for this population. Additional research, including the impact the pandemic has had on this population, can also be expanded to formulate education. This is a rich area for future research. Other areas to be explored in future research could be how staff’s spiritual and religious beliefs impact comfort and attitudes.

As seen in prior public health emergencies such as war, Ebola, and natural disasters, nurses have demonstrated using science to provide leadership and patient care. The COVID-19 pandemic poses another opportunity for nursing research to help meet the challenges made evident by this pandemic about how to integrate palliative care needs during a global health crisis with strict lockdown measures and limited patient–family contact due to visitation restrictions (Rosa et al.,2020). According to D'Antonio et al. (2020), “Nursing research is coronavirus research” (p. 215). For many years now, nursing scientists have been creating and implementing a research agenda to improve EOL care (Ferrell et al., 2017). The challenges brought by the COVID-19 emergency can help reshape the research agenda for improving the provision of EOL care and incorporating all the new issues raised by the pandemic. Some of these issues include symptom management, rapid patient decline, increased use of intensive care and social and family dynamics affected by isolation mandates, quarantining, visitation restrictions, and social distancing (Rosa et al., 2020).

Policy

The results of this study could have an impact on future policy creation about managing the impact of global health crisis on palliative and hospice care delivery. These study results highlight the impact the pandemic has had on home health care workers' comfort with and attitudes toward hospice and palliative care and fear of death and dying. Comfort of the participants with discussing the dying process decreased one year into the pandemic. Participants' attitude toward pain control changed as well, with the attitude becoming more negative when it came to pain control at EOL. This warrants future study, as the concept of pain control and hastening death related to hospice and palliative care has been at the forefront of numerous debates throughout the years. There are those who are advocates for pain control as a primary goal of EOL care even if this means it could hasten a patient's death in some cases. The original tool (F-S Hospice Scale: Views of Hospice [Feeg & Stewart, 2000]) used for the Attitude Toward Hospice Scale is an older tool still deemed reliable but could elicit a mixed response from participants related to attitude toward pain control at EOL.

> Nurses should not hesitate to use full and effective doses of pain medication for the proper management of pain in the dying patient. The increasing titration of medication to achieve adequate symptom control, even at the expense of life, thus hastening death secondarily, is ethically justified (Hockenberger, 1992, p. 1).

Nonetheless, the results of this study demonstrated a change in the attitude toward pain control at Time 2, and further research is warranted.

The study findings demonstrated that participants were affected by the pandemic regarding fear of death and dying of self and others. The following fears were at a higher level one year into the pandemic: death and the shortness of life, dying in hospital away from others, and dying of others—reminder of own death. It makes sense that these fears were at a higher level as a result of living through a global health crisis. The quarantine restrictions and lack of in-hospital visitation impacted not only patients and their caregivers but nurses as well. Nursing staff had to adjust, be creative, and overcome many barriers during restrictions from the effects of the COVID-19 health crisis. Home care staff had to also adapt and find ways to care for the patients and families that lived through all the quarantine restrictions and returned home. Patient- and family-centered EOL care can often be difficult to achieve, and the restrictions of family visitations and strict infection-prevention measures have presented new barriers. According to a study by Azad et al. (2021), COVID-19 policies restricting family visitation may have delayed EOL decisions for many patients. Future policies and programs allowing access to family- centered and palliative care during a global health crisis such as the COVID-19 pandemic need to be implemented.

Limitations

A limitation of this study is that all data were obtained through self-reporting via survey method. Response bias may have occurred by use of this method. Limitations of the study may also include a lack of generalizability due to the population of the sample coming from one healthcare organization in the Northeast area of the United States. The agency where the study was conducted is a faith-based organization, which could affect results. Staff were not asked about religion or religious/spiritual beliefs as a personal characteristic. The population of the sample was predominantly female; although this is indicative of the industry, it could prevent the detection of differences that may exist between male and female home care workers. Another limitation may be that the level of palliative care training was not specified in the survey question, which could affect the result. Further research is warranted in these areas. Selection bias could also be a limitation, considering the population was strictly home health care workers and those who responded could have more of an interest in EOL and palliative care.

Conclusion

This study explored the relationship between home health care providers' personal characteristics and their comfort with and attitudes toward hospice and palliative care, and fear of death and dying of self and others. The findings of the study yielded significant results regarding staff level of comfort, attitudes, and fear of death and dying in relation to staff personal characteristics. For comfort level, the findings demonstrated there was a lower level of comfort with providing EOL care for those staff who were non-nurses compared to those who were nurses. The results demonstrated that staff who reported some type of formal palliative care or hospice care training, those having personally cared for a dying loved one had a higher level of comfort. The study results regarding attitudes of staff toward EOL care and personal characteristics demonstrated that staff who had personally cared for a dying loved one had a more positive attitude toward providing EOL and palliative care. Regarding personal characteristics and staff fear of death and dying of self and others, the study findings showed that women were more likely to have a fear of dying and younger staff (under the age of 45) were more likely to fear the death of others.

The study demonstrated changes in staff comfort and attitudes toward palliative and EOL care during the onset of the pandemic. Differences were seen between Time 1 and Time 2 in one’s comfort level in discussing the dying process, attitudes toward hospice related to pain control, caregivers’ feelings toward fear of death of oneself in the measure death and the shortness of life, caregivers’ feelings of fear about dying away from others, and caregivers’ feelings about the dying of others as a reminder of their own death. The study results also identified certain predictors for staff self-reported EPCS in the domains of personal characteristics and level of comfort with and attitudes about providing EOL and palliative care services. These variables need to be understood as a baseline before implementing a focused educational program about palliative and EOL care.

Further research is needed to guide future policies and programs to improve access to family-centered palliative care during a global health crisis such as the COVID-19 pandemic need to be implemented. An investment in further research and the resultant policy changes from the study findings can further support home health care workers in caring for EOL patients and their families.

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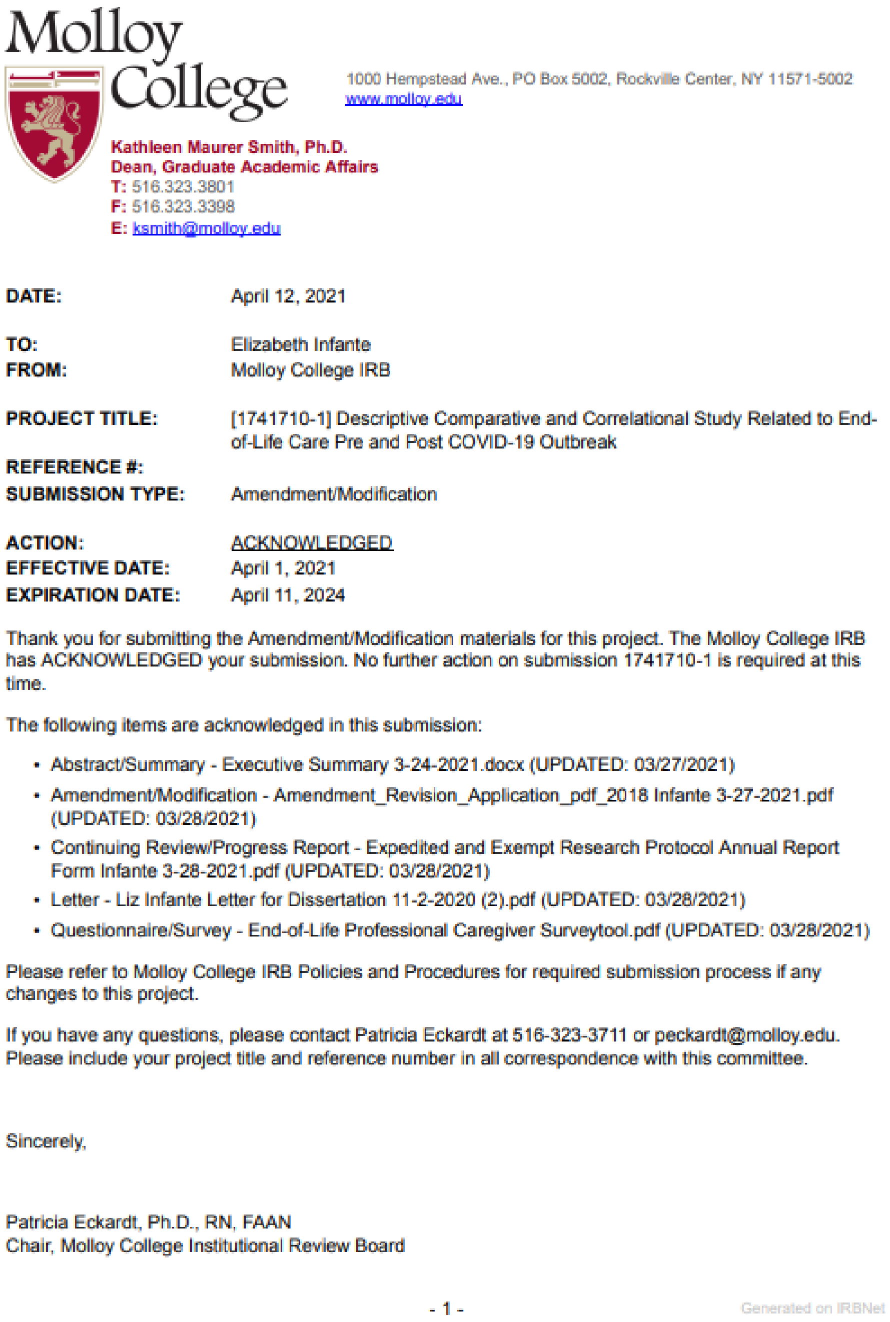
Appendix A: Molloy College IRB Approval



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Kathleen Maurer Smith, Ph.D.
Dean, Graduate Academic Affairs
T: 516.323.3801
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E: ksmith@molloy.edu

DATE:	April 12, 2021
TO:	Elizabeth Infante
FROM:	Molloy College IRB
PROJECT TITLE:	[1741710-1] Descriptive Comparative and Correlational Study Related to End-of-Life Care Pre and Post COVID-19 Outbreak
REFERENCE #:	
SUBMISSION TYPE:	Amendment/Modification
ACTION:	ACKNOWLEDGED
EFFECTIVE DATE:	April 1, 2021
EXPIRATION DATE:	April 11, 2024

Thank you for submitting the Amendment/Modification materials for this project. The Molloy College IRB has ACKNOWLEDGED your submission. No further action on submission 1741710-1 is required at this time.

The following items are acknowledged in this submission:

- Abstract/Summary - Executive Summary 3-24-2021.docx (UPDATED: 03/27/2021)
- Amendment/Modification - Amendment_Revision_Application_pdf_2018 Infante 3-27-2021.pdf (UPDATED: 03/28/2021)
- Continuing Review/Progress Report - Expedited and Exempt Research Protocol Annual Report Form Infante 3-28-2021.pdf (UPDATED: 03/28/2021)
- Letter - Liz Infante Letter for Dissertation 11-2-2020 (2).pdf (UPDATED: 03/28/2021)
- Questionnaire/Survey - End-of-Life Professional Caregiver Surveytool.pdf (UPDATED: 03/28/2021)

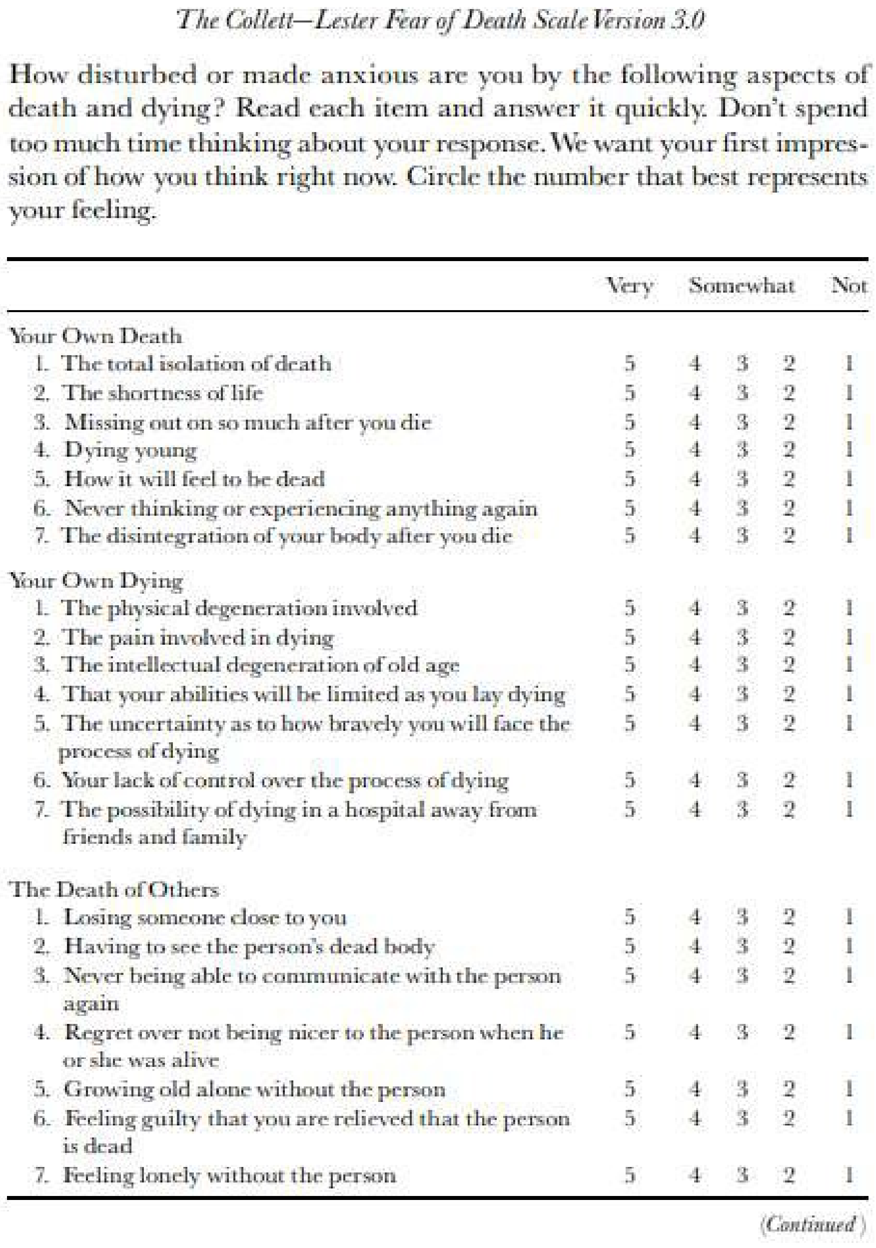
Please refer to Molloy College IRB Policies and Procedures for required submission process if any changes to this project.

If you have any questions, please contact Patricia Eckardt at 516-323-3711 or peckardt@molloy.edu. Please include your project title and reference number in all correspondence with this committee.

Sincerely,

Patricia Eckardt, Ph.D., RN, FAAN
Chair, Molloy College Institutional Review Board

Appendix B: The Collett-Lester Fear of Death Scale

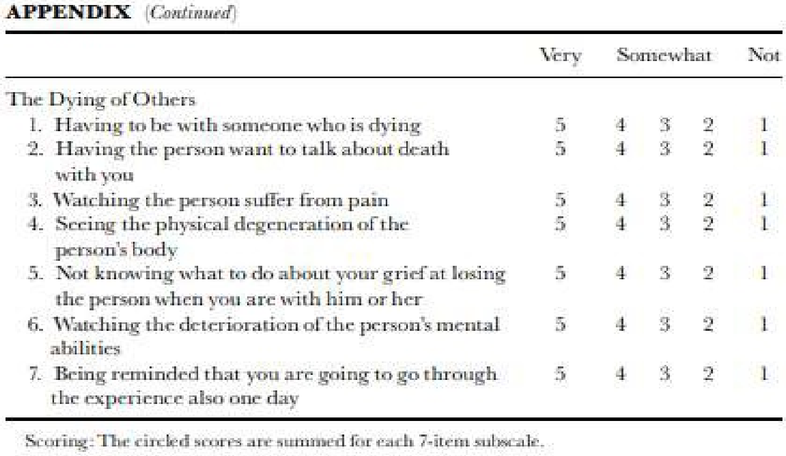


The Collett—Lester Fear of Death Scale Version 3.0

How disturbed or made anxious are you by the following aspects of death and dying? Read each item and answer it quickly. Don't spend too much time thinking about your response. We want your first impression of how you think right now. Circle the number that best represents your feeling.

	Very	Somewhat			Not
Your Own Death					
1. The total isolation of death	5	4	3	2	1
2. The shortness of life	5	4	3	2	1
3. Missing out on so much after you die	5	4	3	2	1
4. Dying young	5	4	3	2	1
5. How it will feel to be dead	5	4	3	2	1
6. Never thinking or experiencing anything again	5	4	3	2	1
7. The disintegration of your body after you die	5	4	3	2	1
Your Own Dying					
1. The physical degeneration involved	5	4	3	2	1
2. The pain involved in dying	5	4	3	2	1
3. The intellectual degeneration of old age	5	4	3	2	1
4. That your abilities will be limited as you lay dying	5	4	3	2	1
5. The uncertainty as to how bravely you will face the process of dying	5	4	3	2	1
6. Your lack of control over the process of dying	5	4	3	2	1
7. The possibility of dying in a hospital away from friends and family	5	4	3	2	1
The Death of Others					
1. Losing someone close to you	5	4	3	2	1
2. Having to see the person's dead body	5	4	3	2	1
3. Never being able to communicate with the person again	5	4	3	2	1
4. Regret over not being nicer to the person when he or she was alive	5	4	3	2	1
5. Growing old alone without the person	5	4	3	2	1
6. Feeling guilty that you are relieved that the person is dead	5	4	3	2	1
7. Feeling lonely without the person	5	4	3	2	1

(*Continued*)



APPENDIX *(Continued)*

	Very	Somewhat			Not
The Dying of Others					
1. Having to be with someone who is dying	5	4	3	2	1
2. Having the person want to talk about death with you	5	4	3	2	1
3. Watching the person suffer from pain	5	4	3	2	1
4. Seeing the physical degeneration of the person's body	5	4	3	2	1
5. Not knowing what to do about your grief at losing the person when you are with him or her	5	4	3	2	1
6. Watching the deterioration of the person's mental abilities	5	4	3	2	1
7. Being reminded that you are going to go through the experience also one day	5	4	3	2	1

Scoring: The circled scores are summed for each 7-item subscale.

Appendix C: Permission to Use Instrument

FW: The Collett-Lester Fear of Death Scale

Research Residency

Infante, Elizabeth <Elizabeth.Infante@chsli.org> Oct 23,

2017,

8:59 AM

From: Lester, David [mailto:David.Lester@stockton.edu]

Sent: Monday, October 23, 2017 8:51 AM

To: Infante, Elizabeth <Elizabeth.Infante@chsli.org>

Subject: Re: The Collett7Lester Fear of Death Scale Yes, you have my permission.

I've attached my "manual" for the scale. best wishes

David

David Lester, Ph.D.

Distinguished Professor of Psychology, Emeritus Stockton University

101 Vera King Farris Drive Galloway, NJ 08205-9441 USA

www.drdavidlester.net

Superficially I appear to be deep, but deep down I'm really shallow

David Lester has retired: e-mails may be answered eventually

From: Infante, Elizabeth <Elizabeth.Infante@chsli.org>

Sent: Thursday, October 19, 2017 11:00 AM

To: Lester, David

Subject: The Collett7Lester Fear of Death Scale

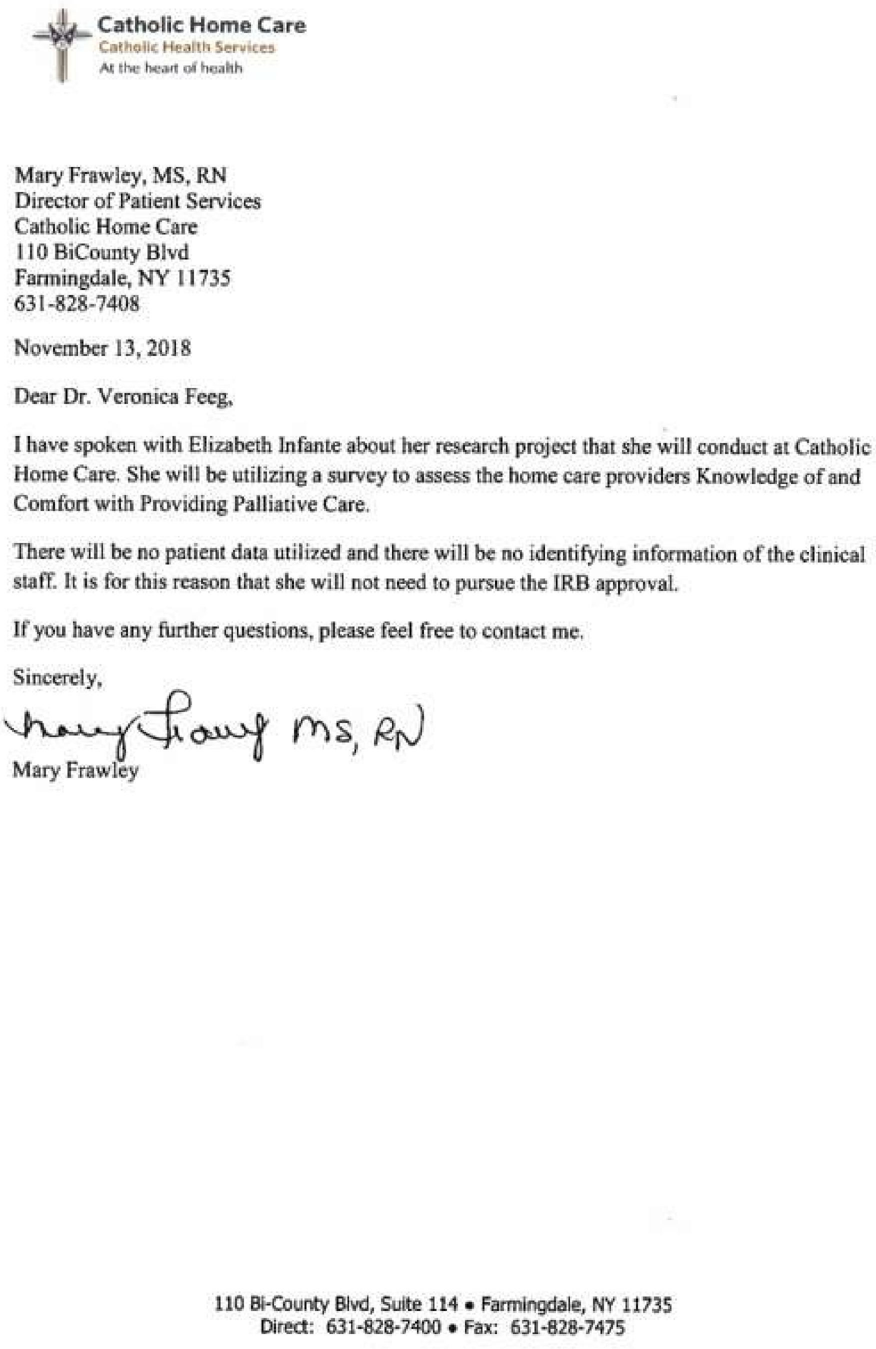
Dr. Lester,

I am a doctoral student at Molloy College in New York. I am studying for my PhD in the Philosophy of Nursing. I was hoping to have permission to use The Collett-Lester Fear of Death Scale for a study that may be used eventually for my dissertation. I was hoping to have your permission to use your instrument for a pre-education survey for knowledge needs assessment prior to implementation of a multi-disciplinary educational intervention regarding initiating end-of-life decision making conversations and palliative care.

Thank you, Elizabeth Infante

Elizabeth Infante RN MS
Clinical Systems Educator/Performance Improvement Nurse Good Shepherd Hospice
110 Bi-County Blvd. suite 114
Farmingdale, N.Y. 11735
631-828-7654
cell 631-459-1109

Appendix D: Permission to Conduct Survey –Time 1



Catholic Home Care
Catholic Health Services
At the heart of health

Mary Frawley, MS, RN
Director of Patient Services
Catholic Home Care
110 BiCounty Blvd
Farmingdale, NY 11735
631-828-7408

November 13, 2018

Dear Dr. Veronica Feeg,

I have spoken with Elizabeth Infante about her research project that she will conduct at Catholic Home Care. She will be utilizing a survey to assess the home care providers Knowledge of and Comfort with Providing Palliative Care.

There will be no patient data utilized and there will be no identifying information of the clinical staff. It is for this reason that she will not need to pursue the IRB approval.

If you have any further questions, please feel free to contact me.

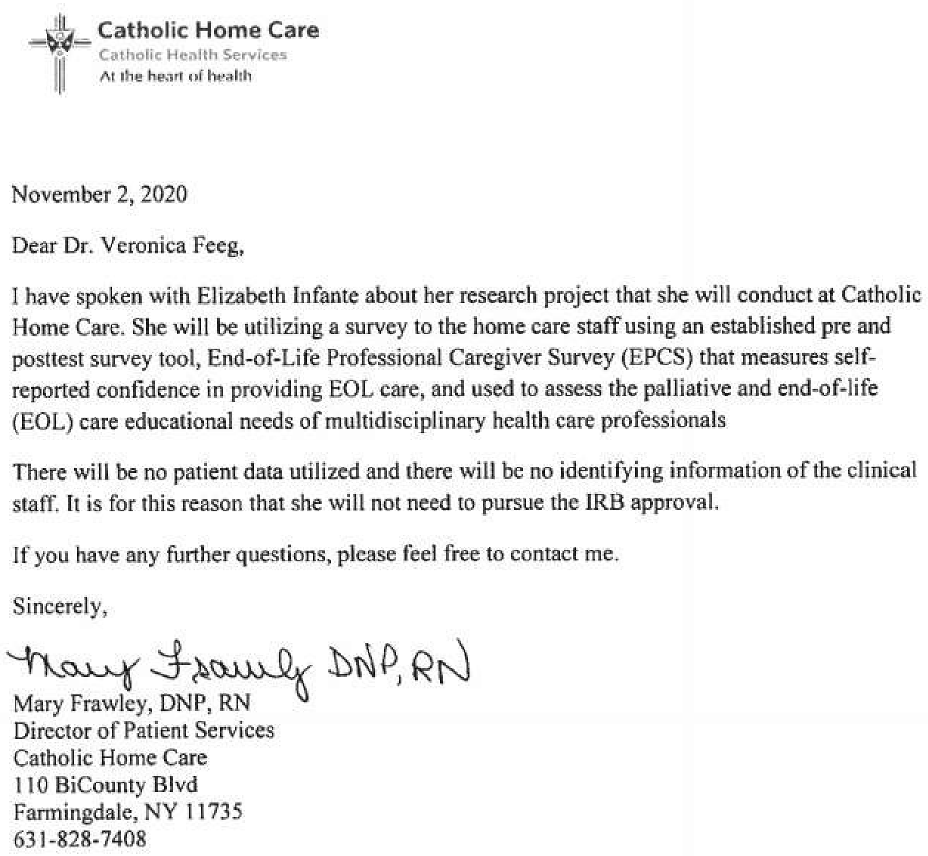
Sincerely,

Mary Frawley MS, RN

Mary Frawley

110 Bi-County Blvd, Suite 114 • Farmingdale, NY 11735
Direct: 631-828-7400 • Fax: 631-828-7475

Appendix E: Permission to Conduct Survey –Time 2



Catholic Home Care
Catholic Health Services
At the heart of health

November 2, 2020

Dear Dr. Veronica Feeg,

I have spoken with Elizabeth Infante about her research project that she will conduct at Catholic Home Care. She will be utilizing a survey to the home care staff using an established pre and posttest survey tool, End-of-Life Professional Caregiver Survey (EPCS) that measures self-reported confidence in providing EOL care, and used to assess the palliative and end-of-life (EOL) care educational needs of multidisciplinary health care professionals

There will be no patient data utilized and there will be no identifying information of the clinical staff. It is for this reason that she will not need to pursue the IRB approval.

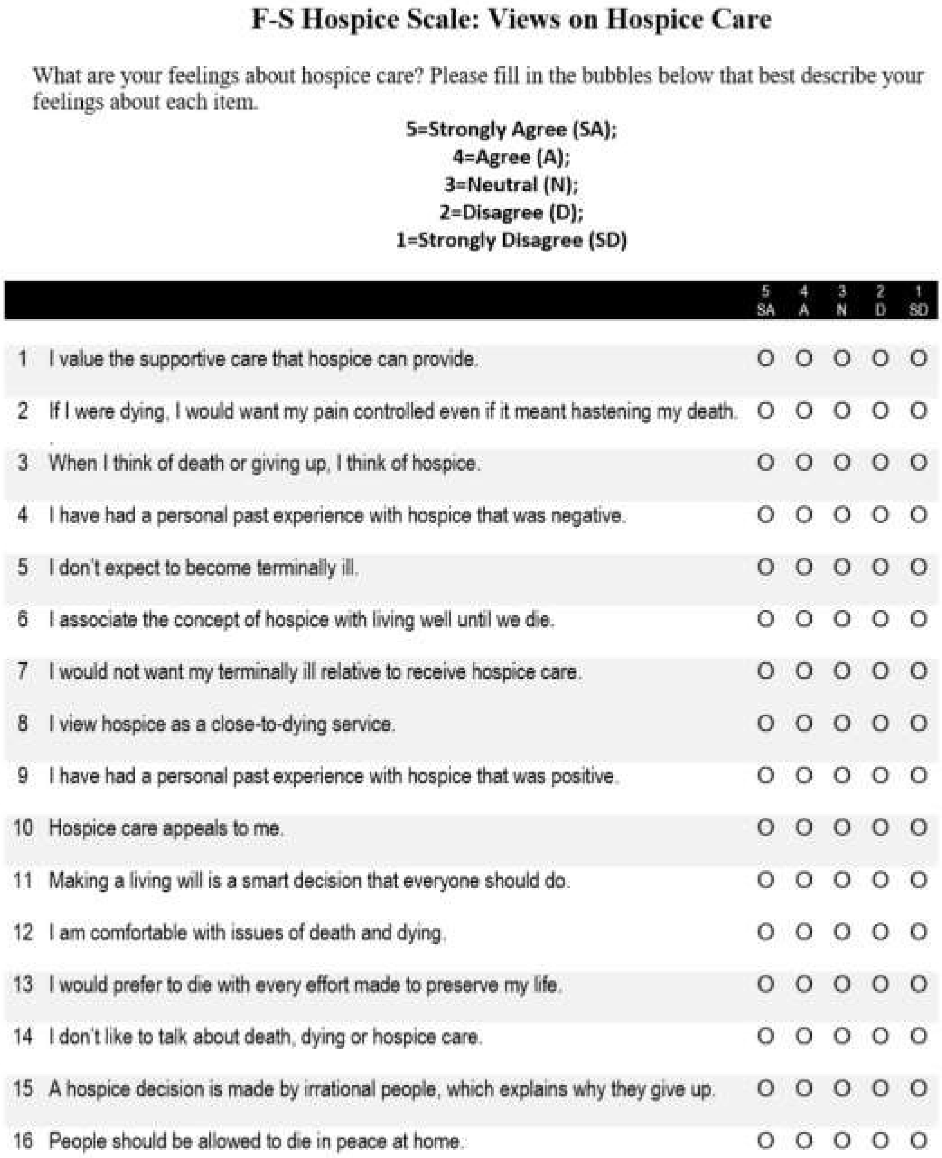
If you have any further questions, please feel free to contact me.

Sincerely,

Mary Frawley DNP, RN

Mary Frawley, DNP, RN
Director of Patient Services
Catholic Home Care
110 BiCounty Blvd
Farmingdale, NY 11735
631-828-7408

Appendix F: F-S Hospice Scale: Views on Hospice Care



F-S Hospice Scale: Views on Hospice Care

What are your feelings about hospice care? Please fill in the bubbles below that best describe your feelings about each item.

5=Strongly Agree (SA);
4=Agree (A);
3=Neutral (N);
2=Disagree (D);
1=Strongly Disagree (SD)

		5 SA	4 A	3 N	2 D	1 SD
1	I value the supportive care that hospice can provide.	○	○	○	○	○
2	If I were dying, I would want my pain controlled even if it meant hastening my death.	○	○	○	○	○
3	When I think of death or giving up, I think of hospice.	○	○	○	○	○
4	I have had a personal past experience with hospice that was negative.	○	○	○	○	○
5	I don't expect to become terminally ill.	○	○	○	○	○
6	I associate the concept of hospice with living well until we die.	○	○	○	○	○
7	I would not want my terminally ill relative to receive hospice care.	○	○	○	○	○
8	I view hospice as a close-to-dying service.	○	○	○	○	○
9	I have had a personal past experience with hospice that was positive.	○	○	○	○	○
10	Hospice care appeals to me.	○	○	○	○	○
11	Making a living will is a smart decision that everyone should do.	○	○	○	○	○
12	I am comfortable with issues of death and dying.	○	○	○	○	○
13	I would prefer to die with every effort made to preserve my life.	○	○	○	○	○
14	I don't like to talk about death, dying or hospice care.	○	○	○	○	○
15	A hospice decision is made by irrational people, which explains why they give up.	○	○	○	○	○
16	People should be allowed to die in peace at home.	○	○	○	○	○

Appendix G: End-of-Life Professional Caregiver Survey

End-of-Life Professional Caregiver Survey

Below is a list of statements that other end-of-life professional caregivers have said are important. **Please circle one number per line to indicate your response as it applies to you <u>today</u>.**

		Not at all	A little bit	Some-what	Quite a bit	Very much
P1	I am comfortable helping families to accept a poor prognosis	0	1	2	3	4
P2	I am able to set goals for care with patients and families	0	1	2	3	4
P3	I am comfortable talking to patients and families about personal choice and self-determination	0	1	2	3	4
P4	I am comfortable starting and participating in discussions about code status	0	1	2	3	4
P5	I can assist family members and others through the grieving process	0	1	2	3	4
P6	I am able to document the needs and interventions of my patients	0	1	2	3	4
P7	I am comfortable talking with other health care professionals about the care of dying patients	0	1	2	3	4
P8	I am comfortable helping to resolve difficult family conflicts about end-of-life care	0	1	2	3	4
P9	I can recognize impending death (physiologic changes)	0	1	2	3	4
P10	I know how to use non-drug therapies in management of patients' symptoms	0	1	2	3	4
P11	I am able to address patients' and family members' fears of getting addicted to pain medications	0	1	2	3	4
P12	I encourage patients and families to complete advanced care planning	0	1	2	3	4
C1	I am comfortable dealing with ethical issues related to end-of-life/hospice/palliative care	0	1	2	3	4
C2	I am able to deal with my feelings related to working with dying patients	0	1	2	3	4

English (Universal)
Copyright 2012
http://dx.doi.org/10.1089/jpm.2011.0246

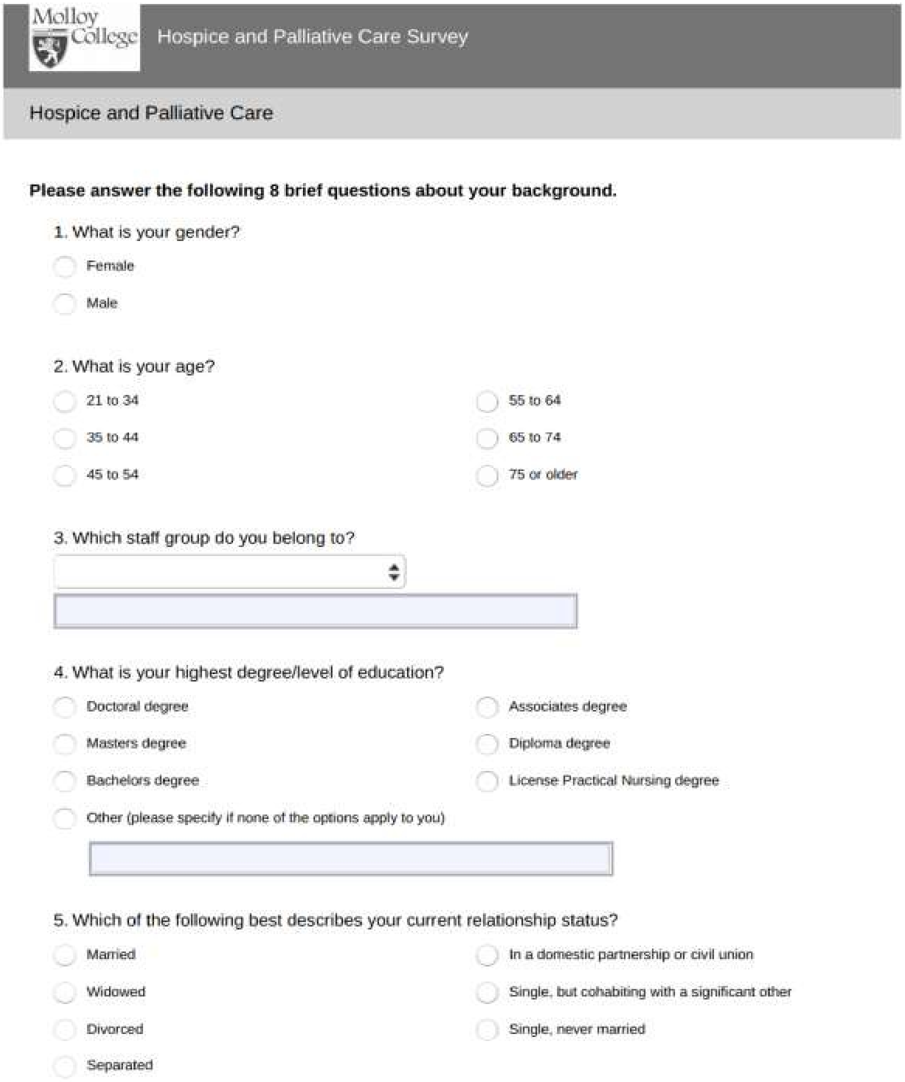
19 April 2012
Page 1 of 3

End-of-Life Professional Caregiver Survey

C3	I am able to be present with dying patients	0	1	2	3	4
C4	I can address spiritual issues with patients and their families	0	1	2	3	4
C5	I am comfortable dealing with patients' and families' religious and cultural perspectives	0	1	2	3	4
C6	I am comfortable providing grief counseling for families	0	1	2	3	4
C7	I am comfortable providing grief counseling for staff	0	1	2	3	4
C8	I am knowledgeable about cultural factors influencing end-of-life care	0	1	2	3	4
E1	I can recognize when patients are appropriate for referral to hospice	0	1	2	3	4
E2	I am familiar with palliative care principles and national guidelines	0	1	2	3	4
E3	I am effective at helping patients and families navigate the health care system	0	1	2	3	4
E4	I am familiar with the services hospice provides	0	1	2	3	4
E5	I am effective at helping to maintain continuity across care settings	0	1	2	3	4
E6	I feel confident addressing requests for assisted suicide	0	1	2	3	4
E7	I have personal resources to help meet my needs when working with dying patients and families	0	1	2	3	4
E8	I feel that my workplace provides resources to support staff who care for dying patients	0	1	2	3	4

http://dx.doi.org/10.1089/jpm.2011.0246

Appendix H: Hospice and Palliative Care Survey –Time 1



Molloy College Hospice and Palliative Care Survey

Hospice and Palliative Care

Please answer the following 8 brief questions about your background.

1. What is your gender?

○ Female
○ Male

2. What is your age?

○ 21 to 34
○ 35 to 44
○ 45 to 54
○ 55 to 64
○ 65 to 74
○ 75 or older

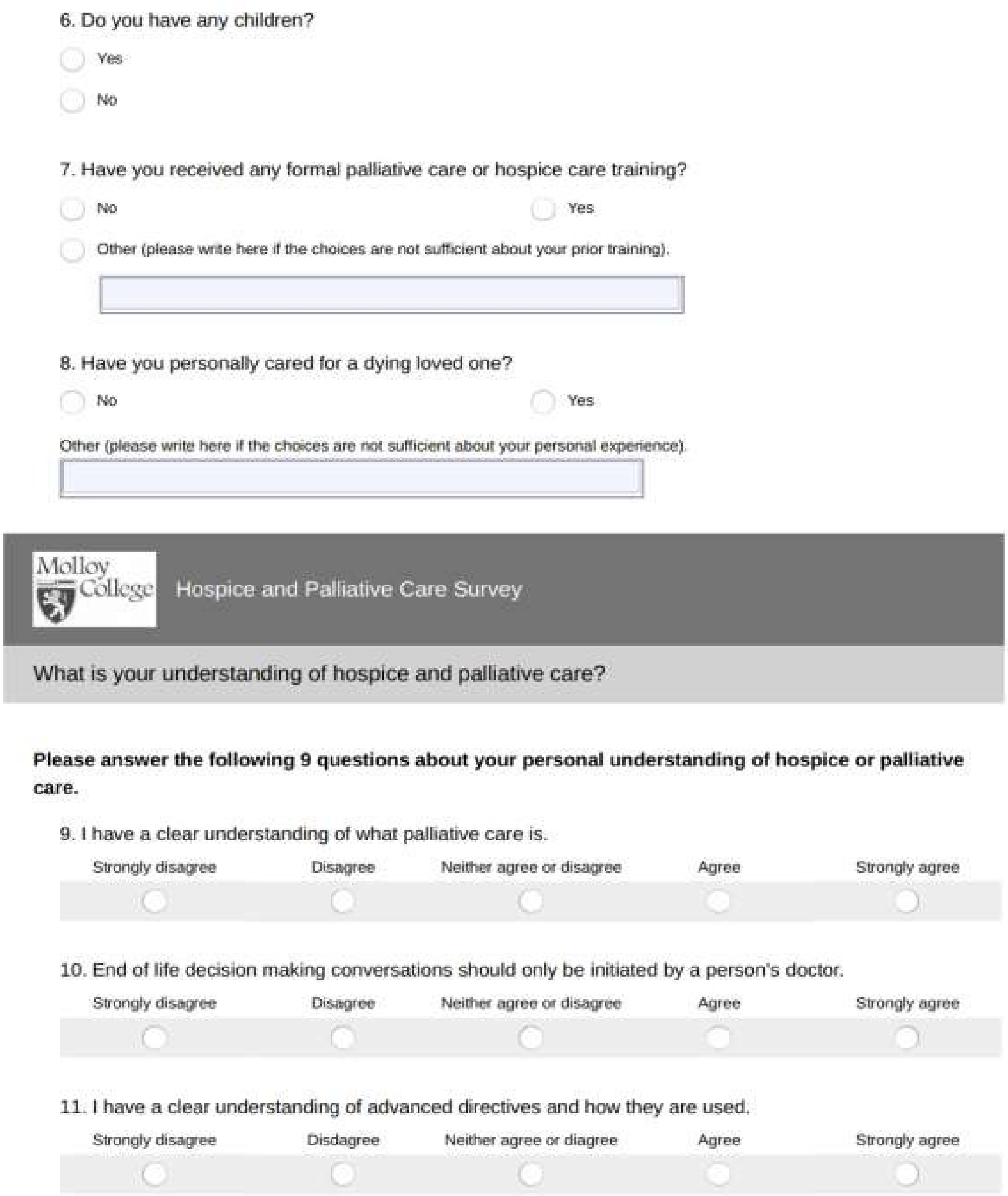
3. Which staff group do you belong to?

4. What is your highest degree/level of education?

○ Doctoral degree
○ Masters degree
○ Bachelors degree
○ Other (please specify if none of the options apply to you)
○ Associates degree
○ Diploma degree
○ License Practical Nursing degree

5. Which of the following best describes your current relationship status?

○ Married
○ Widowed
○ Divorced
○ Separated
○ In a domestic partnership or civil union
○ Single, but cohabiting with a significant other
○ Single, never married



6. Do you have any children?

○ Yes

○ No

7. Have you received any formal palliative care or hospice care training?

○ No ○ Yes

○ Other (please write here if the choices are not sufficient about your prior training).

8. Have you personally cared for a dying loved one?

○ No ○ Yes

Other (please write here if the choices are not sufficient about your personal experience).

Molloy College Hospice and Palliative Care Survey

What is your understanding of hospice and palliative care?

Please answer the following 9 questions about your personal understanding of hospice or palliative care.

9. I have a clear understanding of what palliative care is.

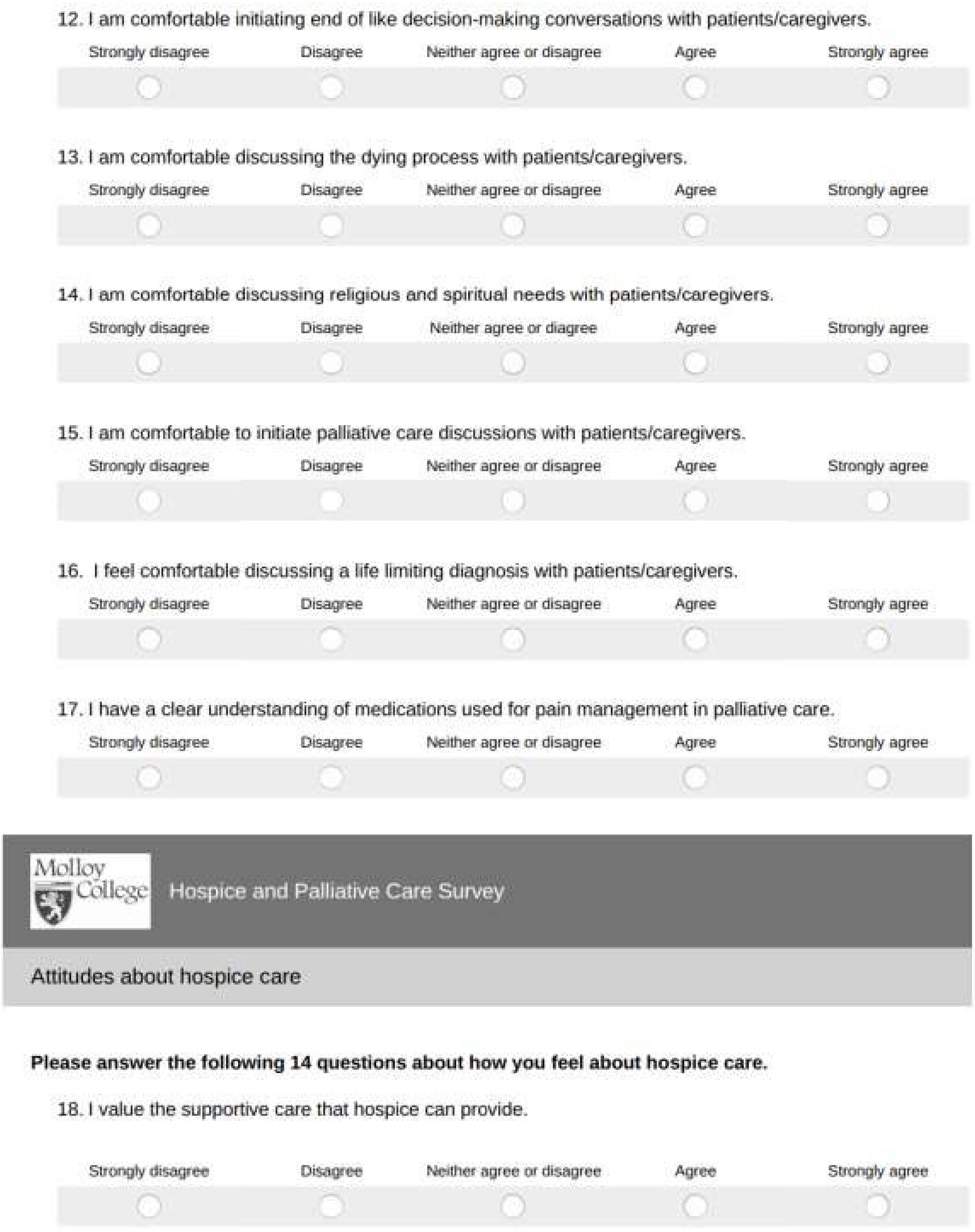
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

10. End of life decision making conversations should only be initiated by a person's doctor.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

11. I have a clear understanding of advanced directives and how they are used.

Strongly disagree	Disdagree	Neither agree or diagree	Agree	Strongly agree
○	○	○	○	○



12. I am comfortable initiating end of like decision-making conversations with patients/caregivers.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

13. I am comfortable discussing the dying process with patients/caregivers.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

14. I am comfortable discussing religious and spiritual needs with patients/caregivers.

Strongly disagree	Disagree	Neither agree or diagree	Agree	Strongly agree
○	○	○	○	○

15. I am comfortable to initiate palliative care discussions with patients/caregivers.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

16. I feel comfortable discussing a life limiting diagnosis with patients/caregivers.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

17. I have a clear understanding of medications used for pain management in palliative care.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

Molloy College

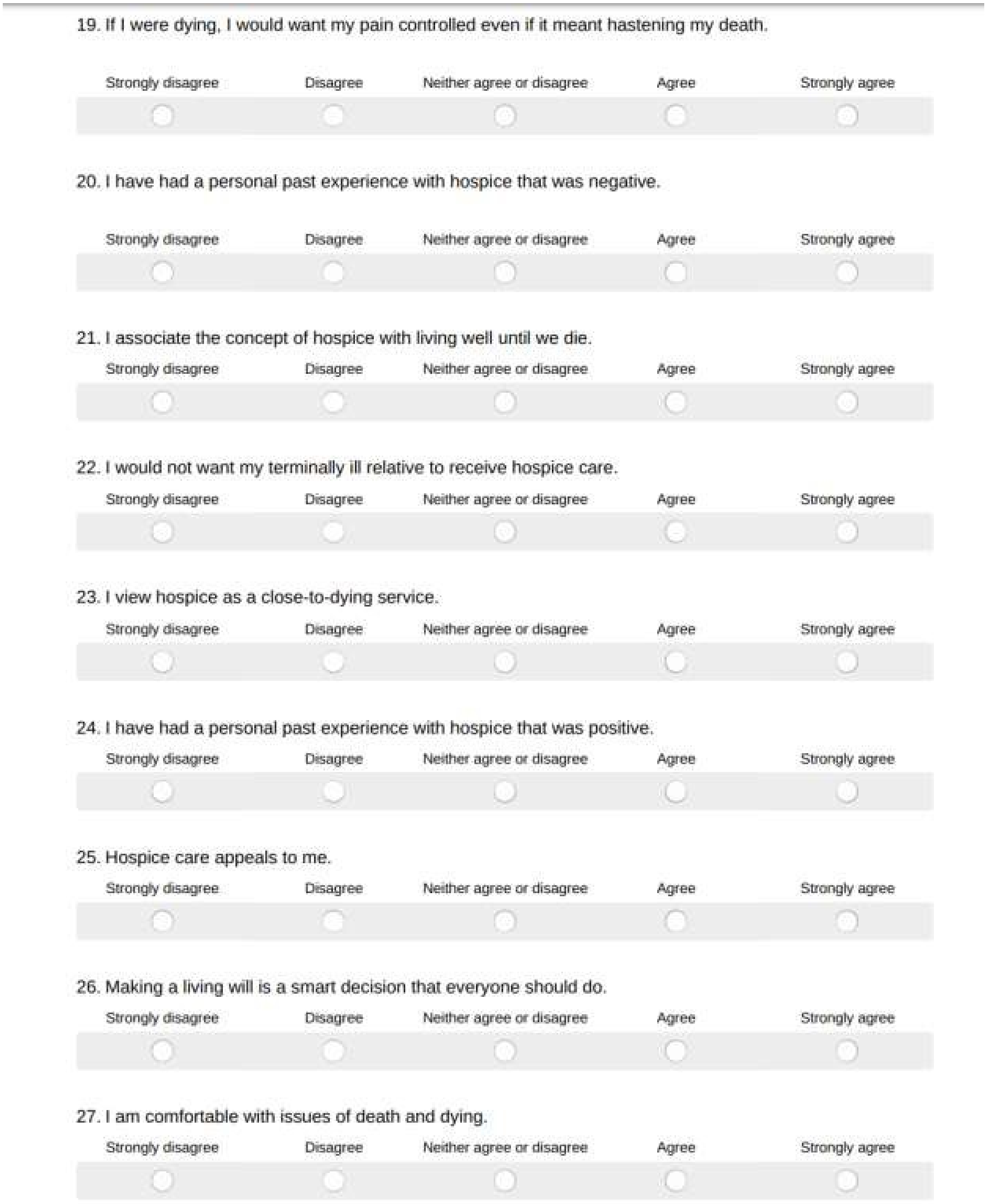
Hospice and Palliative Care Survey

Attitudes about hospice care

Please answer the following 14 questions about how you feel about hospice care.

18. I value the supportive care that hospice can provide.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○



19. If I were dying, I would want my pain controlled even if it meant hastening my death.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

20. I have had a personal past experience with hospice that was negative.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

21. I associate the concept of hospice with living well until we die.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

22. I would not want my terminally ill relative to receive hospice care.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

23. I view hospice as a close-to-dying service.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

24. I have had a personal past experience with hospice that was positive.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

25. Hospice care appeals to me.

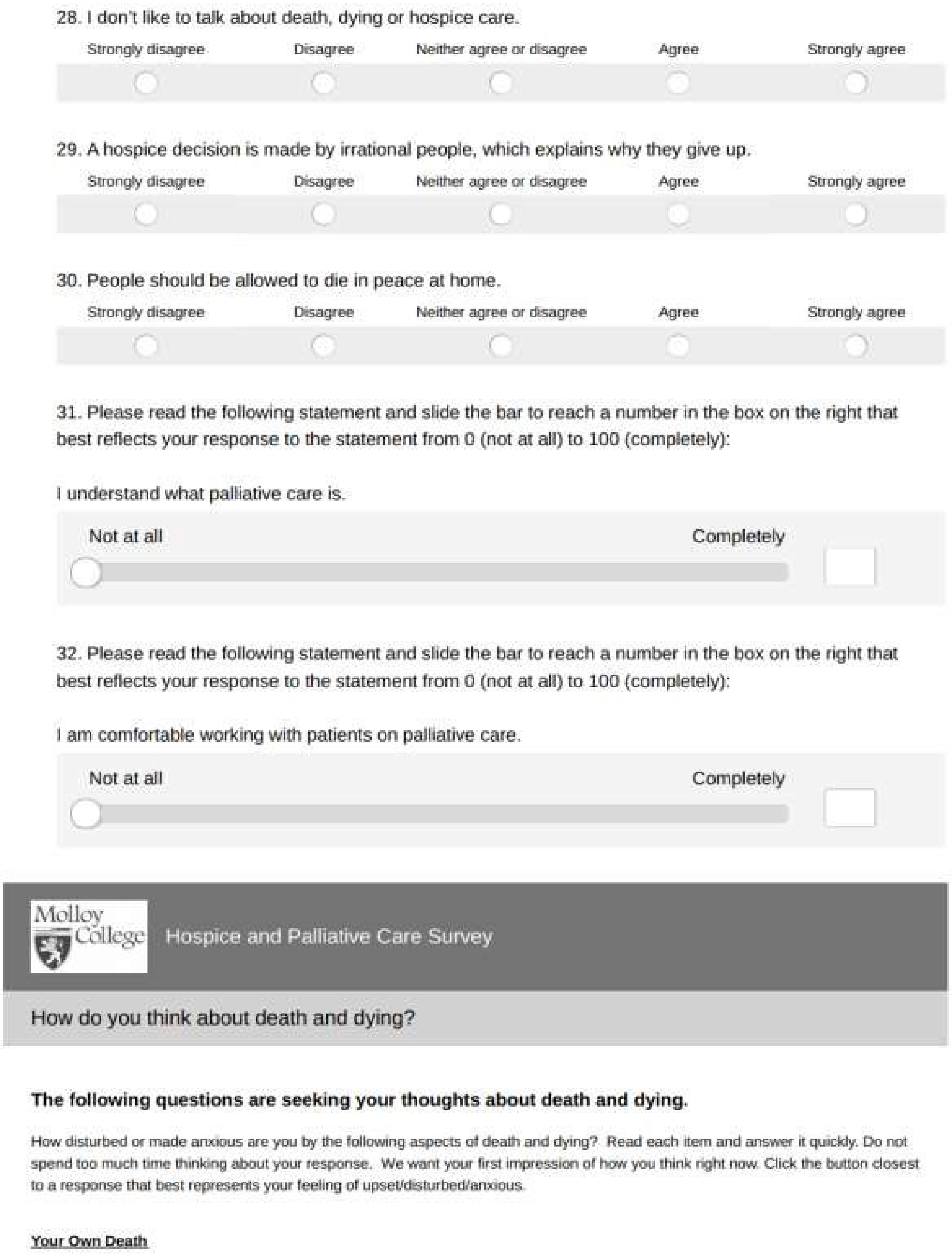
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

26. Making a living will is a smart decision that everyone should do.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

27. I am comfortable with issues of death and dying.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○



28. I don't like to talk about death, dying or hospice care.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

29. A hospice decision is made by irrational people, which explains why they give up.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

30. People should be allowed to die in peace at home.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

31. Please read the following statement and slide the bar to reach a number in the box on the right that best reflects your response to the statement from 0 (not at all) to 100 (completely):

I understand what palliative care is.

Not at all Completely

32. Please read the following statement and slide the bar to reach a number in the box on the right that best reflects your response to the statement from 0 (not at all) to 100 (completely):

I am comfortable working with patients on palliative care.

Not at all Completely

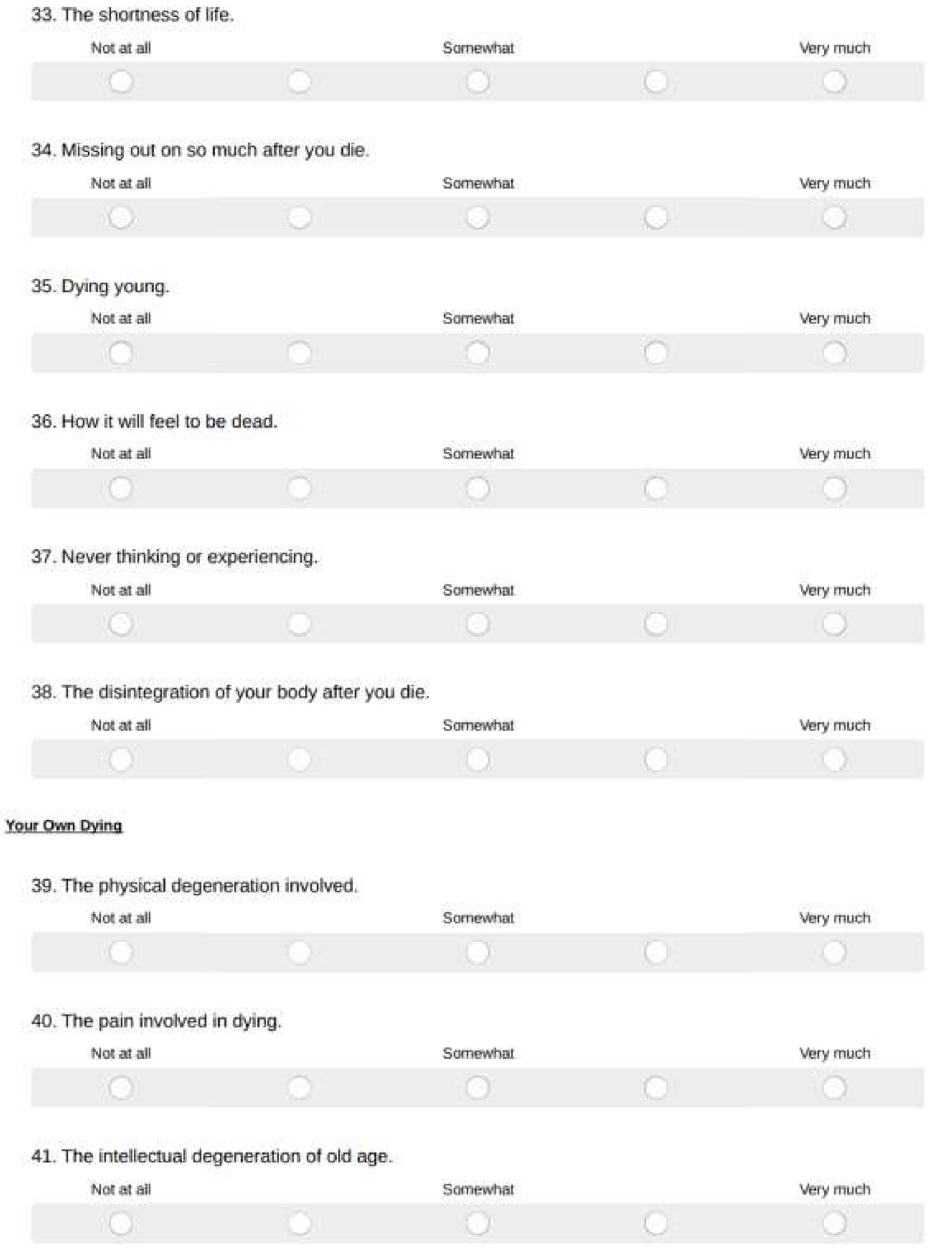
Molloy College Hospice and Palliative Care Survey

How do you think about death and dying?

The following questions are seeking your thoughts about death and dying.

How disturbed or made anxious are you by the following aspects of death and dying? Read each item and answer it quickly. Do not spend too much time thinking about your response. We want your first impression of how you think right now. Click the button closest to a response that best represents your feeling of upset/disturbed/anxious.

Your Own Death



33. The shortness of life.

Not at all		Somewhat		Very much
○	○	○	○	○

34. Missing out on so much after you die.

Not at all		Somewhat		Very much
○	○	○	○	○

35. Dying young.

Not at all		Somewhat		Very much
○	○	○	○	○

36. How it will feel to be dead.

Not at all		Somewhat		Very much
○	○	○	○	○

37. Never thinking or experiencing.

Not at all		Somewhat		Very much
○	○	○	○	○

38. The disintegration of your body after you die.

Not at all		Somewhat		Very much
○	○	○	○	○

Your Own Dying

39. The physical degeneration involved.

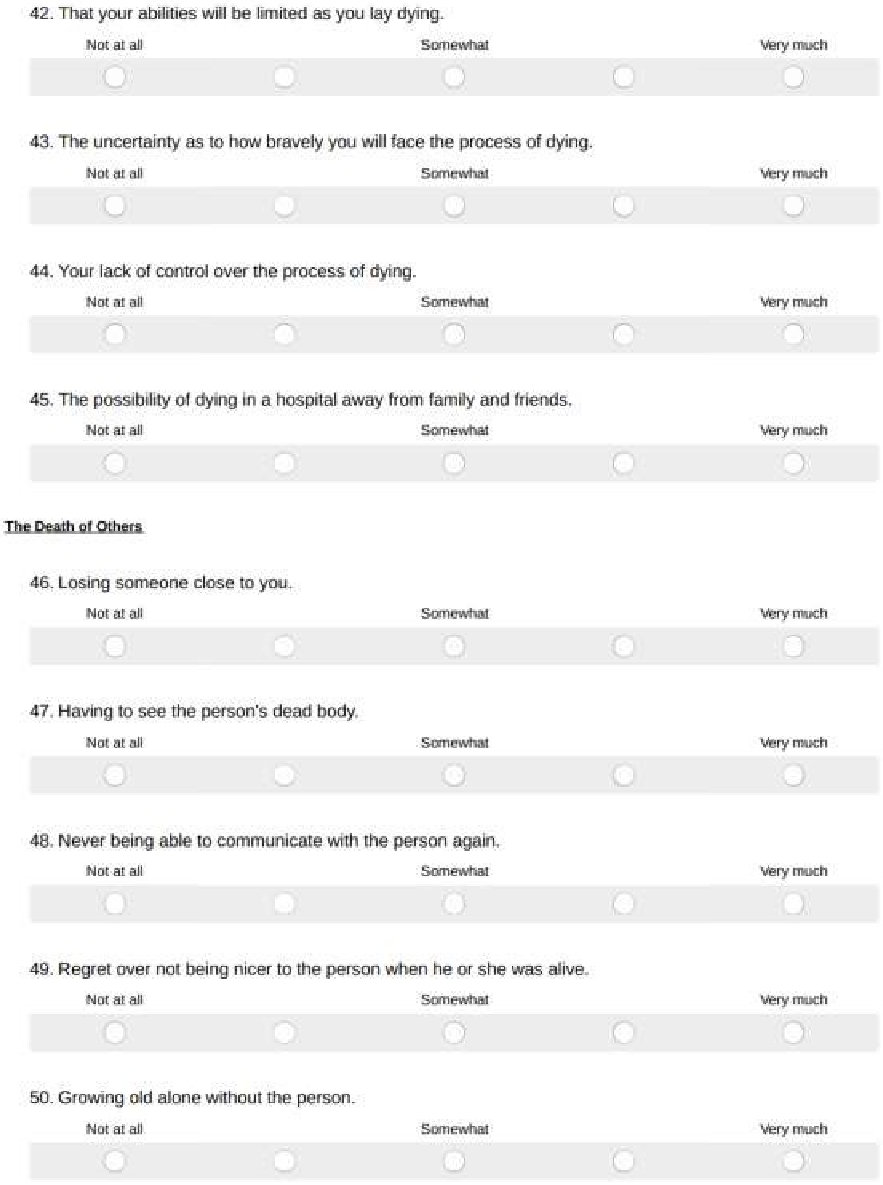
Not at all		Somewhat		Very much
○	○	○	○	○

40. The pain involved in dying.

Not at all		Somewhat		Very much
○	○	○	○	○

41. The intellectual degeneration of old age.

Not at all		Somewhat		Very much
○	○	○	○	○



42. That your abilities will be limited as you lay dying.

Not at all		Somewhat		Very much
○	○	○	○	○

43. The uncertainty as to how bravely you will face the process of dying.

Not at all		Somewhat		Very much
○	○	○	○	○

44. Your lack of control over the process of dying.

Not at all		Somewhat		Very much
○	○	○	○	○

45. The possibility of dying in a hospital away from family and friends.

Not at all		Somewhat		Very much
○	○	○	○	○

The Death of Others

46. Losing someone close to you.

Not at all		Somewhat		Very much
○	○	○	○	○

47. Having to see the person's dead body.

Not at all		Somewhat		Very much
○	○	○	○	○

48. Never being able to communicate with the person again.

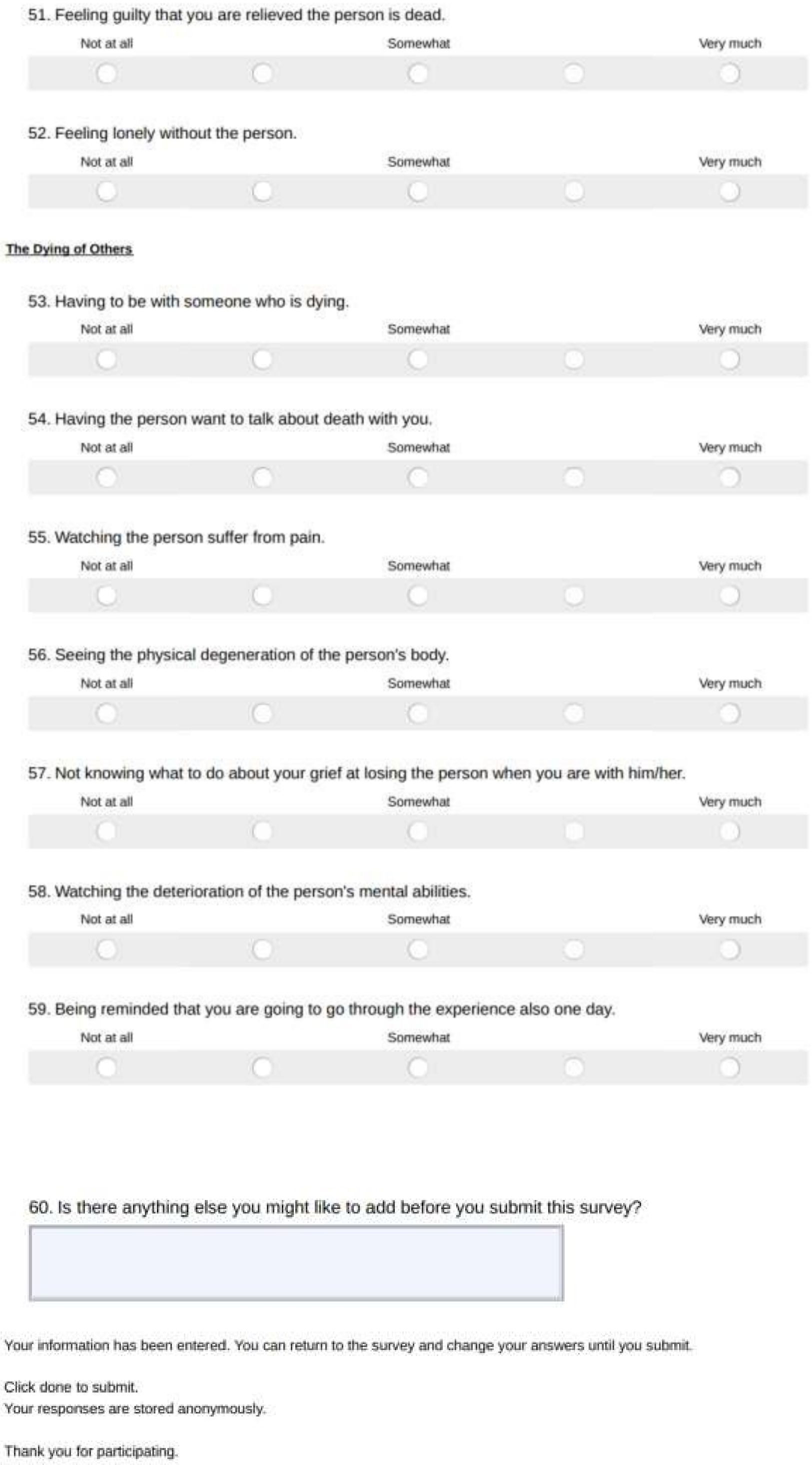
Not at all		Somewhat		Very much
○	○	○	○	○

49. Regret over not being nicer to the person when he or she was alive.

Not at all		Somewhat		Very much
○	○	○	○	○

50. Growing old alone without the person.

Not at all		Somewhat		Very much
○	○	○	○	○



51. Feeling guilty that you are relieved the person is dead.

Not at all		Somewhat		Very much
○	○	○	○	○

52. Feeling lonely without the person.

Not at all		Somewhat		Very much
○	○	○	○	○

The Dying of Others

53. Having to be with someone who is dying.

Not at all		Somewhat		Very much
○	○	○	○	○

54. Having the person want to talk about death with you.

Not at all		Somewhat		Very much
○	○	○	○	○

55. Watching the person suffer from pain.

Not at all		Somewhat		Very much
○	○	○	○	○

56. Seeing the physical degeneration of the person's body.

Not at all		Somewhat		Very much
○	○	○	○	○

57. Not knowing what to do about your grief at losing the person when you are with him/her.

Not at all		Somewhat		Very much
○	○	○	○	○

58. Watching the deterioration of the person's mental abilities.

Not at all		Somewhat		Very much
○	○	○	○	○

59. Being reminded that you are going to go through the experience also one day.

Not at all		Somewhat		Very much
○	○	○	○	○

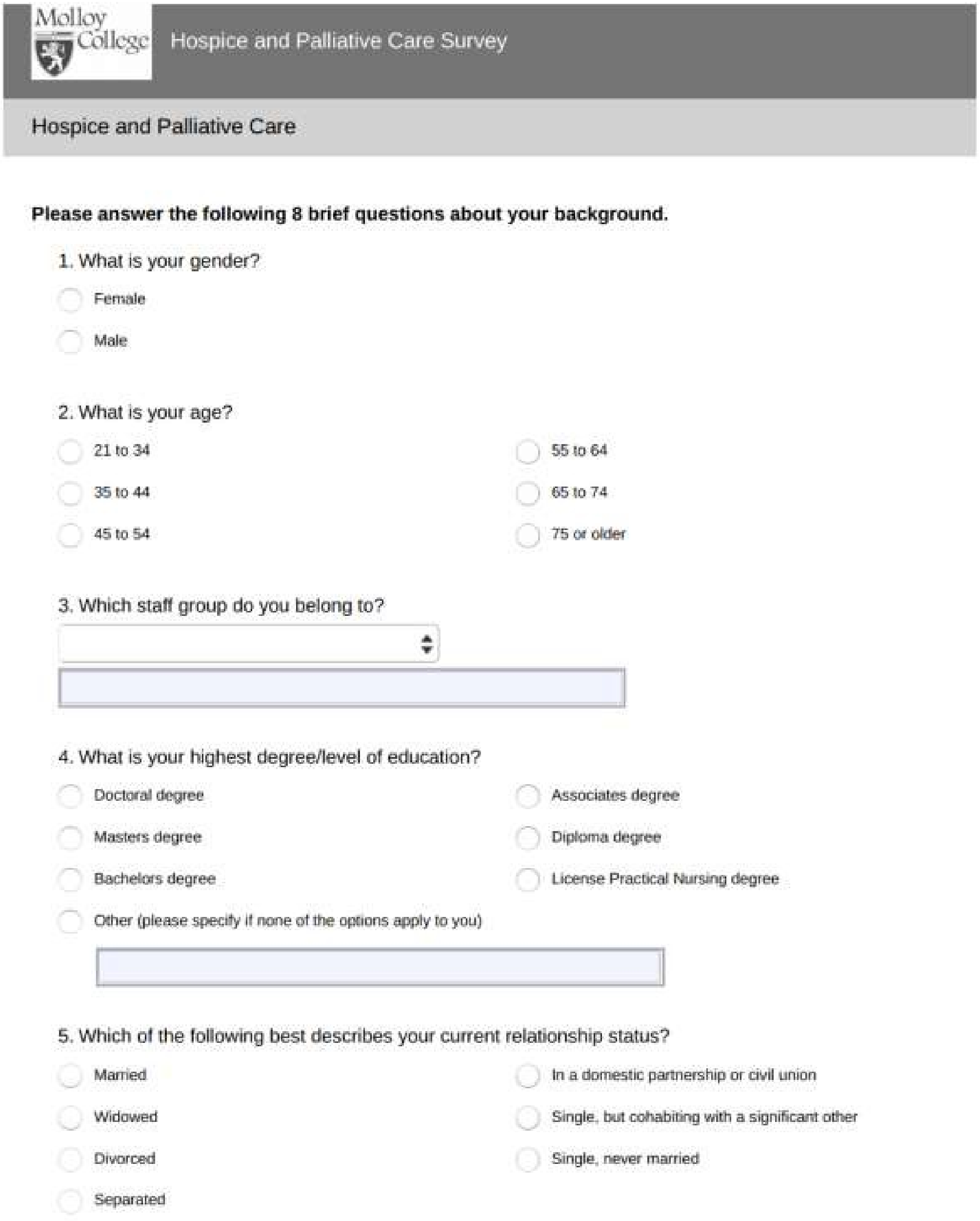
60. Is there anything else you might like to add before you submit this survey?

Your information has been entered. You can return to the survey and change your answers until you submit.

Click done to submit.
Your responses are stored anonymously.

Thank you for participating.

Appendix I: Hospice and Palliative Care Survey –Time 2



Molloy College Hospice and Palliative Care Survey

Hospice and Palliative Care

Please answer the following 8 brief questions about your background.

1. What is your gender?

○ Female
○ Male

2. What is your age?

○ 21 to 34
○ 35 to 44
○ 45 to 54
○ 55 to 64
○ 65 to 74
○ 75 or older

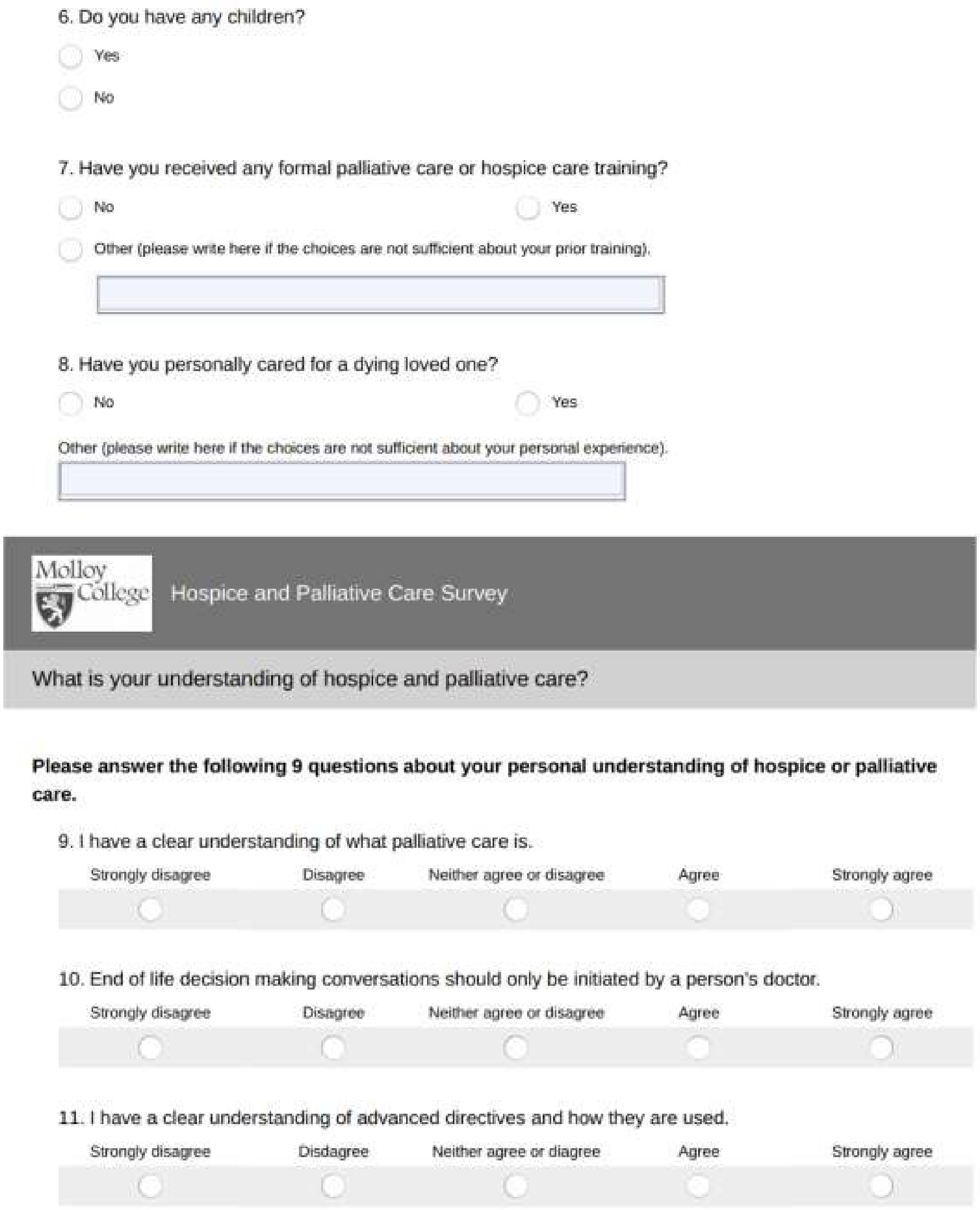
3. Which staff group do you belong to?

4. What is your highest degree/level of education?

○ Doctoral degree
○ Masters degree
○ Bachelors degree
○ Other (please specify if none of the options apply to you)
○ Associates degree
○ Diploma degree
○ License Practical Nursing degree

5. Which of the following best describes your current relationship status?

○ Married
○ Widowed
○ Divorced
○ Separated
○ In a domestic partnership or civil union
○ Single, but cohabiting with a significant other
○ Single, never married



6. Do you have any children?

○ Yes

○ No

7. Have you received any formal palliative care or hospice care training?

○ No ○ Yes

○ Other (please write here if the choices are not sufficient about your prior training).

8. Have you personally cared for a dying loved one?

○ No ○ Yes

Other (please write here if the choices are not sufficient about your personal experience).

Hospice and Palliative Care Survey

What is your understanding of hospice and palliative care?

Please answer the following 9 questions about your personal understanding of hospice or palliative care.

9. I have a clear understanding of what palliative care is.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

10. End of life decision making conversations should only be initiated by a person's doctor.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

11. I have a clear understanding of advanced directives and how they are used.

Strongly disagree	Disdagree	Neither agree or diagree	Agree	Strongly agree
○	○	○	○	○

12. I am comfortable initiating end of like decision-making conversations with patients/caregivers.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

13. I am comfortable discussing the dying process with patients/caregivers.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

14. I am comfortable discussing religious and spiritual needs with patients/caregivers.

Strongly disagree	Disagree	Neither agree or diagree	Agree	Strongly agree
○	○	○	○	○

15. I am comfortable to initiate palliative care discussions with patients/caregivers.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

16. I feel comfortable discussing a life limiting diagnosis with patients/caregivers.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

17. I have a clear understanding of medications used for pain management in palliative care.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

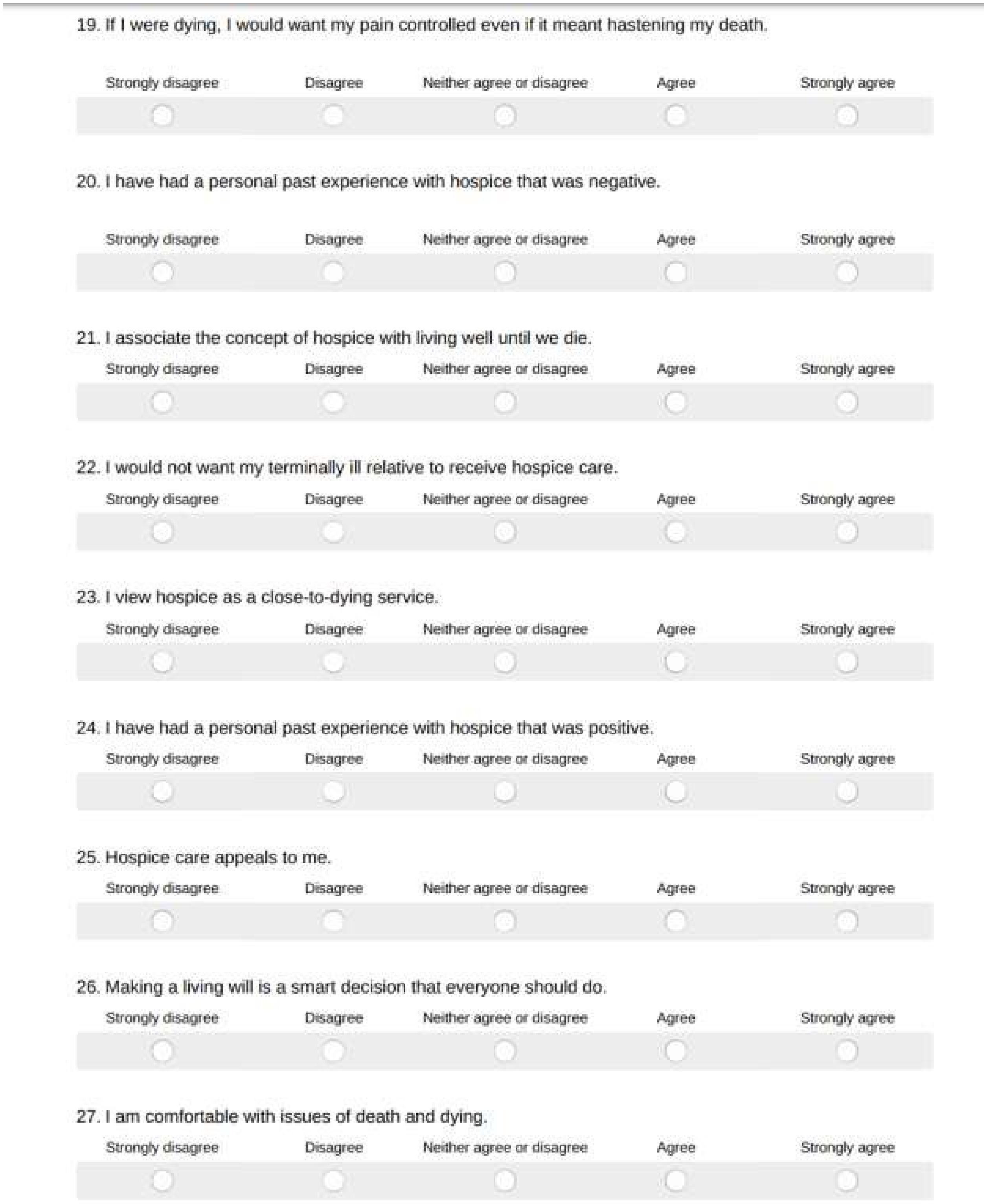
Molloy College Hospice and Palliative Care Survey

Attitudes about hospice care

Please answer the following 14 questions about how you feel about hospice care.

18. I value the supportive care that hospice can provide.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○



19. If I were dying, I would want my pain controlled even if it meant hastening my death.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

20. I have had a personal past experience with hospice that was negative.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

21. I associate the concept of hospice with living well until we die.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

22. I would not want my terminally ill relative to receive hospice care.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

23. I view hospice as a close-to-dying service.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

24. I have had a personal past experience with hospice that was positive.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

25. Hospice care appeals to me.

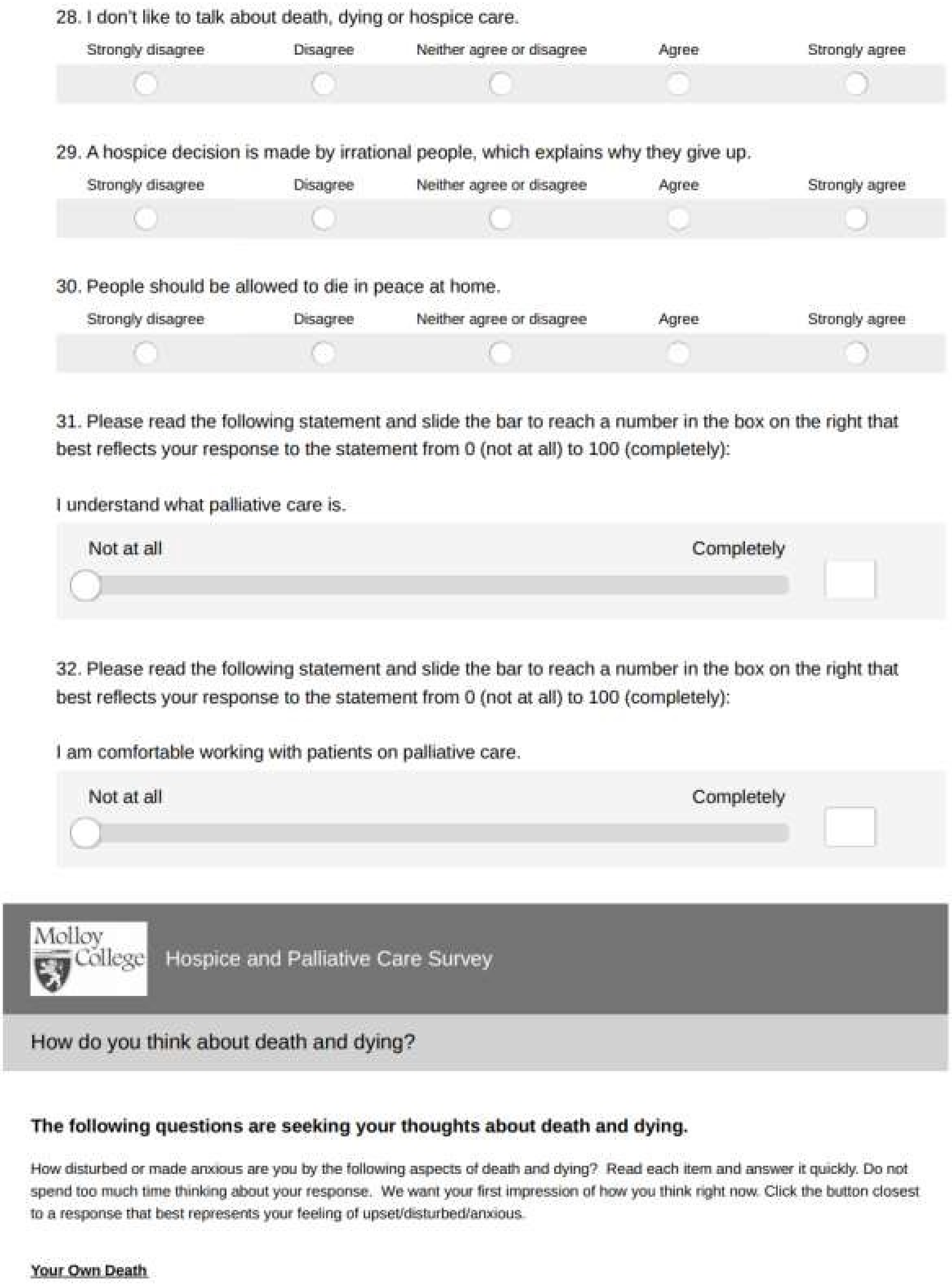
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

26. Making a living will is a smart decision that everyone should do.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

27. I am comfortable with issues of death and dying.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○



28. I don't like to talk about death, dying or hospice care.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

29. A hospice decision is made by irrational people, which explains why they give up.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

30. People should be allowed to die in peace at home.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
○	○	○	○	○

31. Please read the following statement and slide the bar to reach a number in the box on the right that best reflects your response to the statement from 0 (not at all) to 100 (completely):

I understand what palliative care is.

Not at all — Completely ☐

32. Please read the following statement and slide the bar to reach a number in the box on the right that best reflects your response to the statement from 0 (not at all) to 100 (completely):

I am comfortable working with patients on palliative care.

Not at all — Completely ☐

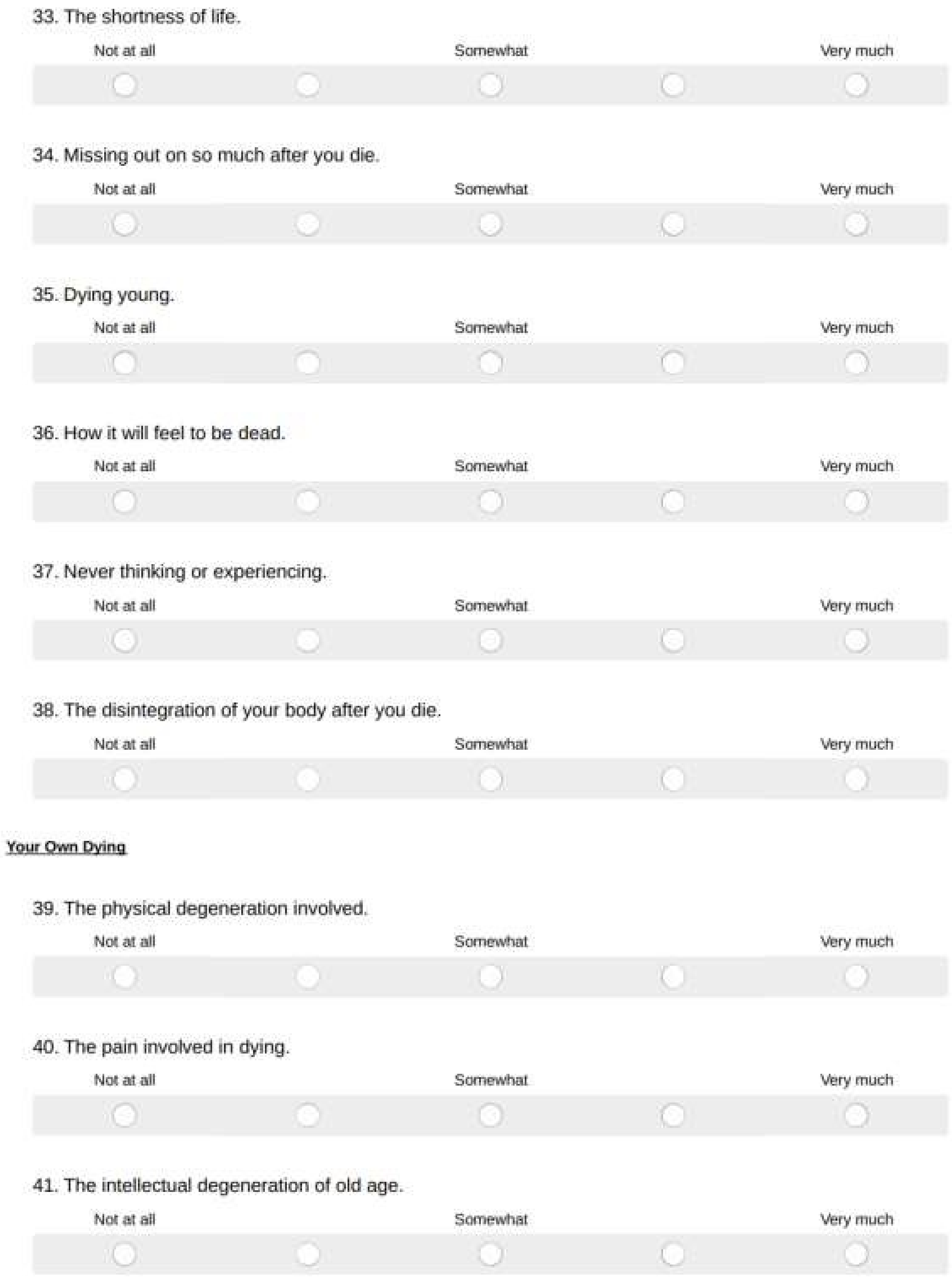
Molloy College Hospice and Palliative Care Survey

How do you think about death and dying?

The following questions are seeking your thoughts about death and dying.

How disturbed or made anxious are you by the following aspects of death and dying? Read each item and answer it quickly. Do not spend too much time thinking about your response. We want your first impression of how you think right now. Click the button closest to a response that best represents your feeling of upset/disturbed/anxious.

Your Own Death



33. The shortness of life.

Not at all		Somewhat		Very much
○	○	○	○	○

34. Missing out on so much after you die.

Not at all		Somewhat		Very much
○	○	○	○	○

35. Dying young.

Not at all		Somewhat		Very much
○	○	○	○	○

36. How it will feel to be dead.

Not at all		Somewhat		Very much
○	○	○	○	○

37. Never thinking or experiencing.

Not at all		Somewhat		Very much
○	○	○	○	○

38. The disintegration of your body after you die.

Not at all		Somewhat		Very much
○	○	○	○	○

Your Own Dying

39. The physical degeneration involved.

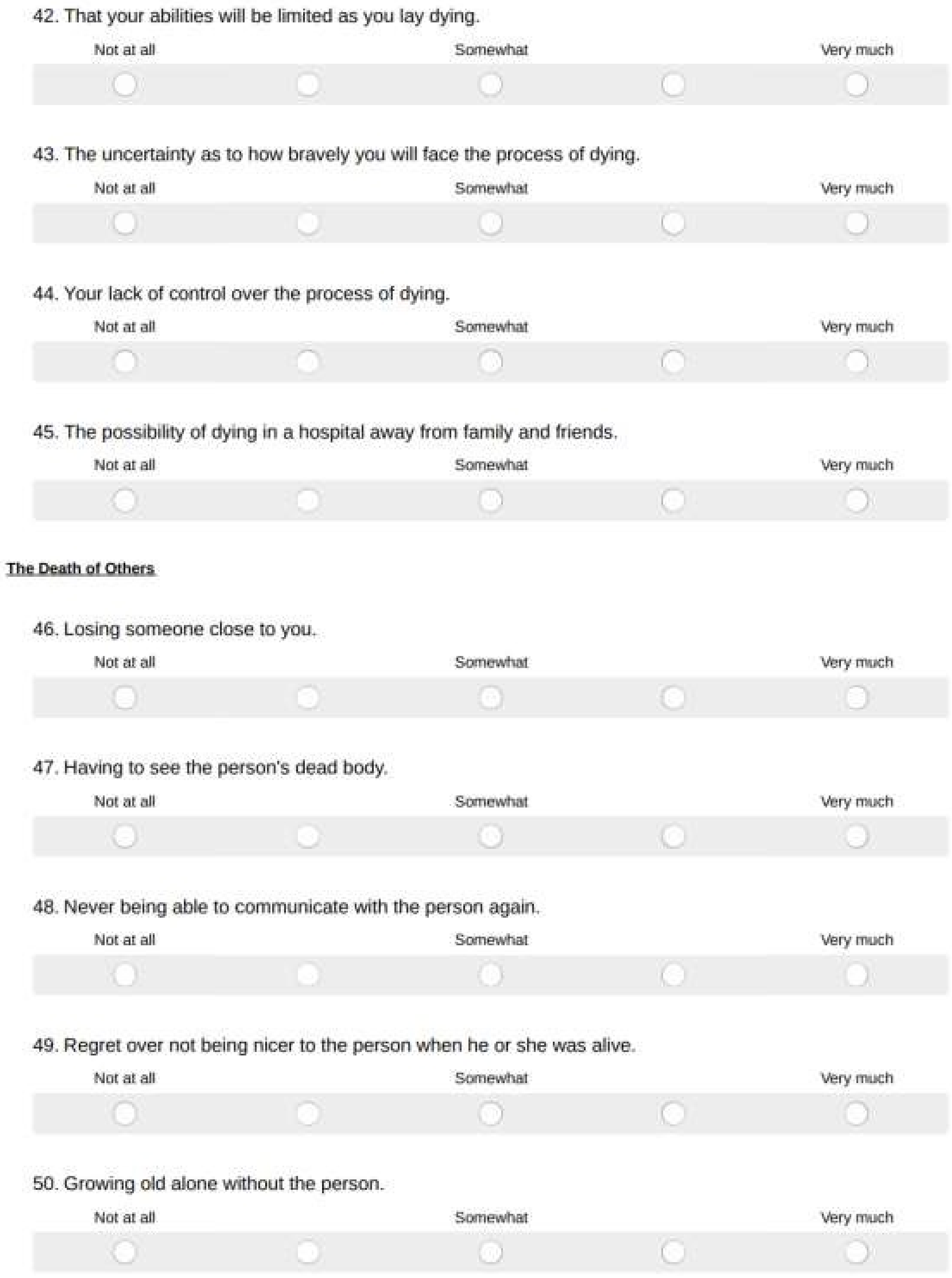
Not at all		Somewhat		Very much
○	○	○	○	○

40. The pain involved in dying.

Not at all		Somewhat		Very much
○	○	○	○	○

41. The intellectual degeneration of old age.

Not at all		Somewhat		Very much
○	○	○	○	○


42. That your abilities will be limited as you lay dying.

Not at all		Somewhat		Very much
○	○	○	○	○

43. The uncertainty as to how bravely you will face the process of dying.

Not at all		Somewhat		Very much
○	○	○	○	○

44. Your lack of control over the process of dying.

Not at all		Somewhat		Very much
○	○	○	○	○

45. The possibility of dying in a hospital away from family and friends.

Not at all		Somewhat		Very much
○	○	○	○	○

The Death of Others

46. Losing someone close to you.

Not at all		Somewhat		Very much
○	○	○	○	○

47. Having to see the person's dead body.

Not at all		Somewhat		Very much
○	○	○	○	○

48. Never being able to communicate with the person again.

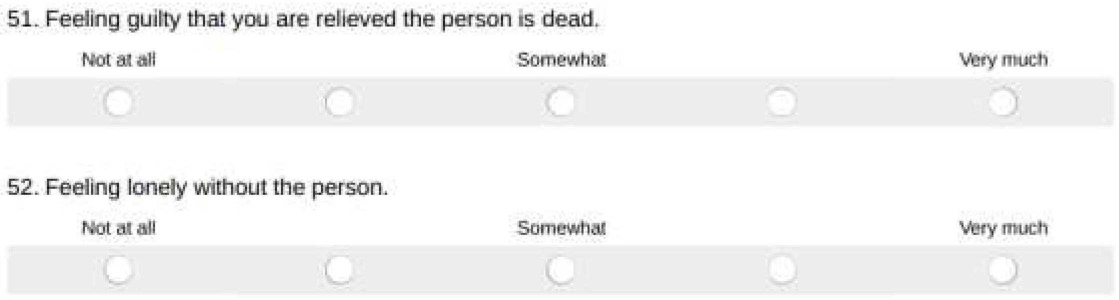
Not at all		Somewhat		Very much
○	○	○	○	○

49. Regret over not being nicer to the person when he or she was alive.

Not at all		Somewhat		Very much
○	○	○	○	○

50. Growing old alone without the person.

Not at all		Somewhat		Very much
○	○	○	○	○



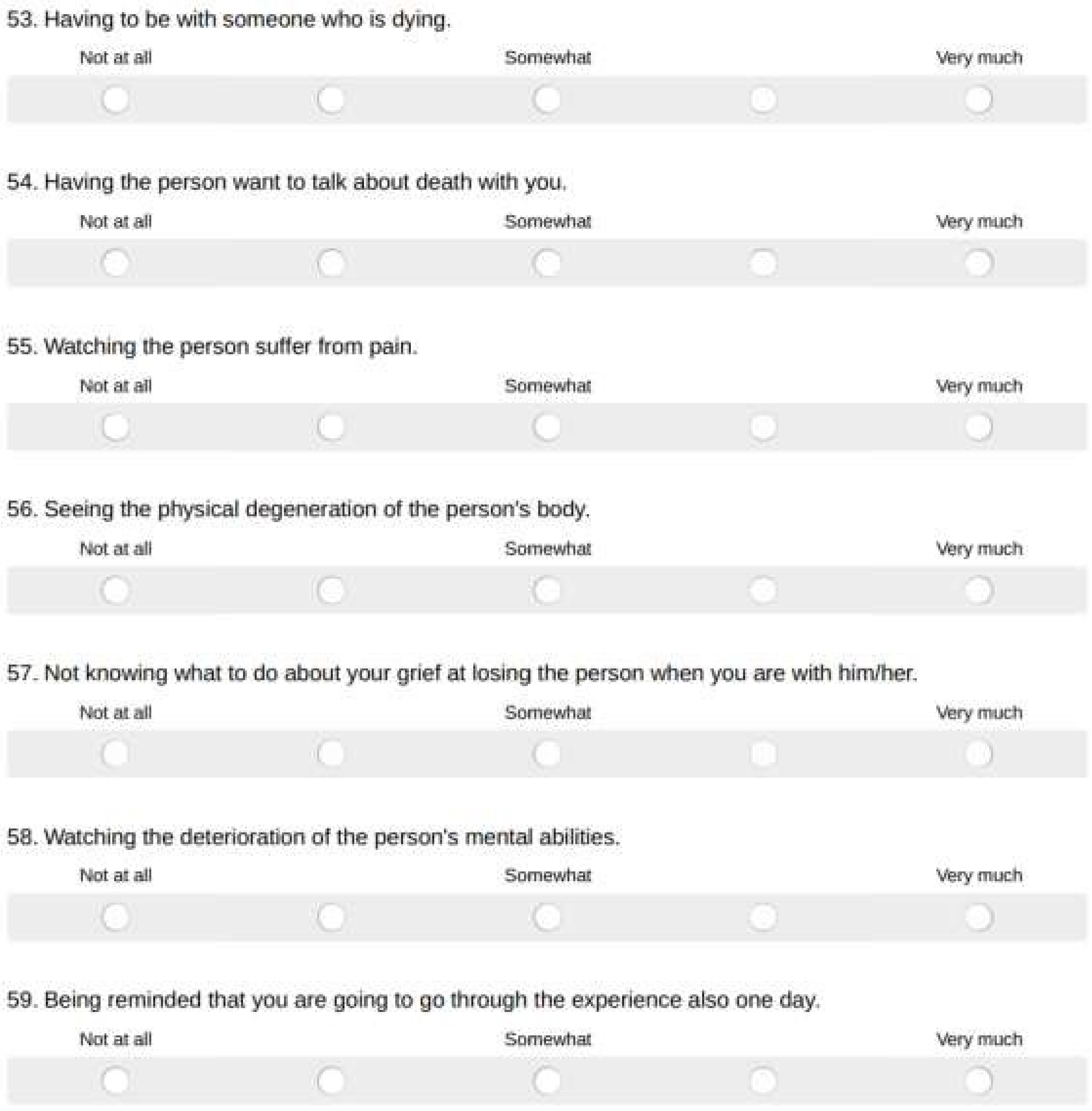
51. Feeling guilty that you are relieved the person is dead.

Not at all		Somewhat		Very much
○	○	○	○	○

52. Feeling lonely without the person.

Not at all		Somewhat		Very much
○	○	○	○	○

The Dying of Others



53. Having to be with someone who is dying.

Not at all		Somewhat		Very much
○	○	○	○	○

54. Having the person want to talk about death with you.

Not at all		Somewhat		Very much
○	○	○	○	○

55. Watching the person suffer from pain.

Not at all		Somewhat		Very much
○	○	○	○	○

56. Seeing the physical degeneration of the person's body.

Not at all		Somewhat		Very much
○	○	○	○	○

57. Not knowing what to do about your grief at losing the person when you are with him/her.

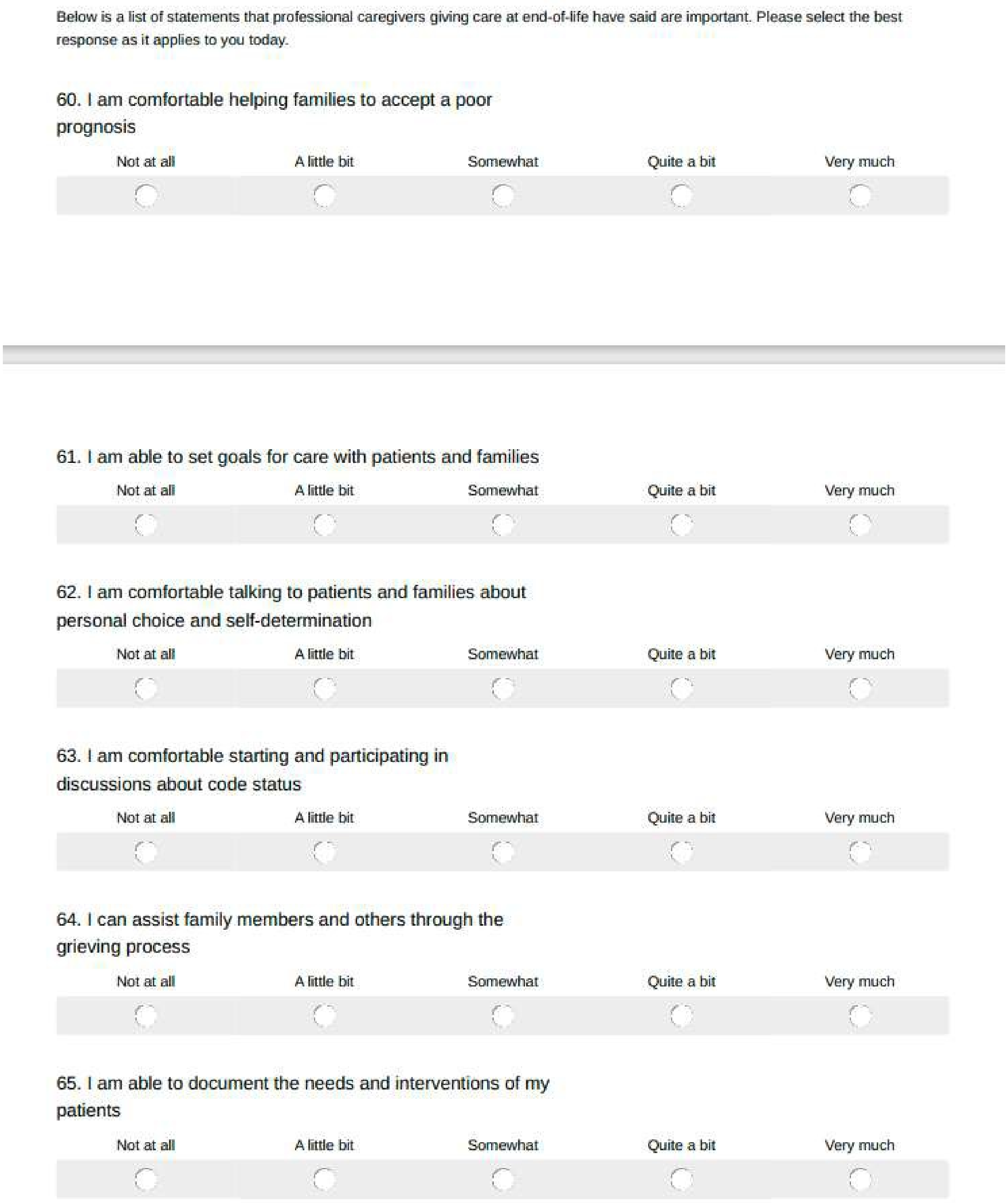
Not at all		Somewhat		Very much
○	○	○	○	○

58. Watching the deterioration of the person's mental abilities.

Not at all		Somewhat		Very much
○	○	○	○	○

59. Being reminded that you are going to go through the experience also one day.

Not at all		Somewhat		Very much
○	○	○	○	○



Below is a list of statements that professional caregivers giving care at end-of-life have said are important. Please select the best response as it applies to you today.

60. I am comfortable helping families to accept a poor prognosis

Not at all	A little bit	Somewhat	Quite a bit	Very much
○	○	○	○	○

61. I am able to set goals for care with patients and families

Not at all	A little bit	Somewhat	Quite a bit	Very much
○	○	○	○	○

62. I am comfortable talking to patients and families about personal choice and self-determination

Not at all	A little bit	Somewhat	Quite a bit	Very much
○	○	○	○	○

63. I am comfortable starting and participating in discussions about code status

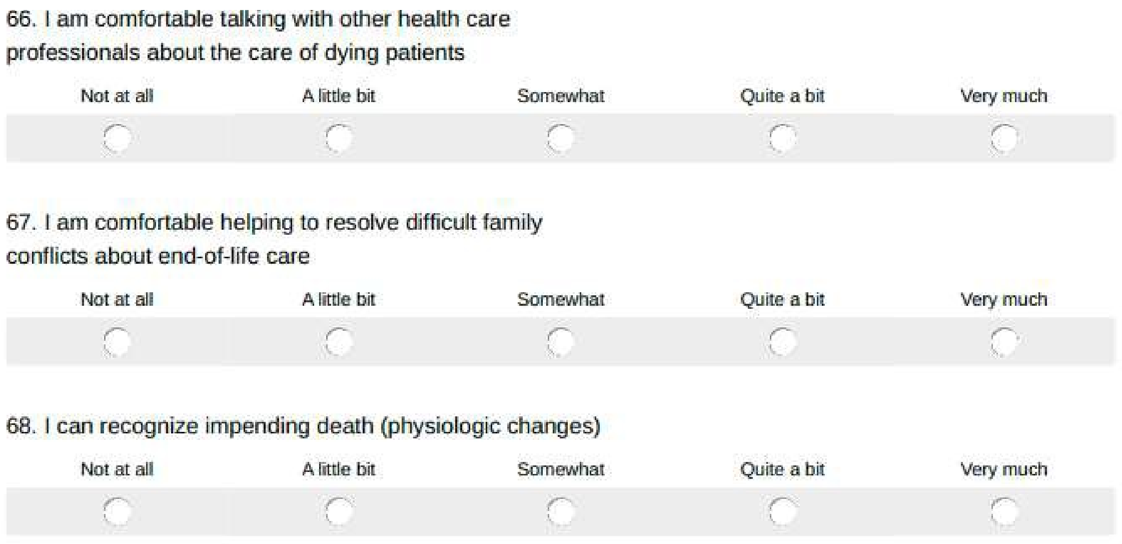
Not at all	A little bit	Somewhat	Quite a bit	Very much
○	○	○	○	○

64. I can assist family members and others through the grieving process

Not at all	A little bit	Somewhat	Quite a bit	Very much
○	○	○	○	○

65. I am able to document the needs and interventions of my patients

Not at all	A little bit	Somewhat	Quite a bit	Very much
○	○	○	○	○



66. I am comfortable talking with other health care professionals about the care of dying patients

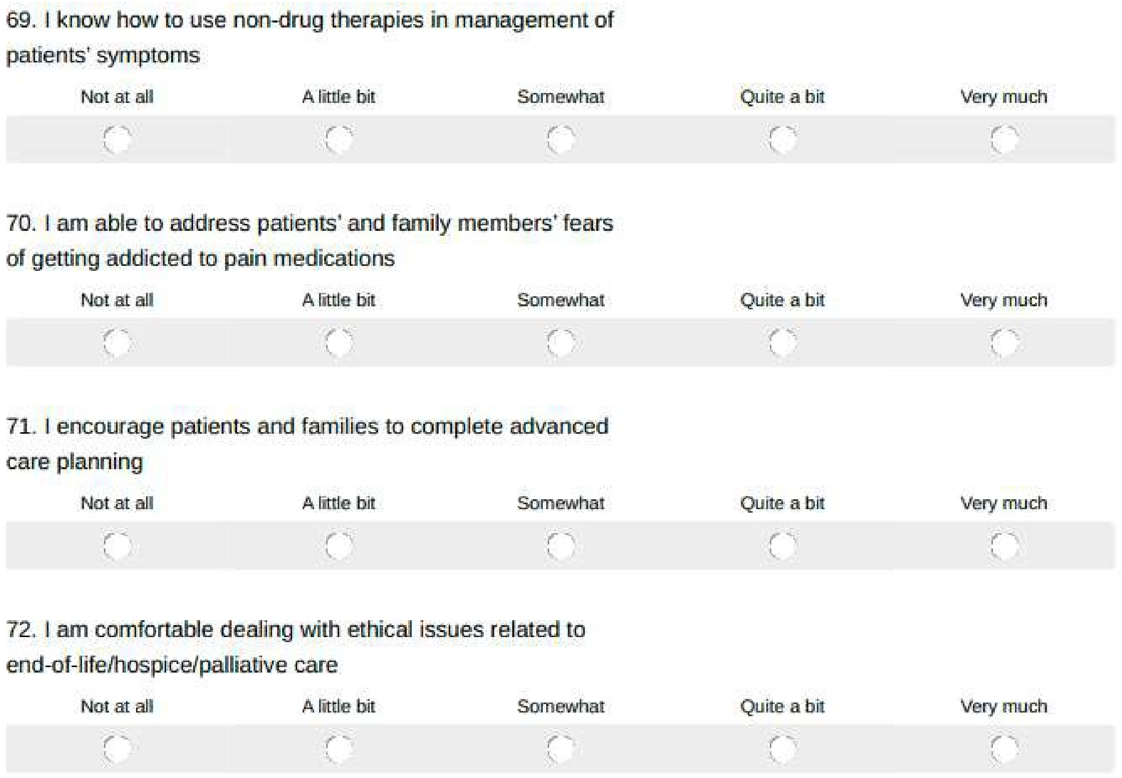
Not at all	A little bit	Somewhat	Quite a bit	Very much
○	○	○	○	○

67. I am comfortable helping to resolve difficult family conflicts about end-of-life care

Not at all	A little bit	Somewhat	Quite a bit	Very much
○	○	○	○	○

68. I can recognize impending death (physiologic changes)

Not at all	A little bit	Somewhat	Quite a bit	Very much
○	○	○	○	○



69. I know how to use non-drug therapies in management of patients' symptoms

Not at all	A little bit	Somewhat	Quite a bit	Very much
○	○	○	○	○

70. I am able to address patients' and family members' fears of getting addicted to pain medications

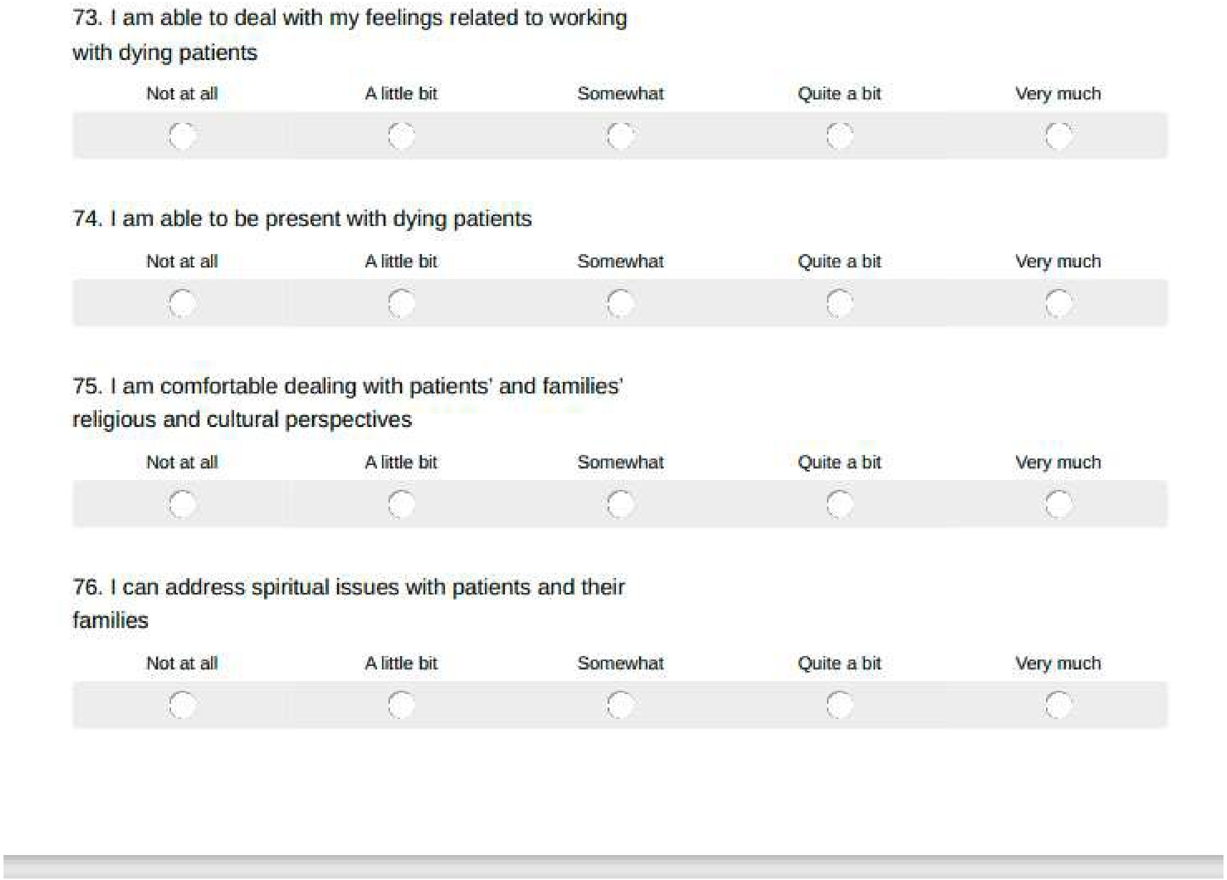
Not at all	A little bit	Somewhat	Quite a bit	Very much
○	○	○	○	○

71. I encourage patients and families to complete advanced care planning

Not at all	A little bit	Somewhat	Quite a bit	Very much
○	○	○	○	○

72. I am comfortable dealing with ethical issues related to end-of-life/hospice/palliative care

Not at all	A little bit	Somewhat	Quite a bit	Very much
○	○	○	○	○



73. I am able to deal with my feelings related to working with dying patients

Not at all	A little bit	Somewhat	Quite a bit	Very much
○	○	○	○	○

74. I am able to be present with dying patients

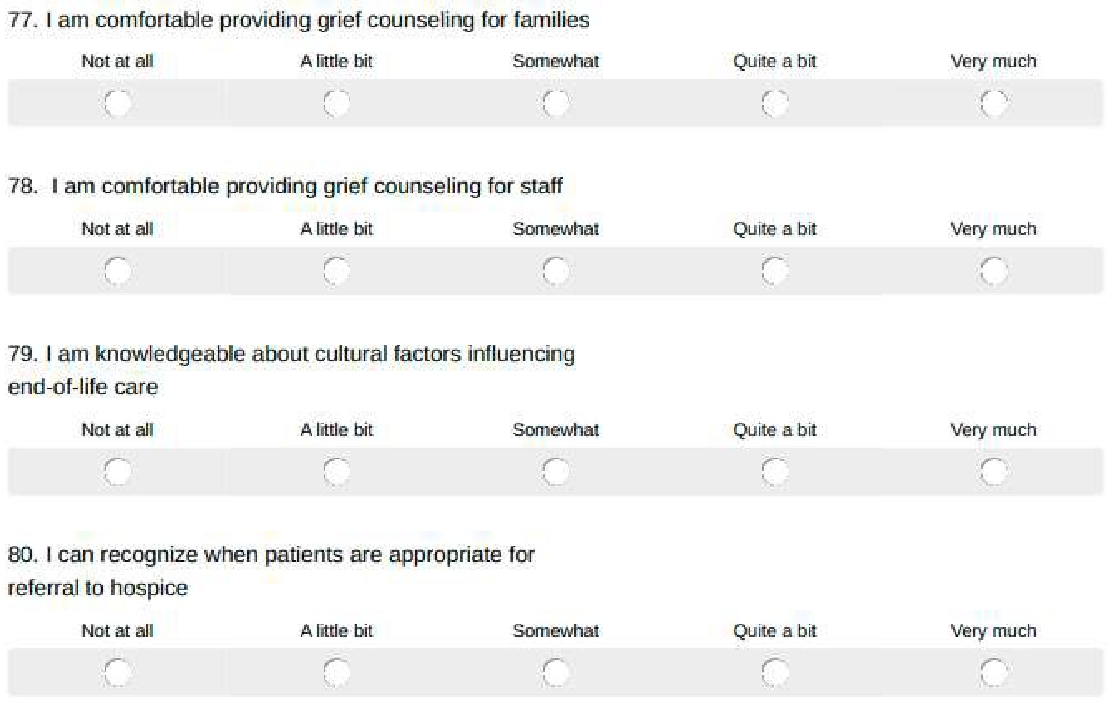
Not at all	A little bit	Somewhat	Quite a bit	Very much
○	○	○	○	○

75. I am comfortable dealing with patients' and families' religious and cultural perspectives

Not at all	A little bit	Somewhat	Quite a bit	Very much
○	○	○	○	○

76. I can address spiritual issues with patients and their families

Not at all	A little bit	Somewhat	Quite a bit	Very much
○	○	○	○	○



77. I am comfortable providing grief counseling for families

Not at all	A little bit	Somewhat	Quite a bit	Very much
○	○	○	○	○

78. I am comfortable providing grief counseling for staff

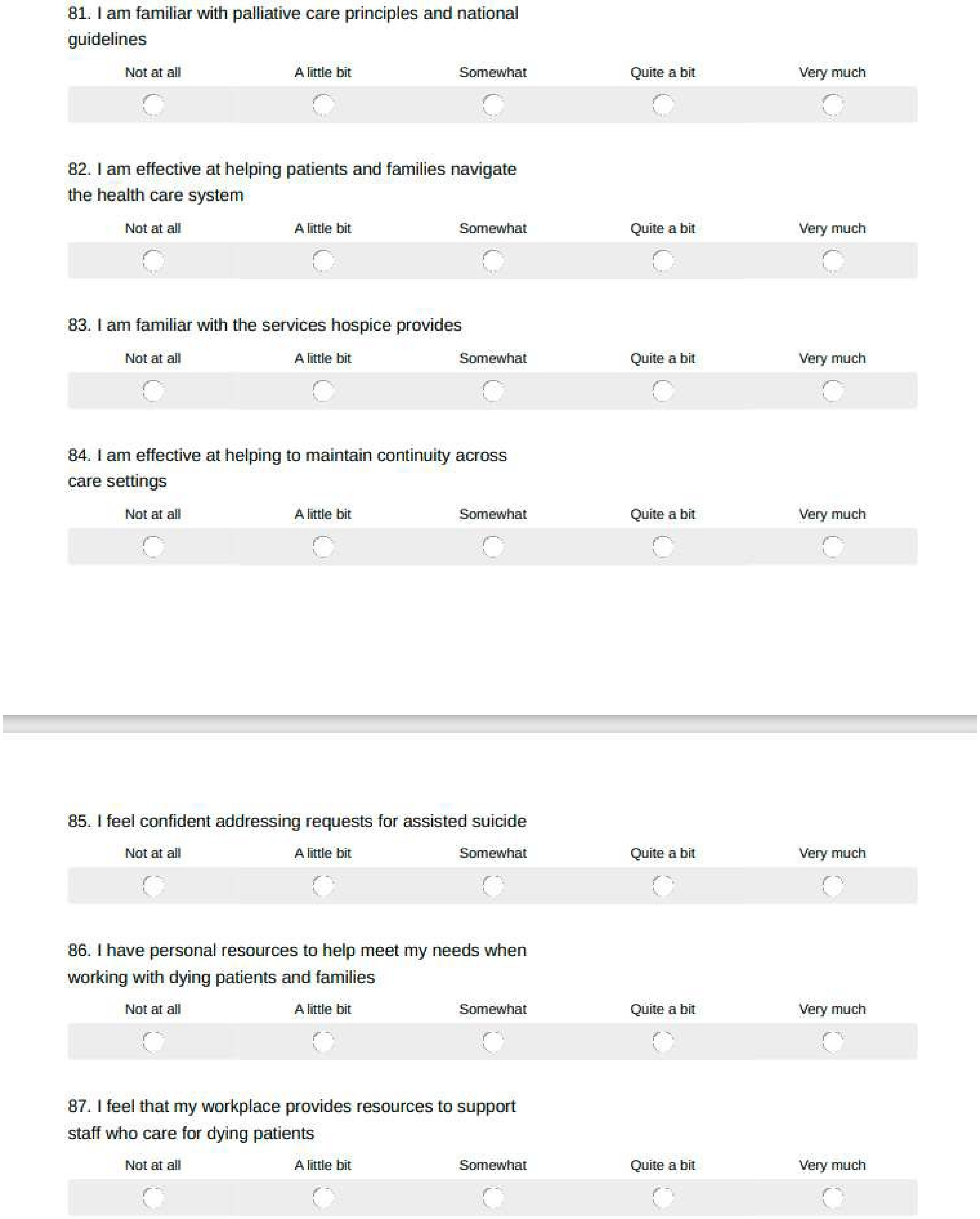
Not at all	A little bit	Somewhat	Quite a bit	Very much
○	○	○	○	○

79. I am knowledgeable about cultural factors influencing end-of-life care

Not at all	A little bit	Somewhat	Quite a bit	Very much
○	○	○	○	○

80. I can recognize when patients are appropriate for referral to hospice

Not at all	A little bit	Somewhat	Quite a bit	Very much
○	○	○	○	○



81. I am familiar with palliative care principles and national guidelines

Not at all	A little bit	Somewhat	Quite a bit	Very much
○	○	○	○	○

82. I am effective at helping patients and families navigate the health care system

Not at all	A little bit	Somewhat	Quite a bit	Very much
○	○	○	○	○

83. I am familiar with the services hospice provides

Not at all	A little bit	Somewhat	Quite a bit	Very much
○	○	○	○	○

84. I am effective at helping to maintain continuity across care settings

Not at all	A little bit	Somewhat	Quite a bit	Very much
○	○	○	○	○

85. I feel confident addressing requests for assisted suicide

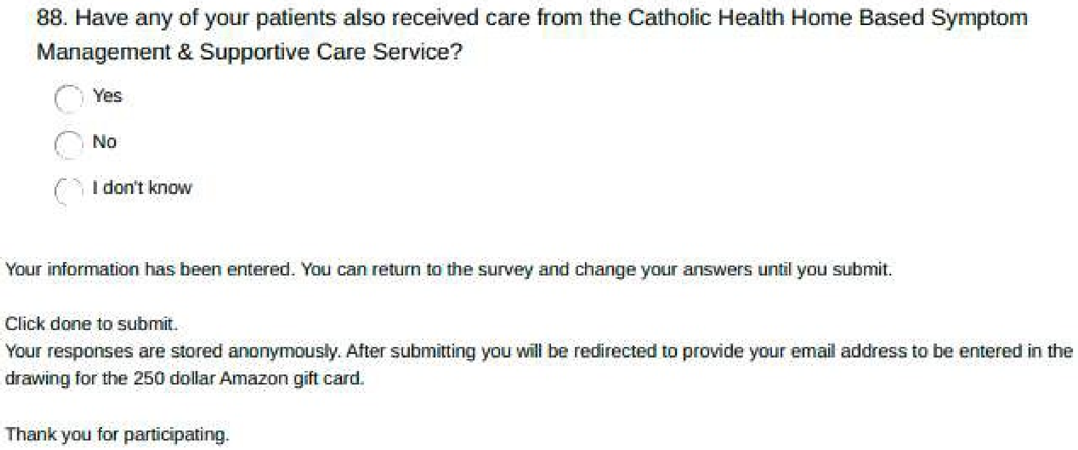
Not at all	A little bit	Somewhat	Quite a bit	Very much
○	○	○	○	○

86. I have personal resources to help meet my needs when working with dying patients and families

Not at all	A little bit	Somewhat	Quite a bit	Very much
○	○	○	○	○

87. I feel that my workplace provides resources to support staff who care for dying patients

Not at all	A little bit	Somewhat	Quite a bit	Very much
○	○	○	○	○



88. Have any of your patients also received care from the Catholic Health Home Based Symptom Management & Supportive Care Service?

○ Yes

○ No

○ I don't know

Your information has been entered. You can return to the survey and change your answers until you submit.

Click done to submit.
Your responses are stored anonymously. After submitting you will be redirected to provide your email address to be entered in the drawing for the 250 dollar Amazon gift card.

Thank you for participating.