

A Dissertation

entitled

End-of-Life Training in US Internal Medicine Residency Programs: A National Study

by

Derek S. Cegelka

Submitted to the Graduate Faculty as partial fulfillment of the requirements for the  
Doctor of Philosophy Degree in Health Education

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Timothy R. Jordan, PhD, M.Ed., Committee Chair

---

Jiunn-Jye Sheu, PhD, Committee Member

---

Joseph A. Dake, PhD, MPH, Committee Member

---

Ragheb A. Assaly, M.D., Committee Member

---

Patricia R. Komuniecki, PhD, Dean  
College of Graduate Studies

The University of Toledo

May 2016

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An Abstract of  
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**Purpose:** The purpose of this study was to survey the directors of internal medicine residency programs in the United States to determine the current status of end-of-life care education for internal medicine residents.

**Methods:** The study featured a cross-sectional design with total population sampling. All 403 internal medicine residency directors in the United States were surveyed using a 4-wave data collection method to ensure an optimum return rate. The response rate was 52.4% (211/403).

**Results:** Residency directors reported very high outcome expectations regarding the potential positive outcomes of providing residents with formal training in end-of-life skills. More than 90% of directors believed that the quality of care for patients at the end-of-life phase would increase if their residents were taught specific knowledge and skills related to end-of-life care. Although directors believed in the potential benefits of providing end-of-life training to their residents, nearly 1 in 4 programs (24%) reported not having a formal end-of-life curriculum in place. Another 39% had recently decided to implement an end-of-life curriculum or had implemented a curriculum in the last 3 years. Thus, 63% of residency programs either did not have a formal end-of-life

curriculum in place or just recently implemented one. Only 36% of programs reported having formal end-of-life curriculum in place for more than three years.

Most programs reported spending nine or less hours of instructional time during residency on multiple end-of-life topical areas such as socio-cultural issues (71%), patient care (56%), professionalism (54%), ethical issues (50%), and communication (46%).

The majority of residency directors reported that their programs do not formally evaluate residents' competence in end-of-life topical areas such as socio-cultural issues (77%), patient care (60%), and ethical issues (55%). The most common method used to evaluate residents' skill competence in caring for patients at end-of-life was verbal feedback by attending physicians and preceptors.

The three most prevalent teaching techniques used to teach end-of-life topics were hospital rounds, classroom/conference style teaching, and teaching by preceptors during outpatient clinics. The most common barriers to increasing and/or improving end-of-life education were lack of time in the teaching schedule (46%), lack of faculty members certified in Hospice and Palliative Medicine (26%), and lack of rotation sites/lack of preceptors with needed experience (15%).

**Conclusion:** Internal medicine physicians play an important role in treating patients with life-threatening illnesses, including those at the end-of-life stage. It is important that internal medicine residents are well educated in providing excellent care and communication to such patients. Although there has been progress over the years in end-of-life training of US physicians, internal medicine residency programs still need improvement in this area.

## Acknowledgements

When I first started college as an undergraduate student, receiving a doctoral degree was something that I would have never imagined. It is amazing how things change over a course of a just a few years. There are a few people who helped me along the way that I would like to thank.

First off, I would like to thank Dr. Jordan for his continuous guidance and mentorship throughout this entire process. Without you, I don't think that obtaining my doctoral degree would have been possible. I am grateful for the opportunity to have worked with you and look forward to future endeavors.

To my mom, dad, and Nicole, I want to thank you for all the love and support over the years as I travelled on this journey. You have been very influential in my life and I want to thank you from the bottom of my heart. I love you guys.

To my wife Brielle, you are my rock and I'm glad that you helped me stay grounded during the entire dissertation process. I want to thank you for being so understanding of this whole process and being there whenever I needed you. I love you! Now it's your turn.

Thanks to my committee members Dr. Dake, Dr. Sheu, and Dr. Assaly for all the help and guidance throughout this process. Thanks to Terri, and the rest of the UT health faculty for being a great department. I have learned a lot from you.

Thanks to my doctoral student peers and friends, Aaron, Phil, Rob, Molly, Kit, Erin, and Erica...thanks for all the fun memories we made over the years. Our fun times together helped us stay sane.

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# **CHAPTER 1**

## **INTRODUCTION**

This chapter will focus on the issues associated with end-of-life curricula within internal medicine residency training programs including, a description of the purpose and scope of the study. The following topics will be covered: 1) background, 2) problem statement, 3) purpose of the study, 4) significance of the problem, 5) research questions, 6) hypotheses, 7) limitations, 8) delimitations, 9) definitions, and 8) summary.

### **Background**

The circumstances surrounding death in America have changed substantially in the last 100 years. During the early 20<sup>th</sup> century, more people died at home than in an institution. Within that same time frame, doctors and undertakers provided care in the home (DeSpelder & Strickland, 2011). Today, approximately 70% of deaths in the US occur in a hospital, nursing home or other institutional setting, and the older the individual, the more likely he or she is to die in an institution (Broad et al, 2013).

Preventative and public health measures over the years have significantly reduced or eradicated many acute illnesses (U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality [AHRQ], 2004). As a result, the dying process today is typically longer than in the past. Due to advanced chronic illness and in many cases multiple illnesses, the process of dying is slower and often consists of a prolonged period of medical care (DeSpelder & Strickland, 2011).

In years gone by, the circumstances surrounding death were not directly influenced by the emphasis on the prolongation of life. In contrast, the dying process

today frequently features high use of technology and inappropriate or unwanted institutionalized treatment that causes unnecessary suffering to the dying person and his/her family members (Bomba, 2005).

Medical advances over the last half-century have allowed physicians to cure many diseases. These same medical advances have also provided physicians with the ability to sustain biological life, even after the patient is considered clinically dead. Technology has redefined physicians' knowledge and approaches to treating their patients' illnesses (Sanders, Burkett, Dickinson, & Tournier, 2004).

Although medical technology is a blessing to some, it is a curse to others, prolonging death unnecessarily. Physicians are often driven by the culture of medicine and its emphasis on saving and curing at all costs. Along with giving physicians the knowledge and skills to prolong life, physicians must also be taught how to deal with and accept the inevitability of death (DeMiranda et al., 2005). Education and training for physicians in the area of end-of-life care must start during their undergraduate education and continue throughout medical school and residency.

### **End-of-life Defined**

The term *end-of-life* has various definitions depending on the organization or publication. Within the published research literature, end-of-life definitions follow the delivery of care model.

Lunney (2001) defined end-of-life in the following manner:

“The restriction to those with a 6-month-or-less prognosis has only further cemented the notion that the end-of-life is constrained to a short period of time during which a person is clinically recognized as dying.” (p. 5)

Lamont (2005) defined *end-of-life* as “the period preceding an individual's natural death from a process that is unlikely to be arrested by medical care” (p. S-13). Some organizations tend to define *end-of-life* in more personal terms. The Association for Death Education and Counseling defines end-of-life decision making as “the aspects of life-threatening illness/terminal illness that involve choices and decisions to be taken, for individuals, families, and professional caregivers” (Balk, Wogrin, Thornton, & Meagher, 2007, p. 53). For the current study, end-of-life care will be defined as follows:

The period of life before an individual’s natural death within a 6-month-or-less time-period, including the choices and decisions that must be made by the patient, his/her family members, and the patient’s health care providers.

### **Problem Statement**

The push for end-of-life care reform has improved medicine over the last 25 years. The American Board of Medical Specialties (2006) approved hospice and palliative medicine as a subspecialty in 2006. According to the American Academy of Hospice and Palliative Medicine (2014), more than 2,800 physicians in 2007 obtained certification in this subspecialty. In 2008, nearly 1,300 hospitals in the US reported having a palliative care program (Center to Advance Palliative Care, 2010). There has also been an increasing presence of end-of-life education in the curricula of medical schools, nursing programs, and residency programs (Penrod & Morrison, 2004). Despite these advances there is still a lack of education and training in end-of-life care at both the undergraduate and graduate medical education levels (Gibbins, McCourbrie, & Forbes, 2011).



End-of-life care does not follow a set of clear guidelines because each patient is treated very differently based on his or her specific diagnosis and prognosis. Likewise, learning how to handle and communicate with dying patients and their family members is difficult because of the many factors involved. The process of dying and end-of-life care touches many domains including medical, ethical, cultural, spiritual, psychological, and social. Over the last 30 years, the medical community has broadened its educational efforts to include more of these domains in the training programs of health care providers. However, as the research described below will attest, improvements in the training and education of US physicians are still needed.

The SUPPORT study (1995) was the first study to assess the quality of end-of-life care in America and found that most Americans die:

- in hospitals,
- usually alone and in pain,
- after days or weeks of futile treatment,
- with little advance planning, and
- at high cost to the institution and the family.

The Institute of Medicine (IOM) published *Approaching Death: Care at the End-of-life* in 1997, as a call to action for the medical community to map the nature and extent of published research themes related to end-of-life care and palliative care. In connection with the IOM, Field & Cassel (1997) analyzed end-of-life care at that time and found that the medical community needed to address the following problems:

- Too many people suffer needlessly at the end-of-life both from errors and omission;
- Legal, organizational, and economic obstacles conspire to obstruct reliably excellent care at the end-of-life,
- Education and training of physicians and other health care professionals fails to provide them with the knowledge, skills, and attitudes required to care well for the dying patient

- Current knowledge and understanding are inadequate to guide and support the consistent practice of evidence-based medicine at the end-of-life

The Robert Wood Johnson Foundation (2003) addressed the weaknesses in end-of-life care from the SUPPORT study and the Institute of Medicine's call to action by providing \$170 million in grants from 1996-2005. This grant funding was designed to do the following:

1. To improve the knowledge and capacity of health care professionals and others to care for the dying
2. To improve the institutional environment in health care institutions and in public policies and regulatory apparatus to enable better care of the dying
3. To engage the public and professions in efforts to improve end-of-life care

Around the same time, the Open Society Institute project on Death in America (2003) invested \$45 million in grants to organizations to improve care for dying patients and their families. Additionally, a consortium of grant makers came together to tackle the end-of-life care dilemma (The Open Society Institute Project on Death in America, 2003). Without these foundations and their grant funding, it unlikely that reform in end-of-life care education and training would be such a priority today.

Since the reports and initiatives described above, end-of-life curricula within medical training programs have improved (Back et al., 2009; Seoane et al., 2012). The Institute of Medicine (2014) recognized some of these improvements in end-of-life care, but identified the following problems that continue to persist:

- Widespread adoption of timely referral to palliative care appears slow.
- The default mode of hospital treatment is acute care; advance planning and medical orders are needed to ensure that these preferences are honored.
- Clinicians need to initiate conversations about end-of-life care choices and work to ensure that patient and family decision making is based on adequate information and understanding.

- Insufficient attention to palliative care in medical and nursing school curricula.
- Educational silos that impede the development of inter-professional teams; and deficits in equipping physicians with sufficient communication skills.
- Need for public education and engagement about end-of-life care issues is manifest at the societal, community/family, and individual levels.

Therefore, even after many years of reports, various grant programs, and improvement initiatives, the training and education in end-of-life care among US health care providers still need improvement.

### **Significance of the Problem**

Life-sustaining medical care for patients at end-of-life is costly. In 2012, the national healthcare expenditures grew 3.7% to \$2.8 trillion dollars, and that number is expected to grow more within the next decade (Department of Health and Human Services, Centers for Medicare and Medicaid Services [CMMS], 2012). Unfortunately, a disproportionate amount of those expenditures are spent at the end-of-life. Five percent of Medicare enrollees who die each year account for 30% of the overall end-of-life spending (Barnato, McClellan, Kagay, & Garber 2004). During the last year of life, about one-third of an individual's expenditures are spent within the final month of life (Emanuel et al., 2002). Additionally, people with chronic conditions account for approximately 85% of all American health care spending (Anderson, 2010).

As a result of increased health care costs at end-of-life, 1 in 3 family members who were caring for sick relative or friend used their own savings account or cut back on basic maintenance for their homes; 1 in 4 caregivers cut back on spending for their own health or dental care to help with the expenses associated with care for their relative or friend (Family Caregiver Alliance, National Center on Caregiving [NCC], 2009). Most of these medical costs come from medical treatments that have little chance of actually

restoring patients' health and wellness. The high costs, high burden, and low benefits of such spending raise important questions about the wisdom and logic of such expenditures.

It must be very difficult for physicians who are trained to delay or defeat death, to adequately care for patients who are dying slowly from life-threatening illness. The increased stress and anxiety of caring for increasing numbers of patients who are slowly dying may cause the quality of care provided to all patients to decrease (Meier, Back, & Morrison, 2001). The lack of training among physicians may result in decreased quality of care delivered to the dying patient and their families (Smith & Hough, 2011). Therefore, physicians need strong education and training to assist them in caring for patients who are living with or dying from life-threatening illness.

Other problems may arise when physicians are not properly trained in end-of-life care. According to Teno et al. (2004), patients and families have reported being unhappy with physicians' abilities to address end-of-life issues. Due to multiple demands and intensity of the occupation, physicians may end their careers early due to burnout (Shanafelt et al., 2002). The job may also lead physicians to have negative attitudes, beliefs, and values regarding death and dying (Smith & Hough, 2011).

Past research with medical students and residents suggests that certain types of education may be most effective. Medical students have reported that: 1) formal courses are often not as helpful as clinical experiences (Fraser, Kutner, & Pfeifer, 2001); 2) that observation of end-of-life communication with patients is more useful than formal teaching (Ury, Berkman, Weber, Pignotti, & Leipzig, 2003); and 3) that mentoring from residents is more useful than didactic lecture-style teaching (Ratanawongasa, Teheranu,

& Hauer, 2005). Additionally, residents in family practice reported that they needed more information on communication skills and end-of-life ethics to improve their palliative care education (Celso, Graham, Tepas, Meenrajan, & Schinco, 2010). Even faculty members, despite scoring higher than residents on an end-of-life knowledge survey, nonetheless reveal a lack in their overall knowledge of end-of-life (Mullen, Weissman, Ambuel, & Von Gunten, 2002).

Strategies to improve end-of-life training and care are available to any physician who seeks them. Adding a one-hour per week, informal non-didactic session for physicians to discuss emotional issues surrounding patient deaths has been shown to decrease avoidance of end-of-life discussions with patients and families (Smith & Hough, 2011). Also, adding a hospice and palliative care rotation during an internal medicine residency was found to increase knowledge and improve communication and interviewing skills surrounding end-of-life care (von Gunten et al., 2005). Likewise, adding a two-day intensive palliative care retreat can improve the end-of-life communication skills of medical residents (Alexander, Keitz, Sloane, & Tulskey, 2006).

### **Purpose of the Study**

The purpose of this study is to survey the directors of internal medicine residency programs in the United States to determine the current status of end-of-life care education for internal medicine residents. Since internists care for adult patients, many whom suffer from life-threatening illnesses, internists should be adequately prepared for end-of-life issues. According to the Accreditation Council for Graduate Medical Education (2013), “graduate medical education is to provide an organized educational program with guidance and supervision of the resident, facilitating resident’s ethical, professional, and

personal development while ensuring safe and appropriate care for patients (p. 2).” The residency director has a responsibility to the graduate medical education committee and the Accreditation Council for Graduate Medical Education’s Residency Review Committee to ensure that residents are well equipped for future medical practice. Since residency directors are responsible for the organization and implementation of curricula, they are the *de facto* gatekeepers and decision-makers for curricular issues.

## **Research Questions and Hypotheses**

### **1. Do internal medicine residency programs in the United States have a formal end-of-life curriculum?**

- 1.1: There will be no statistically significant difference in the presence/absence of a formal end-of-life curriculum by the type of program (i.e. university versus community).
- 1.2: There will be no statistically significant difference in the presence/absence of a formal end-of-life curriculum by the number of faculty members in the residency program.
- 1.3: There will be no statistically significant difference in the presence/absence of a formal end-of-life curriculum by the number of barriers perceived by the directors.
- 1.4: There will be no statistically significant difference in the presence/absence of a formal end-of-life curriculum by the directors’ level of outcome expectations.
- 1.5: There will be no statistically significant difference in the presence/absence of a formal end-of-life curriculum by the directors’ perceived quality of education received during their residency program.

**2. In what stage of PAPM readiness are residency programs regarding implementing a formal end-of-life curriculum?**

- 2.1: There will be no statistically significant difference in residency program's PAPM stage of readiness by type of residency program (i.e., university sponsored versus community based).
- 2.2: There will be no statistically significant difference in the residency program's PAPM stage of readiness to implement a curriculum by the number of full-time faculty members.
- 2.3: There will be no statistically significant difference in the residency program's PAPM stage of readiness to implement a curriculum by the number of barriers perceived by the directors.
- 2.4: There will be no statistically significant difference in the residency program's PAPM stage of readiness to implement by directors' level of outcome expectations.
- 2.5: There will be no statistically significant difference in the residency program's PAPM stage of readiness to implement a curriculum by directors' perceived quality of education received during their residency program.

**3. What teaching topics are covered in residency programs' end-of-life curriculum?**

- 3.1: The majority of residency programs provide training for less than half (i.e. 9 or less) of the topics commonly found in recommended end-of-life curricula.
- 3.2: There will be no statistically significant difference in the number of end-of-life topics (0-12 vs. 13-17) covered in a curriculum by the number of faculty members in the residency program.

- 3.3: There will be no statistically significant difference in the number of end-of-life topics (0-12 vs. 13-17) covered in a curriculum by the residency type (i.e., university sponsored versus community based).
- 3.4: There will be no statistically significant difference in the number of end-of-life topics (0-12 vs. 13-17) covered in a curriculum by the number of barriers perceived by the directors.
- 3.5: There will be no statistically significant difference in the number of end-of-life topics (0-12 vs. 13-17) covered in a curriculum by directors' level of outcome expectations.
- 3.6: There will be no statistically significant difference in the number of end-of-life topics (0-12 vs. 13-17) covered in a curriculum by the perceived quality of education received during their residency program.
- 3.7: There will be no statistically significant difference in the number of end-of-life topics (0-12 vs. 13-17) covered in a curriculum by the residency directors' history of their spouses or loved ones experiencing a life-threatening illness.

**4. How much time is invested in residency programs' end-of-life teaching?**

- 4.1: The majority of residency programs provide 15 hours or less of instruction in recommended end-of-life topics.
- 4.2: There will be no statistically significant difference in time invested in teaching recommended end-of-life topics by residency type (i.e., university sponsored versus community based).
- 4.3: There will be no statistically significant difference in time invested in teaching recommended end-of-life topics by the number of faculty members.



- 4.4: There will be no statistically significant difference in time invested in teaching recommended end-of-life topics by the number of perceived barriers identified by the director.
- 4.5: There will be no statistically significant difference in time invested in teaching recommended end-of-life topics by directors' level of outcome expectations.
- 4.6: There will be no statistically significant difference in time invested in teaching recommended end-of-life topics by directors' perceived quality of education received during their residency program.
- 4.7: There will be no statistically significant difference in time invested in teaching recommended end-of-life topics by the residency directors' history of their spouse or loved one experiencing a life-threatening illness.
- 4.8: There will be no statistically significant difference in time invested in teaching recommended end-of-life topics by the number of years the director has been practicing medicine after residency.

**5. What teaching techniques do residency faculty members use to teach end-of-life topics to residents?**

- 5.1: The majority of residency programs use at least five of the teaching techniques commonly used in residency training programs.

**6. Do Residency Directors believe that teaching end-of-life topics to residents will result in improved end-of-life care to patients? (Outcome Expectation)**

- 6.1: There will be no statistically significant difference in the outcome expectations of the director by residency type (i.e., university sponsored versus community based).

- 6.2: There will be no statistically significant difference in outcome expectations of the director by residency directors' gender.
- 6.3: There will be no statistically significant difference in the outcome expectations of the director by the number of years the director has been practicing medicine after residency.
- 6.4: There will be no statistically significant difference in the outcome expectations of the director by the residency directors' history of their spouse or loved one experiencing a life-threatening illness.
- 6.5: There will be no statistically significant difference in the outcome expectations of the director by the number of barriers identified by the director.
- 6.6: There will be no statistically significant difference in the outcome expectations of the director by the presence of a formal end-of-life curriculum.
- 6.7: There will be no statistically significant difference in the outcome expectations of the director by the perceived quality of education received by the directors.

**7. What barriers do Residency Directors identify to teaching end-of-life topics to residents?**

- 7.1: There will be no statistically significant difference in the number of barriers perceived by the director by residency type (i.e., university sponsored versus community based).
- 7.2: There will be no statistically significant difference in the number of barriers perceived by the director by the number of faculty members.

- 7.3: There will be no statistically significant difference in the number of barriers perceived by the director by the number of years the director has been practicing medicine after residency.
- 7.4: There will be no statistically significant difference in the number of barriers perceived by the director by the time reported covering end-of-life topics.
- 7.5: There will be no statistically significant difference in the number of barriers perceived by the director by the internal medicine residency program's policy regarding requiring residents learn end-of-life education.
- 7.6: There will be no statistically significant difference in the number of barriers perceived by the director by the presence/absence of a formal end-of-life curriculum.
- 7.7: There will be no statistically significant difference in the number of barriers perceived by the director by outcome expectations of the director.
- 7.8: There will be no statistically significant difference in the number of barriers perceived by directors' perceived quality of education received during their residency program.

**8. How do residency programs evaluate residents' competence in providing end-of-life care?**

- 8.1: There will be no statistically significant difference in the presence/absence of evaluation of residents by the number of years the director has been practicing medicine after residency.
- 8.2: There will be no statistically significant difference in the presence/absence of evaluation of residents by residency type (i.e., university sponsored versus community based).

- 8.3: There will be no statistically significant difference in the presence/absence of evaluation of residents by the number of barriers perceived by the director.
- 8.4: There will be no statistically significant difference in the presence/absence of evaluation of residents by directors' level of outcome expectations.
- 8.5: There will be no statistically significant difference in the presence/absence of evaluation of residents by directors' perceived quality of education received during their residency.
- 8.6: There will be no statistically significant difference in the presence/absence of evaluation of residents by the number of faculty members.

### **Limitations of the Study**

1. Although the 52% response rate was stronger than many published research studies with physician administrators, 48% of directors across the US did not respond. If those who responded were systematically different from those who did not respond, it is possible that the validity of the results may have been negatively impacted.
2. Self-reporting from the directors of internal medicine residency programs may threaten the internal validity of the results. The findings could be affected by social desirability bias. Thus, the reported presence of end-of-life curricula may actually be over-reported.
3. It is possible that some questions on the survey may have been misunderstood, which would negatively impact the validity of the results.
4. The monothematic nature of the survey may have resulted in response bias, which would be a threat to internal validity.

5. The survey was closed format and did not allow for elaboration of information from the subject, which could result in a threat to internal validity.
6. The residency directors may have handed off the survey to a staff member to complete. If residency directors did not complete the survey, there would be a threat to both internal validity and external validity, making the results less generalizable to the population. However, if the survey were handed off to the person who knew the most about the residency curriculum, this may have actually improved the validity of the results.

### **Delimitations of the Study**

1. Only surveyed residency directors of United States internal medicine residency programs.
2. Only investigated curricula regarding end-of-life education.
3. Only internal medicine residency programs that are currently accredited by the American Medical Association Graduate Medical Education Program Electronic Data were surveyed.

### **Definitions of Key Terms**

1. **Academic Residency Program:** A university based residency program.
2. **Community-Based Residency Program:** A residency program sponsored by a local hospital that utilizes alternative educational sites.
3. **End-of-life:** “The restriction to those with a 6-month-or-less prognosis has only further cemented the notion that the end-of-life is constrained to a short period of time during which a person is clinically recognized as dying.” (Lunney, 2001, p. 5).

4. **End-of-life Care:** The period of life before an individual's natural death within a 6-month-or-less prognosis, alongside the choices and decisions from the individual, their families, and professional caregivers.
5. **Formal End-of-life Curricula:** Either a required or elective rotation in end-of-life care, hospice, or palliative care and the presence of a structured conference curriculum in end-of-life care.
6. **End-of-life-decision making:** "The aspects of life-threatening illness/terminal illness that involve choices and decisions to be taken, for individuals, families, and professional caregivers" (Balk et al., 2007, p. 53).
7. **Health Belief Model:** This model has been used to explain change and maintenance of health-associated behaviors and as a structure for interventions related to health behavior. A key component is perceived barriers.
  - a. **Perceived Barriers:** An individual's belief about the costs, both concrete and psychological, to taking a positive health action (Rosenstock, 1974).
8. **Outcome Expectations:** A construct of the Social Cognitive Theory. An individual's belief that a specific behavior will lead to a specific outcome (Bandura, 1986).
9. **Precaution Adoption Process Model (PAPM):** A stage theory that provides the necessary framework in understanding how to change behavior (Weinstein, 1988).
  - a. Stage 1: Unaware of Issue: An individual is unaware of a possible health problem.
  - b. Stage 2: Unengaged by the Issue: Person has heard about the issue, but does not think it applies to them.

- c. Stage 3: Deciding About Acting: Person is thinking about the issue and weighing the costs and benefits.
- d. Stage 4: Decided Not to Act: Person had decided not to act even with available information, possibly because they think it is unnecessary.
- e. Stage 5: Decided to Act: After reviewing information, the individual decides to act.
- f. Stage 6: Acting: The person is now able to cope with implementation information.
- g. Stage 7- Maintenance: Behavior change has occurred and has become stable (Weinstein & Sandman, 2002).

### **Summary**

The dying process is not the same for everyone yet patients at the end-of-life stage have similar needs. Physicians who care for older adults should be well versed in end-of-life care. Internists must be knowledgeable and skilled at handling patients who are dying from chronic illnesses. In order for physicians to be successful in practice, the educational foundation during medical school and residency must be solid.

The goal of the current study was to determine how American internal medicine residency programs are educating their residents on end-of-life issues. The results of this study can uncover the strengths and weaknesses of end-of-life education among U.S. internal medicine residency programs and identify areas that need improvement.

## **CHAPTER 2**

### **LITERATURE REVIEW**

This chapter will review past research related to 1) life expectancy in the United States, 2) mortality in the United States, 3) patient needs regarding end-of-life care, 4) medical end-of-life curricula, 5) perceptions of physicians currently in practice, 6) the Social Cognitive Theory, 7) the Health Belief Model, 8) the Precaution Adoption Process Model, and 9) summary.

#### **Increased Life Expectancy**

Due to high mortality rates among the young the average life expectancy at the turn of the 20<sup>th</sup> century was approximately 49 years (Shrestha, 2006). Over time the average life expectancy in the United States has increased primarily due to improvements in public health knowledge and practices (e.g., sanitation, immunizations, clean drinking water). Such improvements contributed to a significant decrease in mortality among infants and children. As a result, the average life expectancy for someone born in 2013 is approximately 78.7—76.2 years for males and 81 years for females—with a projected combined life expectancy of 79.5 years by the year 2020 (National Center for Health Statistics, 2013).

With the continued increase in life expectancy, the demographics of the U.S. population continue to change. Older adults (> 65) are becoming a larger proportion of the population. As of 2012, approximately 13.3% of the population (41.4 million) was over age 65 and that number is predicted to increase to 33% over the next two decades (U.S. Department of Health and Human Services, 2012). By 2030, one in five adults will



be aged 65 or older, compared with 1900, when the number was one in 20 (Pan et al., 2005).

Health care related consequences and challenges will accompany these demographic shifts. Older populations are at increased risk for chronic illnesses such as cancers, diabetes, lung disease, and kidney disease (Shrestha, 2006). As the population ages, there will also be an increasing number of deaths in this age group. In 2011, approximately 1.8 million persons aged 65 or older died (U.S. Department of Health and Human Services, 2012), compared with the approximately 645,000 deaths of people under the age of 65 (Heron, 2013).

As the U.S. population gets older, individuals' risk of living with a life-threatening illness increases. One of the consequences living with a life threatening illness is an increased need for medical care and increased utilization of health care services (Shrestha, 2006). Accordingly, medical institutions must prepare physicians and healthcare workers to be proficient in providing care to those who are living with life threatening illness (Shrestha, 2006).

### **Mortality Rates**

Mortality in the United States has decreased at a relatively constant rate of approximately one to two percent per year over the last century (Cutler & Meara, 2001). In 1935, the age-adjusted death rate was 1,860 deaths per 100,000 individuals (Hoyert, 2012). To put this into perspective, that rate was equivalent to approximately one in 42 people dying annually (Cutler & Meara, 2001). In the early 20<sup>th</sup> century, children were dying from acute communicable diseases such as tuberculosis and influenza (Cutler & Meara, 2001). Infectious diseases accounted for 32 percent of total deaths, with

pneumonia and influenza alone accounting for 12 percent of total deaths (Cutler & Meara, 2001).

The mortality rate started to decline in the early 1900's when public health measures such as improved sanitation were implemented, helping people avoid or survive infectious diseases (Cutler & Meara, 2001). The introduction of vaccines into the population during the 1950's also played a key role in decreasing mortality. Vaccinations in the U.S. have been used to control, and in some cases eradicate, diseases such as smallpox, polio, measles, varicella, hepatitis A and B, and rabies (Centers for Disease Control and Prevention [CDC], 1999). What followed after the widespread use of vaccines was a decline in mortality and disease rates (CDC, 1999). The advent of these particular public health measures marked a critical shift in approach by the medical field.

The mortality rate continued to drop in the mid-20<sup>th</sup> century, and the age-adjusted death rate in 1960 was 1,304 deaths per 100,000 (Hoyert, 2012). Acute communicable diseases continued to decline due to public health practices, but medical factors such as antibiotics were important contributors to mortality reduction as well (Cutler & Meara, 2001). The use of antibiotics, including penicillin, became important for helping the elderly as well as the young (Cutler & Meara, 2001). The mid-20<sup>th</sup> century marked the first time in history that health care providers were confronted with the challenges of providing care to an increasing population of older adults.

By the end of the 20<sup>th</sup> century, the death rate declined even more. By 2000, the age-adjusted death rate was 872 deaths per 100,000 (Minino, Arias, Kochanek, Murphy & Smith, 2002). This rate is roughly equivalent to about 1 in 125 people dying annually

for an overall decline of around 70% since the beginning of the 20<sup>th</sup> century (Cutler & Meara, 2001).

A similar decline in death rates has continued into the 21<sup>st</sup> century as well. The latest data show that the age-adjusted death rate in 2011 was 741 deaths per 100,000 (Hoyert & Xu, 2012). With the combination of medical treatment and an improved public health infrastructure, life expectancy has increased by 30 years over the last century, and people are living well into their eighth or ninth decade of life (DeSpelder & Strickland, 2011). Over half of the deaths that occurred in the early 20<sup>th</sup> century were among children age fourteen and younger. In contrast, in the 21<sup>st</sup> century, fewer than two percent of deaths occur among this age group (DeSpelder & Strickland, 2011). Fewer children are dying before the age of five, and fewer people are dying before the age of 60 (World Health Organization, 2013).

The “shift” in mortality causes, from acute communicable diseases to chronic non-communicable diseases, along with an increasingly older age of death, can be best described as an epidemiological transition (Omran, 2005). During this transition, a rapid growth (high birth rates, low death rates) occurred within the U.S. population until an eventual plateau occurred in both rates (i.e., birth and death rates were low). This transition in the United States occurred when public health infrastructure, medical practices, and a higher standard of living were introduced into the population (Harper & Armelagos, 2010).

As a result of the demographic and epidemiological transitions, health care providers today frequently see many middle-aged to older adults who are living with one

or more chronic diseases. Many times these chronic diseases are life threatening. More deaths in the 21<sup>st</sup> century are usually slow and prolonged due to these transitions.

Within the United States today, the top four causes of death (heart disease, cancer, chronic lower respiratory diseases, and cerebrovascular diseases) are linked to unhealthy lifestyle and behavioral decisions. These chronic diseases cost more money to treat than prevent (Goetzel, 2009). With chronic disease on the rise and with the average life expectancy continuing to increase, individuals and their families will likely spend an increasingly great amount of money and time preparing to die.

### **United States Death Rates Compared to the World**

The current world death rate is 8.37 deaths per 1,000 (Central Intelligence Agency, 2014). Death rates among industrialized nations are similar to the world death rate. The death rates in other industrialized countries of the world suggest that these countries also have proper sanitation, vaccinations, antibiotics, and a strong public health system. In comparison, the death rates for unindustrialized countries are significantly higher; nearly double the rates of their industrialized counterparts. Table 1 depicts the differences in death rates between industrialized and unindustrialized countries.

Table 1

**Midyear Crude Death Rates of Industrialized and Unindustrialized Countries 2014**

Country of Origin	Death Rate
<b>Industrialized</b>	
Australia	7.07 deaths/1,000
Switzerland	8.01 deaths/1,000
United States	8.15 deaths/1,000
Spain	9.00 deaths/1,000
France	9.06 deaths/1,000
United Kingdom	9.34 deaths/1,000
Japan	9.38 deaths/1,000
<b>Unindustrialized</b>	
Angola	11.67 deaths/1,000
Somalia	13.91 deaths/1,000
Afghanistan	14.12 deaths/1,000
Chad	14.56 deaths/1,000
Lesotho	14.91 deaths/1,000
Ukraine	15.72 deaths/1,000
South Africa	17.49 deaths/1,000

Note. Adapted from *Central Intelligence Agency* (2014). *The World Factbook* 2013-2014.

## **Causes of Death**

The most common causes of death in a population can provide valuable insights regarding the population's health status. The United States has gone through a change in the leading causes of death over the last century. According to Murphy (2000), the top five leading causes of death in 1910, respectively, were diseases of the heart, (all forms of) pneumonia and influenza, (all forms of) tuberculosis, diarrhea, and stroke. The latest data according to Murphy, Xu, & Kockanek (2013) show the top five leading causes of death in 2010 were diseases of the heart, malignant neoplasms (cancer), chronic lower respiratory diseases, stroke, and accidents (unintentional injuries). While three of the top five diseases in 1910 were acute communicable diseases, in contrast, the leading causes of death in 2010 were chronic non-communicable diseases that have slower death rates and longer treatments.

While the overall causes of death have changed over the last hundred years, when looking at causes of death by race, they have not changed over the years. Table 2 lists the top 14 causes of death by race in 2010. Table 3 lists the top causes of death by age group. Table 4 depicts the distribution of the ten leading causes of death by sex.

Table 2

**Total deaths for the 14 leading causes of death, by race: United States 2010**

Causes of Death	White		Black		American Indian or Alaska Native		Asian or Pacific Islander		Hispanic	
	Rank	Deaths	Rank	Deaths	Rank	Deaths	Rank	Deaths	Rank	Deaths
All causes	2,114,749		286,959		15,565		51,162		144,490	
Diseases of the heart	1	514,323	1	69,083	2	2,793	2	11,490	2	30,006
Malignant neoplasms	2	419,686	2	65,930	1	2,962	1	14,165	1	31,119
Chronic lower respiratory diseases	3	127,176	7	8,715	6	702	7	1,487	7	4,172
Cerebrovascular diseases	4	109,119	3	15,965	7	559	3	3,833	4	7,274
Accidents	5	104,945	5	12,069	3	1,701	4	2,144	3	10,476
Alzheimer's Disease	6	76,928	10	5,220	11	264	9	1,082	8	3,427
Diabetes	7	54,250	4	12,126	4	857	5	1,838	5	6,556
Influenza and pneumonia	8	43,296	12	4,936	10	326	6	1,539	10	3,025
Nephritis	9	40,205	6	8,841	19	339	8	1,091	9	3,252
Intentional self-harm	10	34,690	16	2,144	8	469	10	1,061	12	2,661
Septicemia	12	28,014	9	6,001	13	244	12	582	14	2,035
Chronic liver disease and cirrhosis	11	27,985	15	2,635	5	787	13	467	6	4,348
Homicide	18	7,863	8	7,818	12	257	17	321	11	2,890

Note. Adapted from "Deaths: Leading Causes for 2010" by M. Heron, 2013, National Vital Statistics Reports, 62, 6, p.11.

Table 3

**Leading causes of death by age: United States in 2010**

<b>Age and rank order</b>	<b>Cause of death</b>	<b>Deaths</b>
<b>25-44 years</b>		
	All causes	112,292
1.....	Unintentional injuries	29,365
2.....	Malignant neoplasms	15,428
3.....	Diseases of the heart	13,816
4.....	Suicide	12,306
5.....	Homicide	6,731
6.....	Chronic liver disease and cirrhosis	2,910
7.....	Human immunodeficiency virus (HIV) disease	2,639
8.....	Cerebrovascular diseases	2,421
9.....	Diabetes mellitus	2,395
10.....	Influenza and pneumonia	773
<b>45-64 years</b>		
	All causes	494,009
1.....	Malignant neoplasms	159,712
2.....	Diseases of the heart	104,806
3.....	Unintentional injuries	33,690
4.....	Chronic lower respiratory disease	18,694
5.....	Chronic liver disease and cirrhosis	18,415
6.....	Diabetes mellitus	17,287
7.....	Cerebrovascular diseases	16,603
8.....	Suicide	15,183
9.....	Nephritis, nephrotic syndrome and nephrosis	5,082
10.....	Septicemia	4,604
<b>65 years and over</b>		
	All causes	1,798,276
1.....	Diseases of the heart	477,338
2.....	Malignant neoplasms	396,670
3.....	Chronic lower respiratory disease	118,031
4.....	Cerebrovascular diseases	109,990
5.....	Alzheimer's disease	82,616
6.....	Diabetes mellitus	49,191
7.....	Influenza and pneumonia	42,846
8.....	Nephritis, nephrotic syndrome and nephrosis	41,994
9.....	Unintentional injuries	41,300
10.....	Septicemia	26,310

Note. Adapted from "Deaths: Leading Causes for 2010" by M. Heron, 2013, National Vital Statistics Reports, 62, 6, p.18.



Table 4

**Percent distribution of the 10 leading causes of death, by sex: United States 2010**

Causes of Death deaths	Male	Causes of Death	Female
	Percent of		Percent of deaths
Heart disease	24.9	Heart disease	23.5
Cancer	24.4	Cancer	22.1
Other	23.6	Other	25.5
Unintentional injuries	6.2	Unintentional injuries	3.6
Chronic lower respiratory disease	5.3	Chronic lower respiratory disease	5.9
Stroke	4.2	Stroke	6.2
Diabetes	2.9	Diabetes	2.7
Suicide	2.5	Septicemia	1.5
Alzheimer's disease	2.1	Alzheimer's disease	4.7
Kidney disease	2.0	Kidney disease	2.1
Influenza and pneumonia	1.9	Influenza and pneumonia	2.1

Note. Adapted from "Deaths: Leading Causes for 2010" by M. Heron, 2013, National Vital Statistics Reports, 62, 6, p.9.

## **Location of Death in America**

Dying today can be a lengthy process due to the chronic nature of many diseases. Since people are living longer and dying longer, the location of death in many cases has moved from homes to institutions. Most Americans prefer to die in the home, unfortunately most die within an institutional setting (Grunier et al., 2007). Twenty-two percent of the of the almost 2.5 million people who die in the United States every year die in a nursing home, and that percentage increases with age (Bern-Klug, 2009). Among those 75 years or older, about a third die in a nursing home, and in comparison, almost half of those 85 years and older (43%) die in a nursing home (Bern-Klug, 2009). Deaths within a nursing home is becoming a more common occurrence in Americans aged 85 or older (CDC/NCHS, Morality Statistics, 2004).

### *Impact of Medical Technology*

Medical technology has increased life expectancy over the last century, but it has also extended the dying process, sometimes unnecessarily and with no benefit to the patient. Medical technology can refer to medical and surgical procedures, drugs, medical devices, and support systems (Moseley, 2005). Progressive improvements over time in medical technology have allowed physicians to sustain and prolong life, while curing and treating a variety of diseases (DeMiranda, Doggett, & Evans, 2005). Medical technologies such as open-heart surgery, cancer diagnosis and treatment techniques, and pharmacotherapy have allowed physicians to monitor chronically ill patients for extensive periods of time (DeMiranda et al., 2005). Patients with chronic illnesses are benefiting from newer medicine and diagnostic procedures. However, along with the

benefits comes a curse. Technology that can be used to heal, fix, and cure can also prolong death unnecessarily.

In the 1960s, medical technology advanced to the point where it created the need for American society to redefine methods of determining death. Death was traditionally determined by the irreversible cessation of respiration and cardiac function (DeMiranda et al., 2005). With increased knowledge and improved technology, the definition of human death changed to incorporate cessation of lung, brain, and heart function (Dickerson, 2002). The Uniform Determination of Death Act that was passed in 1980 stipulates that death is established using the measurement of cessation of respiration and circulation, but it adds irreversible cessation of all function of the brain, including the brain stem (Presidents Commission for the Study of Ethical Problems in Medicine, Biomedical, & Behavioral Research, 1980). Most deaths today still incorporate both determinations of death, but medical technology has the ability to prolong life in many patients that are considered clinically dead.

### **Roles of Physicians at End-of-Life**

In the beginning of the 20<sup>th</sup> century, the role of the primary care physician was primarily to provide care focused on quick diagnosis and treatment of patients with acute illnesses (Wagner, 1998). Today, patients and families with chronic diseases have different needs that are not necessarily being met by an acute care model. Care for chronic diseases requires continued assessment, attention to treatment guidelines, behavioral support to help patients learn to self-manage disease, planned regular visits with primary care physicians and specialists, and prevention of reoccurring symptoms

and complications (Wagner, 1998). As such, the treatment of chronic illness is often more challenging for physicians than treating acute infections.

Despite improvements in the technical aspects of medical care, many Americans die slow deaths from chronic illnesses. Today, it is not uncommon for older adults to die slow deaths from life threatening illness after aggressive treatment has failed. Physicians of many disciplines, especially those in primary care specialties, encounter death on a daily basis. Since people are dying more frequently in institutions, patients and their families rely more on physicians to provide information, support, and clear communication during the dying process. Hence physicians must possess certain skills during end-of-life care. Helping to provide care to patients who are slowly and gradually dying should be one of those skills.

Research is mixed regarding how well physicians are prepared to provide care for their patients during end-of-life care.

The SUPPORT (1995) study was a controlled trial to improve care for terminally ill patients who had one or more of nine life-threatening diagnoses and an overall 6-month mortality rate of 50%. The researchers wanted to improve end-of-life decision making for physicians while observing the number of times a physician prolongs the process of dying by use of machines. The study consisted of two phases. Phase I was designed to be descriptive in nature and provided a cross-sectional view of physicians' practices related to end-of-life care. Phase II was an intervention designed to improve patient-physician communication, physicians' knowledge of patients' preferences, physicians' knowledge of patients' reported level of pain, and the timing of written do-

not-resuscitate (DNR) orders. Phase I was an observational study of 4301 patients followed by a second phase that was a clinical trial of 4804 patients.

The results of phase I found shortcomings in physician communication, the number of aggressive treatments, and the characteristics of hospital deaths. Only 47% of physicians knew when their patients preferred to avoid CPR. Forty-six percent of DNR orders were written within two days of death, and 38% of patients who died spent at least 10 days in an intensive care unit (ICU). Lastly, of the 50% of family members of conscious patients who died in hospital, reported that their loved one suffered from moderate to severe pain at least half the time.

For phase II of the study, patients experienced no improvement in patient-physician communication, incidence of timing of written DNR orders, physicians' knowledge of their patients' preferences not to be resuscitated, number of days spent in an ICU, receiving mechanical ventilation for comatose patients before death, or level of reported pain. The intervention also did not reduce use of hospital resources. In summary, phase I of the SUPPORT study (1995) confirmed substantial shortcomings in the care of seriously ill hospitalized adults. The phase II intervention failed to improve care or patient outcomes. Enhancing opportunities for better patient-physician communication, although advocated as the major method for improving patient outcomes, may be inadequate to change established practices.

There have been improvements to end-of-life care, but the Institute of Medicine (2014) found that there are still barriers in access to care that disadvantage certain groups; that there is a mismatch between the services patients and families need and the services they can obtain; that there are inadequate numbers of palliative care specialists and too

little palliative care knowledge among other clinicians who care for individuals with serious advanced illness; and that there is a fragmented care delivery system, that contributes to the lack of service coordination across programs. Table 5 depicts the key recommendations for improving quality and honoring individual preferences near end-of-life.

Table 5

**Key Recommendations for improving quality and honoring individual preferences near end-of-life.**

<p>Recommendation 1: Delivery of Care</p>	<ul style="list-style-type: none"><li>• Consider the evolving physical, emotional, social, and spiritual needs of individuals approaching the end of life, as well as those of their family and/or caregivers</li><li>• Be competently delivered by professionals with appropriate expertise and training;</li><li>• Include coordinated, efficient, and interoperable information transfer across all providers and all settings</li><li>• Be consistent with individuals’ values, goals, and informed preferences.</li></ul> <p>Health care delivery organizations should take the following steps to provide comprehensive care:</p> <ul style="list-style-type: none"><li>-All people with advanced serious illness should have access to skilled palliative care or, when appropriate, hospice care in all settings where they receive care (including health care facilities, the home, and the community).</li><li>-Palliative care should encompass access to an interdisciplinary palliative care team, including board-certified hospice and palliative medicine physicians, nurses, social workers, and chaplains, together with other health professionals as needed (including geriatricians). Depending on local resources, access to this team may be on site, via virtual consultation, or by transfer to a setting with these resources and this expertise.</li><li>-The full range of care that is delivered should be characterized by transparency and accountability through public reporting of aggregate quality and cost measures for all aspects of the health care system related to end-of-life care. The committee believes that informed individual choices should be honored, including the right to decline medical or social services.</li></ul>
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Table 5 continued

**Key Recommendations for improving quality and honoring individual preferences near end-of-life.**

<p>Recommendation 2: Clinician-Patient Communication and Advance Care planning</p>	<p>All individuals, including children with the capacity to do so, to have the opportunity to participate actively in their health care decision making throughout their lives and as they approach death, and receive medical and related social services consistent with their values, goals, and informed preferences</p> <ul style="list-style-type: none"> <li>• Clinicians to initiate high-quality conversations about advance care planning, integrate the results of these conversations into the ongoing care plans of patients, and communicate with other clinicians as requested by the patient; and clinicians to continue to revisit advance care planning discussions with their patients because individuals’ preferences and circumstances may change over time.</li> </ul>
<p>Recommendation 3: Public Education and Engagement</p>	<p>Use appropriate media and other channels to reach their audiences, including underserved populations</p> <ul style="list-style-type: none"> <li>• Provide evidence-based information about care options and informed decision making regarding treatment and care</li> <li>• Encourage meaningful dialogue among individuals and their families and caregivers, clergy, and clinicians about values, care goals, and preferences related to advanced serious illness</li> <li>• Dispel misinformation that may impede informed decision making and public support for health system and policy reform regarding care near the end of life.</li> </ul>



Table 5 continued

**Key Recommendations for improving quality and honoring individual preferences near end-of-life.**

<p>Recommendation 4: Professional and Educational Development</p>	<p>All clinicians across disciplines and specialties who care for people with advanced serious illness should be competent in basic palliative care, including communication skills, inter-professional collaboration, and symptom management;</p> <ul style="list-style-type: none"><li>• Educational institutions and professional societies should provide training in palliative care domains throughout the professional’s career;</li><li>• Accrediting organizations, such as the Accreditation Council on Graduate Medical Education, should require palliative care education and clinical experience in programs for all specialties responsible for managing advanced serious illness (including primary care clinicians);</li><li>• Certifying bodies, such as the medical, nursing, and social work specialty boards, and health systems, should require knowledge, skills, and competency in palliative care;</li><li>• State regulatory agencies should include education and training in palliative care in licensure requirements for physicians, nurses, chaplains, social workers, and others who provide health care to those nearing the end of life</li><li>• Entities that certify specialty-level health care providers should create pathways to certification that increase the number of health care professionals who pursue specialty-level palliative care training; and</li><li>• Entities such as health care delivery organizations, academic medical centers, and teaching hospitals that sponsor specialty-level training positions should commit institutional resources to increasing the number of available training positions for specialty-level palliative care.</li></ul>
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Table 5 continued

**Key Recommendations for improving quality and honoring individual preferences near end-of-life.**

<p>Recommendation 5: Policies and Payment Systems</p>	<p>Provide financial incentives for</p> <ul style="list-style-type: none"><li>– medical and social support services that decrease the need for emergency room and acute care services,</li><li>– coordination of care across settings and providers (from hospital to ambulatory settings as well as home and community), and improved shared decision making and advance care planning that reduces the utilization of unnecessary medical services and those not consistent with a patient’s goals for care;</li></ul> <p>Require the use of interoperable electronic health records that incorporate advance care planning to improve communication of individuals’ wishes across time, settings, and providers, documenting</p> <ol style="list-style-type: none"><li>(1) The designation of a surrogate/decision maker,</li><li>(2) Patient values and beliefs and goals for care,</li><li>(3) The presence of an advance directive, and</li><li>(4) The presence of medical orders for life-sustaining treatment for appropriate populations; and encourage states to develop and implement a Physician Orders for Life-Sustaining Treatment (POLST) paradigm program in accordance with nationally standardized core requirements.</li></ol>
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*Note.* Adapted from Institute of Medicine (2014). Dying in America: Improving honoring individual preferences near the end-of-life. Key findings and recommendations.p.1-8.

Additionally, research has been conducted on improving end-of-life care training. Simply adding a one-hour session dedicated to discussion of emotional reactions to patient death increased confidence levels for internal medicine interns in end-of-life care (Smith & Hough, 2011). An intervention consisting of two one-hour lunch conference sessions and six one-hour morning reports at three university teaching hospitals for internal medicine residents found an impact on resident self-efficacy for end-of-life communication skills (Smith, O'Sullivan, Lo, & Chen, 2013). Another intervention consisting of two one-hour educational sessions designed to teach end-of-life communication skills found a positive trend towards increased comfort level in addressing end-of-life issues among internal medicine residents (Kerai & Wheeler, 2013). Other studies have found that including and completing a hospice rotation broadened knowledge, skills, beliefs, and assumptions about illness and suffering for 137 third year students, (Jacoby, Beehler & Balint, 2011). While there has been improvement in end-of-life care, there are still gains to be made.

#### *Building Relationships with Patients*

Building relationships between physicians and their patients is very important, especially during end-of-life. Since end-of-life care is often complex, patients and their families need increasingly more information during end-of-life care. However, at end-of-life, relationships between physicians and their patients are typically brief. DelVecchio-Good et al., (2004), interviewed 163 internal medicine physicians who recently cared for a dying patient. Of the internal medicine physicians within the study, 69% cared for their patients for a week or less, 34% for three days or less, and only 7% were with the patient at the time of death. Many times at the end-of-life, patients are not necessarily in the best

condition for healthy relationships. Some patients may not be able to speak, may be in and out of consciousness, or just might want to be left alone. DelVecchio-Good et al., (2004), also found that physicians did not report feeling particularly close to patients during end-of-life care.

Curtis et al, (2005) audio taped 51 family conferences that included a physician and family members during end-of-life care in the intensive care unit. The objective was to identify missed opportunities for physicians to provide support for, or information to, family members during the conferences. Out of 36 physicians (some physicians performed more than one conference), 26 of them identified themselves as internal medicine specialists. Curtis et al. (2005) found the most common missed opportunity was physicians' failure to listen and respond appropriately and directly to comments made by family members. Another missed opportunity that was clinicians' failure to acknowledge or address the expression of family members' emotions during the conference. Finally, the last missed opportunity was caused by the physicians' misunderstanding of the patient's illnesses and the use of ill-advised treatment options.

Steinhauser et al., (2000) determined the factors considered important at the end-of-life by surveying seriously ill patients, recently bereaved family, physicians, and other care providers. The researchers also found that respectful treatment of the dying person and comfort talking about death and dying were key factors in building a relationship with patients. In any end-of-life case, the physician should build a proper relationship that includes a full understanding of the patient's condition, needs and desires. Building such a relationship requires good communication.

## *Communication*

Being competent in verbal communication is essential for any physician. Communicating effectively with patients and their family members about end-of-life decision-making is a necessity for internal medicine physicians. The Accreditation Council for Graduate Medical Education lists communication as one of the core competencies for physician training. Furthermore, the American Board of Internal Medicine asks questions on end-of-life care on the internal medicine certificate exam.

Communication in the medical field is not just about asking medical questions and delivering prognoses. Communication is the basic building block of the physician-patient relationship. Research has shown that poor physician communication during end-of-life leads to problematic outcomes such as inadequacy of understanding patient decision making, disagreement on discussing prognosis with patient and family, and infrequent discussions with the patient and family members about hospice (Teno et al., 2004).

One of the bigger communication barriers for physicians is the difficulty in explaining to their patients that a disease is incurable (Cherlin et al., 2005). Miscommunication and misunderstandings between patients and physicians about prognoses of the illnesses are common within end-of-life (Jenkins et al., 2011). Fried, Bradley, & O'Leary (2003) revealed that 46% of physicians reported communicating about impending death from a terminal disease with their patients, while the patients reported no discussion at all. Additionally, Temel et al. (2009) reported that even when protocols were in place to educate patients in a palliative care trial many patients reported the goals of therapy were incorrect.

Physicians sometimes give contradictory information about the patient's illness and prognosis. For example, a physician may comment that the patient has a strong brain and heart even though he is dying from stage four cancer. Confused by the contradictions from the physician, the patient may focus on the information that communicates optimism, thereby misinterpreting the prognosis of the illness (Jacobsen, Thomas & Jackson, 2013). A survey of 206 family members that provided care at home found that nearly 20% of patients were never told that their illness was incurable or that hospice care was an available possibility (Cherlin et al., 2005). Within that same study, family members that provided care at home also reported that the first available discussion of the illness being incurable occurred within one month of the patient's death.

Physicians must also learn to address patients' and family members' unrealistic expectations regarding prognoses. Weeks and Farber (2012) found that 69% of lung cancer and 81% of colon cancer patients did not understand that chemotherapy was unlikely to cure their disease. Avoiding harmful, aggressive, or non-beneficial treatments is an increasingly common concern shared by patients, families, and health care providers (Camhi et al., 2009). Nonetheless, physicians continue either to over-treat or under-treat patients. In one study, only half of the patients that wanted aggressive care for their condition actually received treatment consistent with their wishes (Silveria, Kim, & Langa, 2010). Another study found that physicians tend to withhold life-sustaining treatments when patients indicate on their advance care plan a wish for aggressive treatments (Cosgriff et al., 2007). On the reverse side, patients' next of kin reported of a 51% increase in intensive "all care possible" treatments, even though such treatment options may have been opposite of their stated wishes (Narang, Wright, & Nicholas,

2015). The SUPPORT study (1995) found that there was inadequate communication between patients, their family members, and healthcare providers. Physicians need to communicate with their patients and the families better about advance care planning for the end-of-life.

Teaching physicians to initiate discussions about end-of-life care soon after a terminal diagnosis is given should be emphasized during residency training. In order to reduce any problems with over treating or withholding life-sustaining treatments is to increase communication about advance care planning with their patients. Advance care planning may prevent the unwanted care at end-of-life that is not beneficial or in accordance with the patient's wishes. Narang, Wright, & Nicholas (2015) found that the use of advance care planning such as durable power of attorney increased between the years 2000-2010, but was not associated with the patient's end-of-life care decisions. Symptom burden is high during the end-of-life and the intensity of treatments that are unnecessary could be prevented by advance care discussions from the physician (Teno et. al, 2013). The problem lies within the culture of the so called "white coat" medicine and viewing death as a failure.

### **Structure and Governance of Medical Education of Physicians**

Medical schools and residency programs prepare future physicians to practice medicine within various settings and disciplines. The training that medical students and residents receive is guided by content and skill standards set by governing accredited bodies. Unfortunately, a variety of governing bodies set the numerous standards pertaining to end-of-life care. This lack of standardization and specificity make it difficult to identify exactly what is being taught to physicians who are in training. The

curricula are determined by individual medical schools and can range from no education about end-of-life care to a complete comprehensive curriculum on end-of-life issues. In order to understand what medical schools teach, it is necessary to examine the governing bodies of medical training.

The American Medical Association is the overall governing body for the entire field of medicine. The American Medical Association does not have a specific curriculum for end-of-life care.

The Accreditation Council for Graduate Medical Education is a non-profit council that accredits the majority of graduate medical training programs (i.e. residencies) within the United States. Like the American Medical Association, the Accreditation Council for Graduate Medical Education does not have a specific curriculum for post-graduate education.

The American Board of Internal Medicine is a physician led non-profit organization that serves as the governing certification body for Internal Medicine physicians. The certification proves that the internist has the knowledge and skills necessary to practice internal medicine. The American Board of Internal Medicine does not have a specific curriculum for end-of-life care, but does have a pre-established blueprint examination guide that delineates the competencies of an internist. The blueprint was developed by the American Board of Internal Medicine board of directors. Program directors of residency programs, internal medicine trainees, and practicing internists are periodically surveyed to provide feedback. According to the American Board of Internal Medicine (2014), within the blueprint guide, there is no end-of-life content areas covered within the medical-content category and only about 3% of the



questions asked on the exam are related to palliative/end-of-life care within cross-content categories. Any category that has 5% or fewer questions on the exam is not included in the content distributions (American Board of Internal Medicine, 2014). The Hospice and Palliative Medicine specialty exam evaluates the knowledge, diagnostic reasoning, and clinical judgment skills needed to work within that specialty area.

Even with all of the guidelines listed from various accrediting bodies of Internal Medicine, the details of what is taught and how it is taught are left up to the individual residency programs.

### **End-of-life Curricula at Selected Internal Residency Programs**

A search by the primary investigator of the current study was completed to determine the current end-of-life curricula training during undergraduate (medical school) and graduate (residency programs). Search terms included “palliative care,” “life threatening illness,” “terminal care,” “end-of-life care,” “geriatric,” “rotation,” “curriculum,” “teaching topics,” “courses,” “medical education,” “residency,” and “preceptorship.” After an extensive literature review, these terms were selected to cover an array of topics within undergraduate and graduate education. The United States was divided into 4 regions: Northeast, Southeast, Midwest, and West. Within each region, two medical schools and two residency programs were selected and the investigator consulted a top 100 medical school list found during a web search. The chosen schools were representative of both prestigious and average education in medical education. The investigator then visited the website of each medical school and called each residency director looking for curriculum pertaining to end-of-life care.

### *Undergraduate*

Cornell Medical College and University of Pennsylvania School of Medicine were chosen for the Northeast region. Cornell requires third year students to complete a two-week clerkship that focuses on improving competency in end-of-life patient care. The student is assigned to a single patient and must submit a write-up that addresses patient history, palliative care issues, diagnostic strategies, and provides an in-depth discussion on treatment strategies used. There are no other end-of-life topics covered in the remainder of the degree program. The University of Pennsylvania third year students are given clerkships within internal medicine. During the internal medicine clerkship, students practice discussing advance directives and breaking bad news with a trained standardized patient. The use of a trained, standardized patient allows the students to apply classroom learning to real life situations.

University of North Carolina School of Medicine and Vanderbilt University were chosen for the South region. At the University of North Carolina, medical students are not required to take any classes or clerkships related to geriatric education or end-of-life care. Even in the fourth year, there are no end-of-life related electives from which students can choose. At Vanderbilt University, students do not have a formal end-of-life curriculum. Even during the internal medicine clerkship during the students' third year, no end-of-life topics are included.

The University of Chicago and the University of Wisconsin were chosen for the Midwest region. At the University of Chicago--Pritzker School of Medicine, students do not have a formal end-of-life curriculum during their entire education. Third year clerkships include a three-month rotation in general medicine, but there are no geriatric

rotations. At the University of Wisconsin, students do not have a formal end-of-life curriculum during the duration of their education. A third year core clerkship in internal medicine is required. A fourth year preceptorship in internal medicine allows students to get exposed to palliative care at only one of the eight hospitals available to the students.

The University of California San Francisco campus and Oregon Health and Science University were chosen for the West region. At the University of California San Francisco, students are not given end-of-life core clerkships, and the MD program objectives do not mention any palliative care or end-of-life. At Oregon, year two students are given a six-week course on human growth that covers aging topics. The third year clerkship allows students to choose internal medicine as a subspecialty, but does not include end-of-life topics.

#### *Residency Programs*

Harvard Medical School and Johns Hopkins School of Medicine were chosen for the Northeast. During the three years of residency, Harvard did not include any required end-of-life care in their core curriculum or electives. During an ambulatory rotation, residents spent one day on geriatrics. There was no explanation of which subject areas were covered during the rotation. Johns Hopkins is similar to Harvard in that they do not teach end-of-life in internal medicine either, but they do have a specific track called the general internal medicine track. This track focuses more time at a community based clinic where residents follow frail elderly patients every third month for two years under a preceptor from the division of geriatrics.

Emory University and the University of Florida were chosen for the Southeast region. At Emory University, residents spend one week within the geriatrics department

during their third year rotation. The curriculum does not involve or specifically list any end-of-life care criteria during the rotation for residents. The University of Florida also does a short curriculum concerning geriatrics for internal medicine residents, unless the resident plans on going into a geriatrics sub-specialty. Within the geriatrics department where the sub-specialty is housed, the curriculum is focused on falls, dementia, hygiene, and rehabilitation. There were no end-of-life care topics included within the curriculum.

At the University of Chicago, internal medicine residents spend a week at a local hospice during the geriatrics rotation. During that week, residents learn about grief, bereavement, communication about death and dying, and assessing the dying patient. They also do palliative care rounds within a local hospital. These tasks are required for all internal medicine residents irrespective of sub-specialty. At Washington University in St. Louis, residents attend a four-week geriatric clerkship during their rotations that, focuses on principles of geriatric evaluation, including the medical, psychological, social, and functional assessments of older adults. Residents are also expected to evaluate three patients a week within palliative care during the rotation.

In the western quadrant, Stanford University has a rotation in geriatrics for first year residents but does not explain any subject areas within the rotation. The goals and objectives for the clerkship do not include any end-of-life care either. At the University of California San Diego campus, internal medicine covers two weeks on geriatric medicine which include home, hospice, and assisted living visits.

Internal medicine curricula from these sixteen undergraduate and residency programs from around the country show that end-of-life training is not emphasized. The rotations provided do not guarantee that the medical student/resident will learn and be

proficient in end-of-life care skills and knowledge. Many of the undergraduate education/residency programs combine end-of-life issues into other rotations throughout the course of learning via periodic lectures or conferences. The small amount of time invested in end-of-life care training is likely a factor in the deficits in care and communication noted in the published research.

### **Content and Quality of Physician Training in End-of-life Care**

Physicians face numerous challenges when caring for patients with terminal illnesses. Since almost a quarter of the 2.5 million deaths annually are among the elderly within a health care institution, physicians need to be ready to discuss end-of-life issues with patients and their families (Bern-Klug, 2009). Unfortunately, some physicians are not prepared sufficiently in end-of-life care. The SUPPORT study (1995) found shortcomings within areas of communication, treatment options, and advance care planning for physicians. Dickinson, Tournier, & Still (1999) found a lack of comprehensive training within undergraduate medical schools in end-of-life care within the areas of pain assessment, hospice, and palliative care for internal medicine and geriatrics students.

The National Consensus Project for Quality Care is a one of six partner organizations of the Hospice and Palliative Nurses Association. Their goal is to further define and underscore the value of palliative care and to improve upon the delivery of palliative care within the U.S. According to The National Consensus Project for Quality Care (2013), the eight domains listed below are provided to reflect current practice in end-of-life care for physicians:

- Structure and Processes of Care
- Physical Aspects of Care
- Psychological and Psychiatric Aspects
- Social Aspects of Care
- Spiritual, Religious, and Existential Aspects of Care
- Cultural Aspects of Care
- Care of the Patient at the end-of-life
- Ethical and Legal Aspects of Care

According to the American Board of Internal Medicine (2013), the medical content categories in Hospice and Palliative Medicine are:

- Approach to Care
- Psychosocial and Spiritual Considerations
- Impending Death
- Grief and Bereavement
- Medical Management
- Communication and Team Work
- Ethical and Legal Decision Making
- Prognostication and Natural History of Serious Illness

A study conducted by Weissman & Block (2002) used the requirements set by the ACGME and found nine domains that should be included in the end-of-life care training for medical schools:

- Pain assessment and management
- Non-pain symptoms assessment and management-depression, anxiety, existential, spiritual issues
- Ethics
- Physician-patient communication
- End-of-Life (EOL) communication skills
- Psychosocial care
- Death and dying
- Personal Awareness
- EOL clinical experiences

The domains confirm the deficiencies in pain/non-pain symptom assessment and management, end-of-life communication, psychosocial care/spiritual support, and

bereavement care for patients and their families (Weissman & Block, 2002). Physicians are underprepared and lack the expertise because the training programs fail to hold the residents accountable for competency in end-of-life areas.

Curtis et al. (2001) conducted focus groups on patients with life threatening illnesses, family members, nurses, social workers, and physicians (n=137) to develop a comprehensive understanding of the factors that contribute to the quality of physicians' care for dying patients. Major themes emerged from the focus groups and were developed into domains for end-of-life care. The findings of the focus groups suggest that there are 12 domains that encompass the major skills a physician must have in order to provide high-quality end-of-life care as provided by the perspectives of terminally ill patients, their families, and healthcare professionals (Curtis et al., 2001). Table 6 explains the twelve recommended domains of physicians' skills at providing end-of-life care

Table 6

**Twelve Recommended Domains of physician’s skills at providing end-of-life care**

<i>Domain</i>	<i>Specific components</i>
1. Communication with patients	<ul style="list-style-type: none"> <li>• Listens to patients</li> <li>• Encourages questions from the patient</li> <li>• Talks with patients in an honest and straightforward way</li> <li>• Gives bad news in a sensitive way</li> <li>• Willing to talk about dying</li> <li>• Sensitive to when patients are ready to talk about death</li> </ul>
2. Accessibility and continuity	<ul style="list-style-type: none"> <li>• Takes as much time as needed with the patient</li> <li>• Avoids keeping the patient waiting without explanation</li> <li>• Minimizes interruptions and focuses on the patient during visits</li> <li>• Makes the patient feel confident that he/she will not be abandoned prior to death</li> <li>• Continues to be involved with the patient after referral to hospice</li> <li>• Has contact with the family after the patient’s death</li> </ul>
3. Respect and humility	<ul style="list-style-type: none"> <li>• Polite and considerate</li> <li>• Treats patients (and families) as his/her equal</li> <li>• Admits when he/she does not know something</li> <li>• Comfortable with people who are dying</li> <li>• Does not view death as a medical or personal failure</li> </ul>
4. Patient education	<ul style="list-style-type: none"> <li>• Gives enough detailed information for that the patient understands his/her illness and treatments</li> <li>• Tells patients how the illness may affect his/her life</li> <li>• Guides patient and family to helpful resources</li> <li>• Talks with patients about what their dying might be like</li> </ul>
5. Pain and symptom management	<ul style="list-style-type: none"> <li>• Is not afraid to prescribe medications when needed</li> <li>• Takes into account the patient’s wishes when treating pain and symptoms</li> <li>• Helps patients and families understand what the dying process might be like</li> <li>• Acknowledges and treats anxiety and depression</li> </ul>



Table 6 continued

<i>Domain</i>	<i>Specific components</i>
6. Attention to patient's values	<ul style="list-style-type: none"> <li>• Acknowledges and respects patient's personal beliefs</li> <li>• Respects patient's choices about alternative medicine</li> <li>• Respects patient's culture and religious beliefs</li> <li>• Is not blaming or judgmental about patient's lifestyle</li> </ul>
7. Emotional support	<ul style="list-style-type: none"> <li>• Shows compassion</li> <li>• Maintains hope in a positive way</li> <li>• Provides comfort through touch, such as a hug or holding hands</li> <li>• Responsive to patient's emotional needs</li> </ul>
8. Competence	<ul style="list-style-type: none"> <li>• Knowledgeable about medical care</li> <li>• Takes the patient's symptoms seriously</li> <li>• Recommends appropriate treatment</li> <li>• Has good technical skills</li> <li>• Is prepared for appointments</li> <li>• Appropriately refers the patient to specialists</li> <li>• Knowledgeable about the care needed by patients during the dying process</li> <li>• Knows when to stop treatments that are no longer helpful</li> </ul>
9. Team communication and coordination	<ul style="list-style-type: none"> <li>• Let the patients know who to call for different problems</li> <li>• Makes sure there is someone there to help the patient when the physician is not available</li> <li>• Respects and uses the expertise of nurses, social workers, and other non-physician team members</li> <li>• Helps the patient and family get consistent information</li> <li>• Guides patient or family to hospice in a timely manner</li> </ul>
10. Personalization	<ul style="list-style-type: none"> <li>• Makes patient feel unique and special</li> <li>• Treats the whole person, not just the disease</li> <li>• Considers that patient's social situation when making treatment plans</li> </ul>

Table 6 continued

<i>Domain</i>	<i>Specific components</i>
11. Inclusion/recognition of the family	<ul style="list-style-type: none"> <li>• Openly and willingly communicates with the family</li> <li>• Includes family in decision making</li> <li>• Helps the family understand what the dying process might be like</li> </ul>
12. Support of patient decision making	<ul style="list-style-type: none"> <li>• Provides treatment options and advice about medical care</li> <li>• Lets the patient make decisions about his/her medical care</li> <li>• Honors the patient's wishes about end-of-life care</li> </ul>

Note. Adapted from J. R Curtis, M. D. Wenrich, J.D. Carline, S.E. Shannon, D.M. Ambrozy, & P.G. Ramsey (2001) Understanding Physicians' Skills at Providing End-of-Life Care. 16: 41–49

Previous studies found major skills a physician must possess during end-of-life care; other studies have found deficiencies in end-of-life knowledge. Mullan et al., (2002) examined end-of-life knowledge, teaching content and practices in faculty and residents of thirty-two internal medicine programs of six Midwest states. The authors found that pain assessment and treatment training was required in only 60% of programs. Only 22% of programs required instruction on non-pain symptoms or hospice and non-hospital care settings. Assessing end-of-life depends primarily on faculty's general ratings of residents' global competency and few programs use knowledge examinations or structured skill assessments. The program directors identified barriers and support for improving education. The authors found that existing internal medicine residency education lacks training in critical end-of-life practices and that the residency programs need additional training for residents.

Educational training in end-of-life care also lacks for medical students, residents, and faculty members. Sullivan et al. (2003) surveyed fourth year medical students, residents (internal medicine, family medicine, and surgery), and faculty members concerning education training within end-of-life care. Sullivan et al. (2003) defined end-of-life care as working with patients who have a terminal illness and managing a patient's care during the last few weeks or days of life, including hospice and palliative care. The authors also described end-of-life education as any coursework taken in end-of-life care, rotations completed in end-of-life care, clinical time taught by residents, and the extent of exposure to a dying patient.

The study assessed attitudes, quantity and quality of education, preparation to provide or teach care, and perceived value of care for dying patients. Ninety percent or

more of respondents held positive views about physicians' responsibility and ability to help dying patients. However, fewer than 18% of students and residents reported receiving formal end-of-life care education, 39% of students reported being unprepared to address patients' fears, and nearly half felt unprepared to manage their feelings about patients' deaths or help bereaved families. Additionally, more than 40% of residents felt unprepared to teach end-of-life care. Forty percent of respondents also reported that dying patients were not considered good teaching cases, and that meeting psychosocial needs of dying patients was not considered a core competency. Forty-nine percent of students had told patients about the existence of a life-threatening illness, but only half received verbal feedback from residents or attending physician about the life-threatening illness; nearly all residents had talked with patients about wishes for end-of-life care, and 33% received no feedback on the strengths and weaknesses of the discussions from attending physicians. Students and residents in the United States feel unprepared to provide, and faculty and residents are unprepared to teach, many key components of good care for the dying. Current educational practices and institutional culture in U.S. medical schools do not support adequate end-of-life-care and attention to both curricular and cultural change are needed to improve end-of-life care education.

DeVecchio-Good et al., (2004) observed factors influencing physicians' emotional reactions to patients' deaths, including mentoring training, relationships with patients, emotional and colleague support, and past experiences with death. The researchers recruited first year graduate clinical trainees (interns), second to fourth year trainees (residents), and clinical faculty responsible for teaching students, interns, and residents. The researchers interviewed a sample of internal medicine physicians that

recently cared for dying patients. Sixty-six patients were selected randomly for the qualitative and quantitative study. Within the interviews, the researchers found three major themes surrounding end-of-life care, time and process, medical care and treatment decisions, and communication and negotiations (Figure 1).

<i>Positive</i>	<i>Negative</i>
<b>Time and Process</b>	
Expected Peaceful Timely	Unexpected Chaotic Prolonged
<b>Medical Care and Treatment Decisions</b>	
Rational/coherent “Appropriate” care Facilitating smooth, peaceful or comfortable death	Irrational/lacking coherence Futile or overly aggressive care Adverse events, leading to painful dying and or hastening death
<b>Communication and Negotiations</b>	
Effective communication with patient, family, team	Ineffective or absent communication, conflict or misunderstandings with patient, family medical team

**Fig 1.** Physicians’ perceptions of patient deaths: positive and negative characteristics

DelVecchio-Good et al., (2004) found the physicians’ perceptions of patients’ deaths were split into the positive and negative categories, which could be expressed as skills needed to ensure proper end-of-life care. The authors concluded that continuity of care and long-term physician patient-family relationships are rare in academic internal medicine services, especially at end-of-life.

Ogle, Mavis & Thomason (2005) conducted a statewide survey in Michigan of postgraduate medical training programs to determine the current status of training related to end-of-life care and hospice care training. A mail survey was sent to 275 program directors of all residency and fellowship programs in Michigan seeking information about

training in EOL care and hospice care such as required and elective experiences, teaching formats, and program directors' ratings of the perceived adequacy of training. End-of-life care was defined as formal training (lecture, clinical, small group, readings, other). Less than half (46%) of the residency programs reported any formal training in EOL care, and less than one third (31%) reported training in hospice care. Half of the programs that required hospice training included a clinical component with fewer programs reporting having any clinical component. Most program directors rated their programs as adequate or excellent in terms of EOL and hospice care, whether they had formal training or not. The results of the survey demonstrated considerable differences in end-of-life training. Direct clinical experience was infrequently reported for training according to the directors. There was a lack of reported content curriculum and implementation of end-of-life care trainings.

Pan et al., (2005) surveyed geriatric medicine fellows regarding their educational experiences in end-of-life care. Two hundred ninety six graduating geriatric medicine fellows in a one and two year program in the United States responded to the survey. The researcher measured attitudes, quantity and quality of end-of-life care education, preparation to provide care, and perceived value of caring for dying patients. The researchers found that 95% or more of the respondents held positive attitudes about a physician's abilities in helping a dying patient. Seventy percent of the fellows had completed a rotation focusing on end-of-life care and of the fellows that completed a rotation rated their education within end-of-life care highly. Overall, fellows felt well prepared to care for dying patients.

Stratos, Katz, Bergen, & Hallenbeck, (2006) prepared a faculty development curriculum for 17 medical faculties to address the deficiencies in physician training in end-of-life care. The overall goals of this curriculum were to enhance physician competence in end-of-life care, foster a commitment to improving care for the dying, and improve teaching related to end-of-life care. The researchers selected seven core content domains for the curriculum. The seven content domains were as follows:

- Death and dying in the United States
- Pain management
- Communicating with patients and families
- Making difficult decisions
- Non-pain symptom management
- Venues and systems of care
- Psychiatric issues and spirituality

The researchers found that seminars at the primary place of employment for the physicians enhanced the knowledge, skills, and attitudes of participating faculty and residents. Trained facilitators had disseminated the 16-hour curriculum to approximately 3,400 medical faculty and residents. The programs were effective in disseminating end-of-life training at local, regional, and national levels. Follow-up surveys reported that many home-sites that used the training, implemented palliative care services, and influenced end-of-life care policy.

### *Hidden Curriculum and Medical Culture*

Within any formal education, there is a combination of materials, resources, instructional content, and processes that evaluate a pupil for mastering certain educational objectives. The same is found within the medical community. According to Gofton & Regher (2006), there are three types of curricula that exist:

- 1) Formal curriculum (what is stated, intended, and formally offered)

- 2) Informal curriculum (the unscripted, interpersonal teaching between faculty and students)
- 3) Hidden curriculum (a set of inferred from behaviors influences that function around organizational and cultural level)

The training and education of medical students and residents involves a combination of all three curricula listed above. The hidden curriculum is one that cannot be seen, but has the most impact beyond student learning. According to Hafferty (1998), not everything that is learned within medical training is captured within the syllabi, handouts, guest speakers, and course catalogs. Many times the hidden curriculum consists of certain rituals and, understandings that occur behind closed doors within the clinical section of the medical education (Braddock, Eckstrom, & Haidet, 2004). As students and residents undergo the transition into becoming physicians, the unintended lessons learned through faculty and resident behaviors often conflict with the formal teaching of end-of-life care (Billings et al, 2010). Hafferty (1998) explains that the hidden curriculum affects certain policies, resource allocation, evaluations, and classification that symbolize medical power and authority. Sullivan et al. (2003) reported on the hidden curriculum surrounding medical end-of-life care with the following findings: paucity of teaching about end of life care, lack of exposure to care of dying patients at home and hospice, perceived communications by teachers that end-of-life care is less important than other aspects of clinical care, and lack of preparation for clinically universal tasks related to end-of-life care. Sullivan followed that study with another in 2004 that found 59% of most medical school deans were moderately or very opposed to introducing a required course in end-of-life.



Billings et al. (2010) examined the formal, informal, and hidden curricula surrounding end-of-life care for medical schools. Medical students were asked questions about their medical school coursework. The authors found that quality of end-of-life education was positively associated with the medical students' formal and informal experiences, while the hidden curriculum was negatively associated with the students' perceived preparation and attitudes. Over 85% of students observed others giving bad news more than three times, yet half the students reported never personally giving bad news, and less than half of those students received any feedback from superiors. Students reported extensive experience informally observing end-of-life care with patients but less experience in actually providing it. Sixty percent of students also felt that residents and attending physicians conveyed negative associations with working with dying patients and reported that it is not rewarding. The authors found that medical students still lack comprehensive education about end-of-life care.

A study conducted by Gibbins, McCourbrie, & Forbes (2011) found that newly qualified physicians perceived that they received little formal teaching about palliative and end-of-life care and usually learned from "trial and error" or "while doing the job." Sullivan et al., (2003) surveyed third year medical students (internal medicine, family medicine, and surgery), residents, and faculty members and found that only 18% reported having taken a course in end-of-life care and 9% reported completing a clerkship in this area; 16% of residents had done a rotation in hospice or palliative care; and 17% of faculty reported having taught some aspect of end-of-life care in the past year. A similar study of internal medicine residency programs done by Weissman et al., (2002) found that lack of faculty knowledge in pain and non-pain management, insufficient time

allotted in the curriculum, little comfort with end-of-life issues, and financial and institutional resources were barriers to teaching end-of-life topics within the residency program. The lack of training within medical schools and residency programs is a continued problem within the United States.

### **Challenges/Barriers/Benefits Physicians Report at End-of-Life**

#### *Psychological Issues*

Physicians must care for their dying patients. However, what is more important is how the physicians deal with the experience of death. Many physicians express emotions of guilt, sadness, and stress caused by caring for a patient that is dying (Meier, Back, & Morrison, 2001). These emotions, if not taken care of properly, could pose problems as physicians continue with their careers. According to Redinbaugh et al. (2003), 31% of physicians found that a patient's death had a strong emotional impact on them, and over 50% of the physicians reported that the death disturbed them a little. Other research has found similar results. A qualitative study of physicians by Corker (2010) found that physicians had a difficult time dealing with the emotions surrounding the death of a patient when the physician and patient had a good relationship. The grief from patient deaths is a barrier that physicians need to understand more about.

Seeking help from others is another barrier for physicians when working in the area of death and dying. Redinbaugh et al. (2003) found that the two most commonly used coping methods were "seeking emotional support from others" and "trying to see death in a different light." Gender differences play a role in how physicians deal with end-of-life issues as well. Female physicians are more likely to look for more support from others than their male counterparts (Redinbaugh et al., 2003). Females also report

more symptoms of grief and psychological symptoms such as guilt, feeling sad, and anger (Redinbaugh et al., 2003). Corker (2010) found that female physicians were more emotionally open than male physicians to expressing their feelings towards patients. The medical community has a lack of emotional support and senior physicians tend to underestimate the distress that junior physicians, residents, and attending physicians may endure (Redinbaugh et al., 2003). Coping with the death of a patient should be a priority within the medical community, and more emphasis should be placed on helping the physicians that need it.

### *Benefits*

Even though death has a negative connotation, physicians do report some benefits to dealing with issues related to death. The emotional relationship that a physician has with the patient and their families at the end-of-life can be a positive one. According to Redinbaugh et al. (2003), 74% of physicians surveyed thought that taking care of a dying patient was a satisfying experience, and those with even longer patient relationships reported more satisfying experiences. Physicians also find satisfaction in providing care for their terminally ill patients. One study assessed the attitudinal barriers towards end-of-life care and found that many physicians expressed that providing their patients with relief from suffering was one of the most rewarding aspects of the job (Parker et al., 2012). The authors also found that physicians' anxiety decreased as they had more experiences with hospice patients. Some physicians find a sense of satisfaction and gratitude in dealing with a dying patient, which may include meaningful physician relationships, inner self-reflection, and connection with others such as family, peers, and communities (Boston & Mount, 2006). Physicians who report high satisfaction in

compassion towards dying patients are more likely to empathize with the negative effects of death (Stamm, 2002).

### *Race, Ethnicity, Culture and Language*

A patient's race, ethnicity, and culture each affect the quality and type of treatment received during end-of-life care. In advance care planning, African Americans are less likely than whites to have an advance directive (Hopp & Duffy, 2000). Jones, Moss, & Harris-Kojetin (2011) found that 13 percent of African Americans in home care completed an advance directive compared to 32 percent of whites in home care. The authors also found that 35 percent of African Americans in nursing homes completed an advance directive compared to 70 percent whites in nursing homes. Lastly, the authors found that 80 percent of African Americans in hospice care completed an advance directive compared to 89 percent of whites in hospice care.

Rates of completing advance end-of-life care planning are also lower among Hispanics (Carr, 2011). Latinos/Latinas also have their own beliefs about end-of-life care. Phipps, True, and Murray (2003) found that "fatalism," (which is the feeling that nothing can be done about the problem at hand) influences medical decisions. Religion is a big part of the Latino culture, that religiosity extends to end-of-life care. According to Guntheil & Heyman (2006), older Latinos turn to their church and embrace "God's will" at the end of their lives. Since religion is a big part of the Latino community, Latinos find guidance from the social support system in place from the church. Ai, Hopp, & Shearer (2006) found that elderly Latinos turn to social support as a major factor for end-of-life planning. Physicians understanding the patient's culture, attitudes, and beliefs

behind end-of-life care can improve the relationship and care provided for everyone involved.

Carr (2012) found that whites are 11.1 times as likely to have a durable power of attorney for health care and six times as likely to have a living will when compared to Latinos. There are fewer studies done on advance directives within the Asian community. According to Carr (2012), when compared to other races, Asians are more likely than Latinos and African Americans (32% vs. 13% and 16%, respectively) to have a living will, and Asians are 1.56 times as likely as Caucasians to have a living will. Asians are less likely to talk about advance directives. Given that many Asian cultures are patriarchal and hierarchical in nature, planning an advance directive might be completed without any discussions with family (Lee, 2009). Although racial differences are a barrier to completing an advance directive, the patient may have certain beliefs that the physician must take into account.

Individual beliefs and attitudes are more barriers that physicians should understand when dealing with patients at the end-of-life. Cultural beliefs, values, and patterns of behavior are critical areas of assessment in the care plan (Crawley, Marshall, Lo, & Koenig, 2002). Advance directives and hospice may not be acceptable to many African Americans. African Americans have less favorable beliefs and attitudes about hospice (Bullock, McGraw, Blank, & Bradely, 2005). Many in the African American community prefer life-sustaining therapies. Additionally, they often have greater distrust of the healthcare system (Teno et al., 2004). African Americans also have different spiritual beliefs that may conflict with the goals of hospice care (Teno et al., 2004). Although interventions in church or community settings have increased comfort in, and

dialogue around, discussing end-of-life care, many of these programs have not increased the number of African Americans completing advance directives (Bullock et al., 2005). The cultural surroundings of African Americans have been difficult for physicians to recognize when dealing with end-of-life care.

The Asian culture also has a specific belief and attitude towards end-of-life care as well. Since there are different cultures depending on specific sub-regions of Asia, the research surrounding end-of-life care within the Asian community is difficult to lump together. Matsui (2007) found about 15% of elderly of Japanese descent were in favor of end-of-life care while 27% were opposed. The author also found that 13% of elderly felt that end-of-life care was a decision for the family while 45% for the physician. Chinese descendants are different from the Japanese in that they are more paternalistic in their decisions. Within Chinese culture, there is a negative tone from family for the patient's choices regarding end-of life care (Lee, 2009). A study by Vaughn et al. (2000) found aggressive preferences by the physician for care in Chinese participants and the patients more likely to want a DNR or DNI than any other Asian group. Another study comparing patients with mild dementia and their caregivers revealed that the patients had a tendency to prefer more aggressive care (Nishimoto & Foley, 2001). Physicians need to differentiate between which subculture they are dealing with when treating Asian elderly patients.

### *Ethics*

When physicians graduate from medical school they take the Hippocratic Oath, which is a set of guidelines for ethical behavior. Medical ethics are guided by non-maleficence, confidentiality, beneficence, autonomy, truth-telling, informed consent, and

protecting physician's reputations in light of a medical malpractice suit (Corker, 2010). Ethical dilemmas permeate all areas of medicine, especially at the end-of-life (Clarfield, Gordon, Markwell, & Alibhai, 2003). The education a physician receives should prepare them to face some of the ethical dilemmas in the medical world. Medical ethics is applied within the court systems and review committees. Ethical cases such as *Quinlan v. New Jersey* (1976), *Cruzan v. Missouri* (1990), and *Shiavo v. Florida* (2003-2005) have shaped ethical end-of-life situations in the medical community. Ethical behavior incorporates the ability to recognize ethical issues (moral sensitivity), the determination to do what is right (moral commitment), and the ability to weigh the rights of others and principles at stake (moral reasoning) (Branch, 2001). Physicians encounter problems with medical ethics because they are not the only ones making a decision. Chiswick (2001) found that the ethical decisions within end-of-life care were not made by the physician alone, but by the patients, family, caregivers, the institutional policy, and the public.

Patients are naturally concerned with the end-of-life care they are given. More than 80% of patients say they wish to avoid hospitalization and intensive care during the terminal phase of illness (Meier & Beresford, 2008). The average adult aged 55-64 with at least one chronic condition spent \$7,377 on health care in 2006, compared to \$4,951 for younger persons (Vistnes, Cooper, Bernard & Banthin, 2009). Large numbers of older adults report duplicate testing and procedures, conflicting diagnoses for the same symptoms, medical information that is contradictory, and not receiving adequate information about drug interactions when they fill prescriptions (Anderson, 2010). Unfortunately, prolonging life often comes at a great emotional and financial cost to the

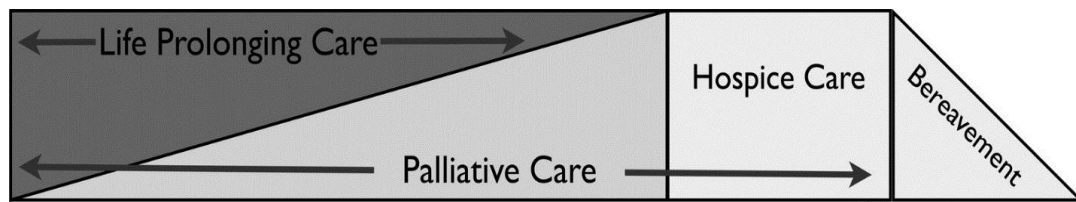
patient, physician, and family (Bomba, 2005). The ethics can be very difficult for a physician to follow when so many people are making a decision about end-of-life.

### *Palliative Care Framework*

Palliative care is important to incorporate into treatments after the diagnosis of a terminal illness. Palliative care aims to relieve suffering using a multidisciplinary and holistic approach that addresses patients' and caregivers' physical, emotional, spiritual, and logistical needs (Adler et al., 2009). According to the WHO (2013), palliative care is an approach that improves the quality of life for the patient as well as caregivers and families, through prevention and relief efforts during a life-threatening disease. Non-hospice palliative medicine is aimed at improving quality of life and supporting patients and the families of patients with serious and complex chronic illnesses where the prognosis is uncertain (Adler et al., 2009). Even though patients have the right to self-determine the treatment given, many times physicians tend to put patients at risk for receiving life-prolonging care (Rady, 2004). The problem lies within treating patients with terminal illnesses. When physicians focus solely on life-prolonging care, the treatment can reduce the amount of comfort care received for the patients (Sahler et al., 2000). Caring for patients at the end-of-life should focus on palliative care especially when all treatment options have been used. The time spent providing life-prolonging treatment with patients allows for less time for palliative care as the disease progresses. Figure 2 shows the differences between the life prolonging model of care and the palliative care model. In traditional life-prolonging care, physicians are taught to cure the disease and provide comfort care to the patient when no more options are available (Adler et al., 2009). Palliative care, on the other hand, is an integrative model that is



started when a patient is diagnosed with a terminal illness and then continues as the patient dies and even extends bereavement to family members who need it (Adler et al., 2009). When a physician stops using the traditional life-prolonging care during the treatment of a life-threatening illness and uses the palliative care, the treatment allows for an overall better care of the patients and their families.



**Figure 2.** Life Prolonging Care vs. Palliative Care. Reprinted from “Palliative Care in the Treatment of Advanced Heart Failure,” by E.D. Adler, J.Z. Goldfinger, J. Killman, M.E. Park, & D.E. Meier. 2009 *Circulation*, 120. pp. 2597-2606.

Since physicians in primary care settings are encountering more patients who are living with life threatening illnesses, it is important they are prepared to help their patients on the journey toward death. The subsequent section will focus on the theoretical background used within the study.

### **Review of Social Cognitive Theory**

Miller and Dollard created the Theory of Proposed Learning in 1941, and it emphasized that humans perform behaviors based within a social context, which was then supported by the observation experiments done in young children (Grusec, 1992). In 1963, Alfred Bandura expanded the Social Learning Theory with responses to a person’s behavior that increase or decrease the likelihood of reoccurrence (Principle of Reinforcement) and behavioral acquisition that occurs by watching the actions and outcomes of others’ behavior (Observational Learning) in what would be the first

workings of the Social Cognitive Theory (Bandura & Walters, 1963). Bandura added to the theory in 1977 with the concept of *self-efficacy*, which accounts for a person's self-confidence in doing a particular behavior (Bandura, 1995). In later versions of the theory, *reciprocal determinism* was added, which is the idea that behavior is influenced by environmental and personal factors (Bandura, 1986). The Social Cognitive Theory is used within the health field because it allows health professionals to understand behavioral change based on the behavior itself or any cognitive or emotional characteristics behind the behavior. Table 7 explains the constructs and definitions of the Social Cognitive Theory.

Table 7

**Constructs and definitions of the Social Cognitive Theory**

Construct	Definition
Environment	Factors physically external to the person; Provides opportunities and social support
Situation	Perception of the environment; correct misperceptions and promote healthful forms
Behavioral capability	Knowledge and skill to perform a given behavior; promote mastery learning through skills training
Expectations	Anticipatory outcomes of a behavior; Model positive outcomes of healthful behavior
Expectancies	The values that the person places on a given outcome, incentives; Present outcomes of change that have functional meaning
Self-control	Personal regulation of goal-directed behavior or performance; Provide opportunities for self-monitoring, goal setting, problem solving, and self-reward
Observational learning	Behavioral acquisition that occurs by watching the actions and outcomes of others' behavior; Include credible role models of the targeted behavior
Reinforcements	Responses to a person's behavior that increase or decrease the likelihood of reoccurrence; Promote self-initiated rewards and incentives
Self-efficacy	The person's confidence in performing a particular behavior; Approach behavioral change in small steps to ensure success
Emotional coping responses	Strategies or tactics that are used by a person to deal with emotional stimuli; provide training in problem solving and stress management
Reciprocal determinism	The dynamic interaction of the person, the behavior, and the environment in which the behavior is performed; consider multiple avenues to behavioral change, including environmental, skill, and personal change

Note. Adapted from *Health Behavior and Health Education Theory, Research and Practice* (2002). K. Glanz, B.K., Rimer & F.M., Lewis. San Francisco: Wiley & Sons.

### *Application of Social Cognitive Theory in Health*

The Social Cognitive Theory is well known for the construct of reciprocal determinism and is a multifaceted and complex relationship. The same concepts can also be used at the organizational level as well. According to Bandura (1988), aspects of the social cognitive theory are especially important in developing skills through mastery modeling, strengthening people's beliefs, and enhancing self-motivation. A study by Doerksen & McAuley (2014) used the social cognitive determinants in dietary behavior change for university employees. Patterson et al., (2014) used the social cognitive theory to understand associations of physical activity behaviors among dialysis patients. Story & Gorski (2013) looked at the global perspectives on peer sex education for college students using the social cognitive theory. Makoul (1998) found that medical educators would do well in teaching residents and medical students the relevance of topics that surround giving bad news to patients. The authors reported that the residents struggled to deliver bad news to patients with specific terminal illnesses as a result of the training programs. By changing the expectations associated with end-of-life care within the resident directors, the residents should be able to be more knowledgeable and confident in end-of-life topics while practicing medicine.

### **Review of the Health Belief Model**

The Health Belief Model (HBM) was originally developed in the 1950's by a group of social psychologists from the U.S. Public Health Service in order to understand why individuals were not getting screened for tuberculosis screenings (Glanz, Rimer, & Lewis, 2002). The underlying concept of the original HBM is that health behavior is determined by personal beliefs or perceptions about a disease and the strategies available

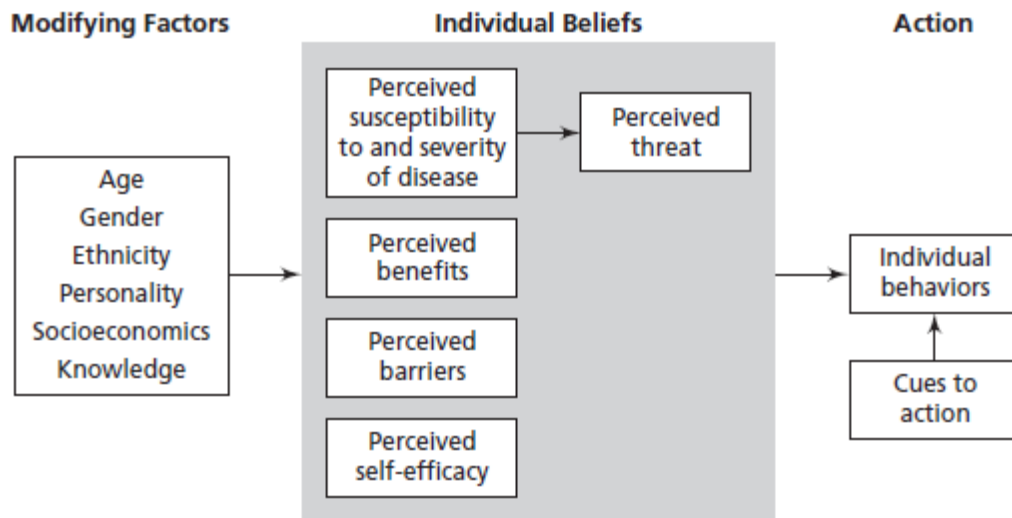
to decrease its occurrence (Hochbaum, 1958). The model helps explain and predict certain health behaviors by focusing on the individual's attitudes and beliefs. The HBM is a value-expectancy theory that relies on two concepts for behavior change: the desire to avoid an illness (value) and the belief that an action would prevent the illness (expectation) (Glanz, Rimer, & Lewis, 2002). The HBM has four main constructs: perceived severity, perceived susceptibility, perceived benefits, and perceived barriers. Other constructs like cues to action and self-efficacy have been added to the HBM since the original conception. Table 8 explains the constructs and definitions while Figure 4 depicts the Health Belief Model.

Table 8

**The constructs and definitions of the Health Belief Model**

Construct	Definition
Perceived Susceptibility	Perceived susceptibility refers to beliefs about the likelihood of getting a disease or condition.
Perceived Severity	Feelings about the seriousness of contracting an illness or of leaving it untreated include evaluations of both medical and clinical consequences and possible social consequences. The combination of susceptibility and severity has been labeled as perceived threat.
Perceived Benefits	Individuals exhibiting optimal beliefs in susceptibility and severity are not expected to accept any recommended health action unless they also perceive the action as potentially beneficial by reducing the threat.
Perceived Barriers	The potential negative aspects of a particular health action—perceived barriers—may act as impediments to undertaking recommended behaviors
Cues to Action	Various early formulations of the HBM included the concept of cues that can trigger actions. Cues to action are difficult to study in explanatory surveys; a cue can be as fleeting as a sneeze or the barely conscious perception of a poster.
Self-Efficacy	Self-efficacy is defined as “the conviction that one can successfully execute the behavior required to produce the outcomes.”

Note. Adapted from *Health Behavior and Health Education Theory, Research and Practice* (2008). K. Glanz, B.K., Rimer & K.Viswanath. San Fransisco: Wiley & Sons.



**Figure 3.** An example of the constructs of the Health Belief Model. Reprinted from Health Behavior and Health Education Theory, Research and Practice K. Glanz, B.K., Rimer & K. Viswanath. (2008).

### *Health Belief Model Applied to Health*

The HBM has been used in a variety of studies across the health field. Many studies have found that the HBM works with mammography screenings within minority women, risky sexual behaviors involving HIV/AIDS, and colorectal cancer screenings. Within end-of-life curricula, the perceived barriers are the most commonly researched construct. A study done by Sullivan et al., (2003) discovered that lack of time to teach end-of-life issues, lack of faculty expertise, lack of faculty interest, lack of faculty leaders, and lack of teaching materials were all barriers to including end-of-life within curricula. Curtis, Patrick, Caldwell, & Collier (2000) found that practicing physicians recalled educational problems, end-of-life counseling, change in culture, and change in health care system as barriers to providing better end-of-life care to their patients.

Another study done by Meisel, Snyder, & Quill (2000) found that the legal aspects of end-of-life care such as forgoing life-sustaining treatment for patients without decision-making, withholding or withdrawing of artificial fluids and nutrition, risk management, advance directives, and a fear of being criminally prosecuted for prescribing high doses of medication were also listed as significant barriers to providing better end-of-life care. Barriers such as the ones listed above pose problems for the physicians and the patients in providing better end-of-life care.

### **Review of PAPM (Precaution Adoption Process Model)**

The Precaution Adoption Process Model (PAPM) is a stage theory that provides the necessary framework in understanding how to change behavior (Weinstein, 1988). A stage theory suggests that individuals might be at different points in changing behavior (Weinstein, 1988). The goal of the PAPM is to explain how an individual feels about changing a health behavior and how he or she interprets that decision in taking action by changing that behavior. The PAPM states an individual will decide to act on changing behavior if he or she feels susceptible to a health problem, believes that the health problem is severe, and also believes that changing the behavior will be beneficial (Weinstein, 1988). The PAPM also suggests that traditional theories for changing behaviors overlooked the processes by which behavior is changed and focused only on the threats to changing or quitting a health behavior (Weinstein, 1988). The first iteration of the PAPM was discussed by Weinstein 1998, in which he qualitatively separated the PAPM from other stage models. Within the PAPM, there are clear stages that an individual or will go through and the stages are not dependent on a time frame. Other stage models depended on a certain number of days spent within a specific stage in order



to progress to the next one. The two versions are different because of an added a seventh stage (maintenance), which was directly influenced by the Trans-theoretical Model by James Prochaska & DiClemente (Weinstein & Sandman, 2002).

Stage 1-Resident directors are unaware about an end-of-life curriculum for their residents

Stage 2-Resident directors are aware there is an end-of-life curriculum for their residents, but have never thought about adopting the curriculum; they are not personally engaged by the issue.

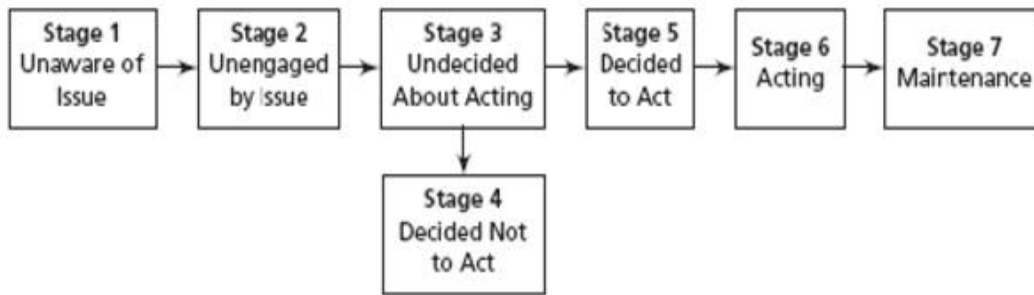
Stage 3- Resident directors are personally engaged about an end-of-life curriculum, but they are undecided about whether to adopt into their own curriculum. If the resident director decides to adopt the end-of-life curriculum they move to stage 5, but if they decide against adopting the curriculum, they move to stage 4.

Stage 4- Decided against adopting the end-of-life curriculum.

Stage 5- Decided to act and implement the end-of-life curriculum for their residents.

Stage 6- Acting by implementing the end-of-life curriculum.

Stage 7- Maintaining the end-of-life curriculum for their residents.  
(Weinstein & Sandman, 2002)



**Figure 4.** Stages of the Precaution Adoption Process Model. (Weinstein & Sandman, 2002) p.125

*Precaution Adoption Process Model Applied to Health*

The PAPM has been applied to a number of health topics. One study of colon cancer screenings examined attitudes and beliefs, perceived vulnerability, and how worried the person was about getting a screening in the future (Costanza et al., 2005).

Individuals were placed into a stage of the PAPM and given intervention materials based on the survey results. Costanza et al. (2005) found that the PAPM, along with physician recommendation, was useful in helping individuals advance through the stages.

Another study used the PAPM for risk reduction surgery decisions in women who were at high risk for breast and ovarian cancer who received genetic counseling. The authors used the PAPM framework for women who were deciding whether to have risk-reduction surgery. Since all of the women had received genetic counseling, they were all aware of the increased risk for cancer. Although the majority of the women “decided not to act” on having risk-reduction mastectomy or oophorectomy, the cross-sectional survey found that decisions could still change on future screening (Ray, Loescher, & Brewer, 2005).

The PAPM was also used in a study determine if people would get a radon test within homes. Weinstein, Lyon, Sandman, & Cuite, (1998), used interventions specifically based on people who were undecided about radon testing (Stage 3), decided to test for radon (Stage 4), and ordering a radon test for the home (Stage 5-6). It was found that the interventions were more effective in helping people move from stage to stage (Weinstein, Lyon, Sandman, & Cuite, 1998)

Although the previous studies show the PAPM used at an individual level involving health issues such as cancer, radon testing, and screenings, the model has also been used at an institutional level. Nims (2008) looked at OB/GYN residency program directors with regard to taking action to formally evaluate tobacco cessation curriculum. Using the PAPM to evaluate an institution's readiness to change, Nims (2008) found that more than half (53%) reported that they program did not have tobacco curriculum and only 8% reported being in the maintenance stage of PAPM. By using the same framework, the PAPM will be used to determine internal medicine residency directors' action in formally evaluating end-of-life care education curriculum.

## **Summary**

End-of-life care involves many different aspects of medicine. This literature review shows that progress has been made in fixing the end-of-life care dilemma surrounding medical education and physician training, but there is still more to do. Problems with time, lack of curricula, physician training, communication, and support for physicians and patients surrounding end-of-life care are being invested poorly. Death and dying will always be realities within the medical field, and whether physicians are prepared through coursework, clerkships, rotations, or mentoring from other physicians,

they must nonetheless be adequately prepared. The literature review has given an overview on problems within end-of-life care education.

## **CHAPTER 3**

### **METHODS**

This chapter presents the methods that will be used to conduct this research. The chapter will focus on the following topics: 1) study design and participants, 2) instrument development, 3) key variables, 4) instrument testing, 5) data collection, 6) data analysis and, 7) summary.

#### **Study Design and Participants**

The study was a cross-sectional, observational study that utilized best practices in survey research. Population sampling was used to obtain potential participants. The participants were all 403 internal medicine residency directors in the United States as of 2015. The names and addresses of the internal medicine residency directors were obtained from the American Medical Association Graduate Medical Education Program Electronic Data product. This list included the contact information for all the programs accredited by the American Medical Association and the Accreditation Council for Graduate Medical Education. In 2015, 49 states had at least one internal medicine residency program accredited by the American Medical Association. The list is updated yearly through the census conducted by the Association of American Medical Colleges Graduate Medical Education.

#### **Instrument Development**

The survey instrument was designed after a comprehensive literature review on the topics of death and dying, end-of-life medical care, physicians' education in end-of-life care, and graduate medical education. Ideas for survey design were derived from

several different studies that assessed medical curricula. Ferry, Grissino, and Runfola (1999) asked associate deans from U.S. medical schools to assess the content and extent of tobacco education and intervention skills in their curricula. Their survey also assessed the number of hours of instruction and whether there was a required clinical application for smoking cessation in the curricula. Ideas regarding how to assess medical curricula were derived from Ferry and colleagues. Price, Mohamed, & Jeffrey (2008) modified the Ferry et al. (1999) instrument to more fully examine smoking cessation education in nurse midwife training programs. Nims et al. (2009) (unpublished dissertation) refined the survey by Price et al., (2008) to assess smoking cessation curricula in U.S. obstetrics and gynecology residency programs.

The survey for the current study consisted of 46 items that were spread across four sections. The last section of the survey was for socio-demographic items. The survey instrument of the current study included theoretical subscales from the Health Belief Model (Rosenstock, 1974), Social Cognitive Theory (Bandura, 1986), and the Precaution Adoption Process Model (Weinstein, 1988).

Part A of the survey included three items and addressed both the barriers to teaching end-of-life topics and the current status regarding having a formal end-of-life education curriculum. More specifically, these items assessed residency programs' PAPM stage of readiness for implementing an end-of-life care curriculum (Weinstein, 1988) and the barriers construct from the Health Belief Model (Rosenstock, 1974).

Part B of the survey instrument included five items that assessed directors' perceptions and beliefs about end-of-life education, including the quality of education that they received. Each item featured a 5-point Likert-type scale that ranged from

“Strongly Agree” to “Strongly Disagree.” This scale was coded as: Strongly Agree=1, Agree= 2, Not Sure= 3, Disagree=4 and Strongly Disagree=5. The potential range of scores for the attitudes and belief scale was 5 to 25.

Part C of the survey instrument featured 14 items that assessed the amount of time residency programs invested in common end-of-life care topics. Directors were asked to place an “X” next to those topics that are taught by their residency program and to estimate how many hours of instruction were provided for each topic. Directors were also asked to indicate whether the residency program formally evaluates residents’ competence in each topical area.

Part D of the survey included four items that asked about the residency programs’ evaluation and teaching techniques for their end-of-life curricula. The fourth item was based on the *outcome expectations* construct from the Social Cognitive Theory (Bandura, 1986). This item assessed director’s perceptions of potential outcomes on clinical care if residents were to execute specific actions. The subscale featured a 5-point Likert-type scale that ranged from “Very Unlikely” to “Very Likely.” The potential range of scores for the attitudes and belief scale was 7 to 35.

### **Key Variables**

The study contained eight primary dependent variables and 8 primary independent variables as delineated in Table 9 below.

Table 9

**Independent and Dependent Variables**

<b><u>Independent Variables</u></b>
Residency type (University sponsored vs. Community based)
Number of Faculty members
Sex of the director
Number of perceived barriers
Residency directors' history of their spouse or loved one experiencing a life-threatening illness
Residency directors' outcome expectation regarding end-of-life curriculum
Quality of education perceived by directors in end-of-life care during their residency program
Number of years as director
<b><u>Dependent Variables</u></b>
Barriers to teaching end-of-life topics to residents
Residency directors' outcome expectation regarding end-of-life curriculum
Evaluation of residents' competence in providing end-of-life care
Teaching techniques used by faculty
Amount of time spent teaching end-of-life topics
Number of teaching topics covered in end-of-life curriculum
Residency Directors' PAPM stage of readiness
Presence of a formal end-of-life curriculum



## **Instrument Testing**

### *Validity*

Face validity of the survey was established by designing the items based on the results of the comprehensive review of the published literature. Face validity was also improved by having an internal medicine residency director carefully review the instrument. Both content and face validity were enhanced by having an external panel of experts (n=5) review the survey and give extensive feedback on readability, content, and use of theoretical constructs. The experts were chosen based on their publication record in the fields of survey research, death and dying, and graduate medical education. A Principal Components Analysis was used to establish the construct validity of the outcome expectations scale (Table 10).

Table 10

**Principal Components Analysis- Outcome Expectations Scale**

**Component Matrix<sup>a</sup>**

	Component
	1
Communicate with the patient and family to establish goals of care	.863
Discuss advance care planning options with the patients and family	.845
Review patients preferences for EOL on a regular basis	.823
Ensure the patient's wishes for EOL are followed	.822
Actively communicate with or seek guidance from healthcare professionals	.808
Integrate palliative care within treatment options for patients nearing EOL	.796
Evaluate the quality of care provided by surveying patients and family	.713

Extraction Method: Principal Component Analysis.

a. 1 components extracted.

### *Reliability*

To establish the internal reliability of the one theoretical subscale, the investigator used the Cronbach's alpha method. The Cronbach's alpha coefficient for the outcome expectations scale was .91.

### **Data Collection**

Prior to the start of data collection, the investigator of for the current study obtained approval from the Institutional Review Board/Human Subjects Committee at the University of Toledo. The data were collected using postal mail, telephone reminder calls, and e-mails. The survey instrument was mailed to the residency directors in multiple waves to maximize return rates (King, Pealer, & Bernard, 2001). The first wave included a personalized cover letter printed on University of Toledo letterhead and hand signed by both the primary investigator and the Residency Director of the internal medicine residency program at the University of Toledo Medical Campus. The first wave also included a copy of the survey, a self-addressed stamped return envelope, and two one-dollar bills as an incentive to increase return rates (Edwards et al., 2002). The survey was printed in booklet format on light blue paper and self-addressed stamped envelopes with unique, colorful stamps were used to increase response rates (King, Pealer, & Bernard, 2001). To track respondents, identify non-responders, and to protect the confidentiality of participants, numeric codes were added to the return mailing address.

The second wave mailing to non-responders was sent two weeks after the first wave mailing and included another personalized cover letter, copy of the survey, and a self-addressed stamped return envelope. A third wave mailing was sent two weeks later

to the non-responders and included a cover letter, another copy of the survey, and a self-addressed stamped return envelope. The third wave cover letter also included a hyperlink that directors could use to access an on-line survey if they preferred. For the fourth and final wave, the investigator called the non-responders by telephone and sent follow up e-mails with instructions for participants to complete the electronic or paper survey.

### **Data Analysis**

Data analysis was conducted using the IBM Statistical Package for the Social Sciences (SPSS), Version 19.0. To reduce type I error, the *a priori* alpha level was set to .05 and post hoc analyses were used when appropriate. Descriptive statistics were used to describe the residency directors, their residency programs, and the end-of-life training curricula. Other statistics such as frequencies, range of scores, means, and standard deviations were used to describe end-of-life training curricula. Independent t-tests, Pearson correlation coefficients, One-way ANOVA, and chi square tests were used to test the specific research hypotheses. Table 11 presents the dependent variable, the independent variable, and the statistical test used for each hypothesis.

### **Summary**

After a literature review, an expert panel review, and pilot testing, the investigator created a valid and reliable questionnaire designed to assess the status of end-of-life education in US internal medicine residency programs. The final questionnaire consisted of 46 items and included constructs from three theories/models. A four wave mailing was completed to all residency directors in 49 states that had accredited residency programs as per the American Medical Association Graduate Medical Education Program Electronic Data.

Table 11

**Statistical Analysis of Hypotheses**

<b>Hypothesis</b>	<b>Independent Variable</b>	<b>Dependent Variable</b>	<b>Statistical Test</b>
1.1	Presence of a formal end-of-life curriculum	Type of program	Chi Square
1.2	Presence of a formal end-of-life curriculum	Number of faculty members	Independent t-test
1.3	Presence of a formal end-of-life curriculum	Number of barriers identified by the director	Independent t-test
1.4	Presence of a formal end-of-life curriculum	Level of outcome expectations of the directors	Independent t-test
1.5	Presence of a formal end-of-life curriculum	Perceived quality of education in end-of-life care received by the directors during their residency program	Independent t-test
2.1	Residency directors' PAPM stage of readiness	Type of program	Chi Square
2.2	Residency directors' PAPM stage of readiness	Number of faculty members	One-way ANOVA
2.3	Residency directors' PAPM stage of readiness	Number of barriers identified by the director	One-way ANOVA
2.4	Residency directors' PAPM stage of readiness	Level of outcome expectations of the directors	One-way ANOVA
2.5	Residency directors' PAPM stage of readiness	Perceived quality of education in end-of-life care received by the directors during their residency program	One-way ANOVA
3.1			Descriptive Statistics
3.2	Number of teaching topics covered (0-12 vs. 13-17)	Number of faculty members	Independent t-test
3.3	Number of teaching topics covered (0-12 vs. 13-17)	Type of program	Chi-Square
3.4	Number of teaching topics covered (0-12 vs. 13-17)	Number of barriers identified by the director	Independent t-test
3.5	Number of teaching topics covered (0-12 vs. 13-17)	Level of outcome expectations of the directors	Independent t-test
3.6	Number of teaching topics covered (0-12 vs. 13-17)	Perceived quality of education in end-of-life care received by the directors during their residency program	Independent t-test

3.7	Number of teaching topics covered (0-12 vs. 13-17)	Residency directors' history of their spouse or loved one experiencing a life-threatening illness	Chi-Square
4.1			Descriptive Statistics
4.2	Type of program	Time spent covering end-of-life topics	Mann-Whitney U
4.3	Number of faculty members	Time spent covering end-of-life topics	Spearman Rho
4.4	Number of barriers identified by the director	Time spent covering end-of-life topics	Spearman Rho
4.5	Level of outcome expectations of the directors	Time spent covering end-of-life topics	Spearman Rho
4.6	Perceived quality of education in end-of-life care received by the directors during their residency program	Time spent covering end-of-life topics	Spearman Rho
4.7	Residency directors' history of their spouse or loved one experiencing a life-threatening illness	Time spent covering end-of-life topics	Mann-Whitney U
4.8	The number of years the director has been practicing medicine after residency	Time spent covering end-of-life topics	Spearman Rho
5.1			Descriptive Statistics
6.1	Type of program	Level of outcome expectations of the directors	Independent t-test
6.2	Residency directors' gender	Level of outcome expectations of the directors	Independent t-test
6.3	The number of years the director has been practicing medicine after residency	Level of outcome expectations of the directors	Pearson
6.4.	Residency directors' history of their spouse or loved one experiencing a life-threatening illness	Level of outcome expectations of the directors	Independent t-test
6.5	Number of barriers identified by the director	Level of outcome expectations of the directors	Pearson
6.6	Presence of a formal end-of-life curriculum	Level of outcome expectations of the directors	Independent t-test
6.7	Perceived quality of education in end-of-life care during their residency program received by the directors	Level of outcome expectations of the directors	Pearson
7.1	Type of program	The number of barriers reported by residency directors	Independent t-test
7.2.	Number of faculty members	The number of barriers reported by residency directors	Pearson
7.3	The number of years the director has been practicing medicine after residency	The number of barriers reported by residency directors	Spearman Rho

7.4	Time spent covering end-of-life topics	The number of barriers reported by residency directors	Spearman Rho
7.5	The internal medicine residency program's policies regarding requiring residents learn end-of-life education	The number of barriers reported by residency directors	Independent t-test
7.6.	Presence of a formal end-of-life curriculum	The number of barriers reported by residency directors	Independent t-test
7.7	Level of outcome expectations of the directors	The number of barriers reported by residency directors	Pearson
7.8	Perceived quality of education in end-of-life care received by the directors during their residency program	The number of barriers reported by residency directors	Pearson
8.1	Whether the residency formally evaluates residents' end-of-life communication skills	The number of years the director has been practicing medicine after residency	Independent t-test
8.2	Whether the residency formally evaluates residents' end-of-life communication skills	Type of program	Chi Square
8.3	Whether the residency formally evaluates residents' end-of-life communication skills	The number of barriers reported by residency directors	Independent t-test
8.4	Whether the residency formally evaluates residents' end-of-life communication skills	Level of outcome expectations of the directors	Independent t-test
8.5	Whether the residency formally evaluates residents' end-of-life communication skills	Perceived quality of education in end-of-life care received by the directors during their residency program	Independent t-test
8.6	Whether the residency formally evaluates residents' end-of-life communication skills	Number of faculty members	Independent t-test

## **CHAPTER 4**

### **RESULTS**

This chapter presents the results of the survey administered to internal medicine residency directors in the United States. The following sections are included: 1) response rate, 2) reliability analysis of survey instrument scales, 3) socio-demographic characteristics of respondents, 4) residency program characteristics, 5) programs' readiness to evaluate end-of-life care curriculum, 6) end-of-life curricula content, 7) teaching techniques used to teach end-of-life care topics, 8) methods of evaluating residents' skill competence in caring for patients at the end-of-life, 9) outcome expectations, 10) barriers to investing more time in teaching end-of-life topics, 11) hypothesis testing and 12) summary.

#### **Response Rate**

Four-hundred and three internal medicine residency programs were identified as being accredited by the American Medical Association Graduate Medical Education Program. Surveys were mailed to all 403 program directors. A total of 211 of 403 returned completed surveys (52.4%).

#### **Internal Reliability of the Outcome Expectations Scale**

The survey featured one theoretical subscale based on Bandura's (1997) construct of outcome expectations. The internal reliability of this scale was established using Cronbach's alpha. The Cronbach's alpha coefficient for this scale was .91.



## **Socio-demographic Characteristics of the Residency Directors**

The internal medicine residency directors can be described as white (70%), male (68%), with a mean age of 53 years (SD=9). The age range of the residency directors was 35 to 80 years (Table 12).

Almost all of the residency directors (98%) were allopathic physicians (MD). Only 2% of directors were osteopathic physicians (DO). Nearly 3 of the 4 directors (72%) had been a residency director for less than ten years. Slightly more than half (55%) had been practicing medicine for at least twenty years. The vast majority of directors (94%) spent 50% or less of their time seeing patients. Of those who did see patients, 60% spent most of their clinical time in an inpatient/hospital setting. Since the start of their medical practices, a plurality of directors (37%) reported that they had referred nine or less patients to palliative care (Table 12).

Because personal experiences may impact work life perceptions and decisions, the investigator asked the directors if they had ever personally been diagnosed with a life-threatening illness and if his/her spouse or other family members had experienced a life-threatening illness. Fifteen percent of directors reported experiencing a life-threatening illness and 62% reported that his/her spouse or another family member had experienced life-threatening illness. Nearly half of the directors (47%) reported that his/her spouse or another family member had used palliative care and/or hospice care (Table 12).

## **Residency Program Characteristics**

The majority of internal medicine residency programs were in an urban setting (66%) and were community based programs (53%) (versus academic programs). A plurality of programs (38%) was small with 9 or less full time faculty members.

Table 12

**Socio-demographic Characteristics of Program Directors**

<b>Item</b>		
	N	(%)
<b>Sex</b>		
Male	140	(68)
Female	67	(32)
<b>Age (M= 53, SD= 9)</b>		
35-39	13	(10)
40-49	56	(24)
50-59	83	(42)
60-69	40	(21)
70+	6	(3)
<b>Race/Ethnicity</b>		
White	144	(70)
Asian	33	(16)
Hispanic	11	(5)
Other	8	(4)
African American	6	(3)
<b>Training Type</b>		
M.D.	203	(98)
D.O	4	(2)

Note: percentages may not equal 100% due to rounding and due to non-responses for specific survey items.

Table 12 Continued Socio-demographic Characteristics of Program Directors

<b>Item</b>	<b>N</b>	<b>(%)</b>
<b>Years as director (M=7.15, SD= 7)</b>		
0-9	149	(72)
10-19	38	(19)
20-29	14	(7)
30+	4	(2)
<b>Years in practice after residency (M=20, SD= 10.5)</b>		
0-9	23	(11)
10-19	68	(33)
20-29	65	(32)
30-39	35	(17)
40+	12	(7)
<b>Professional time seeing patients (M=33%, SD=18)</b>		
25% or less	91	(45)
26% to 50%	100	(49)
51% to 75%	10	(5)
Over 75%	2	(1)
<b>Location of clinical time</b>		
Inpatient setting/hospital	123	(60)
Outpatient clinic affiliated with residency program	44	(22)
Outpatient clinic/private practice	31	(15)
Not a clinician	3	(2)
Other	6	(1)
<b>Number of patients referred to palliative care</b>		
0-9	79	(37)
10-19	50	(24)
20-29	30	(14)
30-39	15	(7)
40+	37	(18)

Note: percentages may not equal 100% due to rounding and due to non-responses for specific survey items

Table 12 Continued Socio-demographic Characteristics of Program Directors

<b>Item</b>	<b>N</b>	<b>(%)</b>
<b>Ever experienced a life threatening illness</b>		
Yes	31	(15)
No	175	(83)
<b>Spouse/family member experienced life threatening illness</b>		
Yes	130	(62)
No	76	(36)
<b>Spouse/family member ever used hospice/palliative care</b>		
Yes	100	(47)
No	106	(50)

Note: percentages may not equal 100% due to rounding and due to non-responses for specific survey items

On the other end of the size spectrum, 37% of programs had 30 or more full time faculty members (Table 13).

In terms of graduates per year over the last three years, a plurality of programs (40%) averaged 10-19 graduates per year over the last three years, with seven programs reporting zero graduates due to being a newly implemented program (Table 13).

Few residency programs (16%) had a required rotation in hospice care while 34% had a required rotation in palliative care. A greater proportion of programs had elective rotations in hospice care (45%) and palliative care (51%). Surprisingly 34% of programs did not offer any type of rotation in hospice care; 31% did not have a structured conference curriculum in end-of-life care topics; and 13% did not offer a rotation in palliative care (Table 13).

#### **Programs' Readiness to Implement an End-of-life Care Curriculum (PAPM stage)**

To assess residency programs' readiness to implement an end-of-life care curriculum, directors were asked to identify which stage of the Precaution Adoption Process Model (PAPM) best described their residency program. Approximately 1 in 4 residency programs (24%) reported not having a formal end-of-life curriculum in place (Stage 1, 2, 3, and 4). Another 39% had either just decided to implement an end-of-life care curriculum or had implemented such a curriculum in the last 3 years (Stages 5 and 6, decided to act/acting). Thus, 63% of residency programs either did not have a formal end-of-life curriculum in place or had just recently implemented one. Only 36% of programs reported having formal end-of-life curriculum in place for more than three years (Stage 7 maintenance) (Table 14).

Table 13

**Residency Program Characteristics**

<b>Item</b>	<b>N</b>	<b>(%)</b>
<b>Residency Location</b>		
Urban	139	(66)
Suburban	61	(29)
Rural	7	(3)
<b>Residency Type</b>		
Academic/University Sponsored	94	(45)
Community based program	112	(53)
<b>Graduates per year for last three years</b>		
0-9	45	(21)
10-19	84	(40)
20-29	33	(16)
30+	49	(23)
<b>Number of full-time physician faculty members</b>		
0-9	80	(38)
10-19	34	(16)
20-29	18	(9)
30+	79	(37)
<b>Rotations in hospice care</b>		
Required	34	(16)
Elective	94	(45)
No Rotation	71	(34)
<b>Rotations in palliative care</b>		
Required	71	(34)
Elective	108	(51)
No Rotation	28	(13)

Table 13 continued Residency Program Characteristics

<b>Item</b>		
	N	(%)
<b>Structured conference curriculum in EOL care</b>		
Yes	137	(65)
No	65	(31)

Note: percentages may not equal 100% due to rounding and due to non-responses for specific survey items

Table 14

**Programs' Readiness to Implement End-of-life care education curriculum (PAPM stage of readiness)**

<b>Stage of PAPM</b>	<b>N</b>	<b>(%)</b>
<b>Stage 1: Unaware.</b> Unaware if the residency program has a formal end-of-life care curriculum	7	(3)
<b>Stage 2: Unengaged.</b> Never seriously thought about implementing a formal end-of-life care curriculum	19	(9)
<b>Stage 3: Undecided.</b> Undecided about implementing a formal end-of-life care curriculum	23	(11)
<b>Stage 4: Decided not to act.</b> Thought about it and decided not to implement a formal end-of-life care curriculum	1	(1)
<b>Stage 5: Decided to act.</b> Recently decided to implement a formal end-of-life care curriculum	23	(11)
<b>Stage 6: Acting.</b> Implemented a formal end-of-life care curriculum in the last 3 years	58	(28)
<b>Stage 7: Maintenance.</b> Have had a formal end-of-life care curriculum for more than 3 years.	76	(36)

Note: percentages may not equal 100% due to rounding and due to non-responses for specific survey items



A one-way ANOVA with Tukey post hoc analyses were used to determine if the number of full time faculty members and number of perceived barriers identified by the director differed in a statistically significant way by the residency programs' PAPM stage of readiness to implement an end-of-life education curriculum. The number of full time faculty members did not differ in a statistically significant way by residency programs' PAPM stage of readiness to implement an end-of-life education curriculum [F (4, 187) = 1.403, p = .235]. However, directors/programs in the acting stage of readiness (i.e. had recently implemented an end-of-life curriculum) reported a lower number of perceived barriers compared to those programs in the unaware/unengaged stage of readiness [F (4,202) = 2.685, p = .034]. Furthermore, it was very interesting to note that residency programs' readiness to implement an end-of-life care education curriculum (PAPM stage) differed significantly by director's perceived quality of education in end-of-life care received during his/her residency program [F (4, 197) = 3.970, p = .004]. A Tukey post hoc test revealed that program directors in the acting stage of readiness reported receiving higher/better quality of education in end-of-life care during residency training than those directors in the unaware/unengaged stages (p = .008). There were no statistically significant differences in directors' outcome expectations by PAPM stage of readiness [F (4, 202) = .430, p = .787].

### **End-of-life Curricular Content and Teaching Time**

Residency Program Directors were asked to report the amount of instructional time their programs invested in five curricular content areas that are found in many end-of-life curricula (Curtis et al., 2001; Stratos, Katz, Bergen, & Hallenbeck, 2006). Those five curricular areas included: 1) communication, 2) ethical issues, 3) socio-cultural

aspects, 4) patient care, and 5) professionalism. Within each of the five curricular content categories, specific topics and skills were listed. Directors were asked to indicate whether the residency program taught each topic and skill and how much teaching time was invested in that topic. Directors were also asked if the residency programs evaluated residents' competence in those skills.

*Communication topics/skills for end-of-life curricula*

Within the overall content area of communication, a plurality of directors (46%) reported that during the 3-year residency program term, their faculty spent 0 to 9 hours teaching these topics. The most prevalent teaching topic/skill in the area of communication was how to deliver bad news in a sensitive way to patients and family members (79%). The two teaching topics/skills that were taught the least were how to discuss the prognosis with patient and family members (31% did not teach the topic) and how to establish patient centered goals of care for seriously ill patients (32% did not teach the topic). Half of the directors reported that their residents' skills in communication were formally evaluated (Table 15).

T-tests were used to determine if the presence or absence of a formal evaluation of residents differed by selected independent variables. Those independent variables included: a) the number of years the director has been practicing medicine after residency, b) the number of barriers reported by the residency directors, c) the level of outcome expectations of the directors, d) the perceived quality of end-of-life education received by the directors during their residency and, e) the number of full time faculty members in the residency program.

Table 15

**Communication Topics/Skills in End-of-Life Curricula: Topics Taught and Time Invested**

<b>Item</b>	<b>N</b>	<b>(%)</b>
<b>Estimated # of hours invested in communication skills during the 3 year residency</b>		
0-9	96	(46)
10-19	42	(20)
20-29	19	(9)
30+	54	(26)
<b>Communication Topics Taught</b>		
How to deliver bad news in a sensitive way to patients and family members	167	(79)
How to make a referral for hospice or palliative care and discuss it	161	(76)
How to discuss prognosis with patient and family members	146	(69)
How to establish patient centered goals of care for seriously ill patients	143	(68)
<b>Formally evaluate residents' competence in topics</b>		
Yes	106	(50)
No	97	(46)

Note: percentages may not equal 100% due to rounding and due to non-responses for specific survey items

Programs that did *not* evaluate residents' end-of-life communication skills had program directors who reported more perceived barriers than programs that did evaluate their residents ( $t = -3.706$ ,  $df = 179.8$ ,  $p < .001$ ). Programs that *did* evaluate residents' competence in communication skills had more full time faculty members than programs that did not evaluate their residents' competence in communication skills ( $t = 2.065$ ,  $df = 171.234$ ,  $p = .040$ ). Interestingly, programs that did evaluate residents' communication skills had directors who reported receiving a higher quality residency education in end-of-life education ( $t = 3.395$ ,  $df = 196$ ,  $p = .001$ ).

A Chi-square test was used to determine the relationship between the presence of formal evaluation of residents' end-of-life communication skills (yes vs. no) and the type of residency program (academic/university sponsored vs. community based programs). Results indicated that there was no statistically significant relationship between the evaluation of residents' end-of-life communication skills and the type of program (academic/university sponsored vs. community based programs) ( $X^2(1, 199) = 3.37$ ,  $p = .066$ ).

#### *Medical Ethics in End-of-Life Curricula*

In the area of medical ethics, directors were asked to report the total amount of teaching time invested during the 3-year residency program. Half of the directors reported that their faculty invested 0-9 hours of total teaching time in the area of medical ethics. Conversely, 23% of the directors reported spending 30 hours or more on ethical issues. In terms of teaching topics the majority of residency programs (63%) did not teach residents how to explain to the patient and family members that future medical treatment may have little benefit and may not extend the length of life. More than half of

the programs (55%) did not formally evaluate residents' competence in the topical area of ethical issues (Table 16).

*Socio-Cultural Topics/Skills for End-of-Life curricula*

Of the five curricular content areas that were assessed, socio-cultural topics related to end-of-life were taught the least. The vast majority of programs (71%) invested 0 to 9 hours of instruction in this area. Although this area was taught the least, 44% of the programs did invest teaching time on grief, bereavement, and mourning and 40% of the programs taught religious and cultural aspects of dying. Nearly 8 of 10 residency programs did not formally evaluate residents' competence in this topical area (Table 17).

*Patient Care Topics/Skills for End-of-Life Curricula*

In the patient care content area, 56% of the program directors reported that residency faculty spent 0 to 9 hours of teaching these topics during three year residency. In contrast, 27% of programs invested 30 or more hours of teaching in this area. The most prevalent teaching topic was how to manage pain in the final months/weeks of life (76% of programs taught this). The least prevalent teaching topic in this content area was how to manage nutrition and hydration in the final weeks of life. More than half (60%) of the program directors reported that their residents were not formally evaluated in this area (Table 18).

Table 16

**Ethical Issues topics/skills for end-of-life curricula**

<b>Item</b>	<b>N</b>	<b>(%)</b>
<b>Estimated # of hours invested in Ethical Issues during the 3 year residency</b>		
0-9	106	(50)
10-19	43	(20)
20-29	14	(7)
30+	48	(23)
<b>Ethical Topics Taught</b>		
How to discuss the withdrawal of life sustaining treatments	158	(75)
How to discuss advance care planning with patients and family members	154	(73)
How to explain to the patient and family members that future treatment is likely to have little benefit or extend length of life	142	(37)
<b>Formally evaluate residents' competence in topics</b>		
Yes	85	40%
No	115	55%

Note: percentages may not equal 100% due to rounding and due to non-responses for specific survey items

Table 17

**Socio-Cultural Aspect topics/skills for end-of-life curricula**

<b>Item</b>	<b>N</b>	<b>(%)</b>
<b>Estimated # of hours invested in Socio-Cultural Aspects during the 3 year residency</b>		
0-9	149	71%
10-19	18	9%
20-29	3	1%
30+	41	19%
<b>Socio-Cultural Topics Taught</b>		
Knowledge of bereavement, grief, and mourning	92	44%
Knowledge of psychological aspects of dying for the patient and family members	90	43%
Knowledge of religious and cultural aspects of dying	84	40%
<b>Formally evaluate residents' competence in topics</b>		
Yes	39	19%
No	162	77%

Note: percentages may not equal 100% due to rounding and due to non-responses for specific survey items

Table 18

**Patient Care topics/skills for end-of-life curricula**

<b>Item</b>	<b>N</b>	<b>(%)</b>
<b>Estimated # of hours invested in Patient Care during the 3 year residency</b>		
0-9	119	56%
10-19	24	11%
20-29	12	6%
30+	56	27%
<b>Patient Care Topics Taught</b>		
How to provide symptom management in the final months/weeks of life	155	74%
How to manage pain in the final months/weeks of life	161	76%
How to manage nutrition in the final months/weeks of life	119	56%
How to manage hydration in the final months/weeks of life	116	55%
<b>Formally evaluate residents' competence in topics</b>		
Yes	75	36%
No	126	60%

Note: percentages may not equal 100% due to rounding and due to non-responses for specific survey items



### *Professionalism Topics/Skills in End-of-Life Curricula*

In the content area of professionalism, 54% of the program directors reported that their faculty members invested 0 to 9 hours of teaching time in this area during three year residency. The most prevalent teaching topic in this area was how to refer to and use other health care resources and personnel at end-of-life (75%). The least prevalent teaching topic was how to stay current in one's knowledge and skills to ensure quality care at end-of-life (42%). Nearly half (45%) reported that their residents were not formally evaluated in this content area (Table 19).

### *Differences in Teaching Time by Selected Program Director and Residency Variables*

A Mann-Whitney U test was performed to determine if teaching time in the end-of-life topics differed by type of program (academic/university sponsored vs. community based program) and by residency directors' history of their spouse or loved one experiencing a life-threatening illness. Results of these analyses revealed that there was no statistically significant difference in teaching time by type of program ( $U(175) = 3286, Z = -1.49, p = .136$ ) or by residency directors' history of their spouse or loved one experiencing a life-threatening illness ( $U(175) = 3365, Z = -.431, p = .667$ ).

Spearman Rho correlation analyses were used to determine if there was a significant relationship between teaching time and selected variables including number of faculty members, number of barriers reported by the director, level of outcome expectations, perceived quality of education in end-of-life care received by the directors during their residency program, and the number of years the director has been practicing medicine after residency. Results indicated there was a moderate, positive correlation

Table 19

**Professionalism topics/skills for end-of-life curricula**

<b>Item</b>	<b>N</b>	<b>(%)</b>
<b>Estimated # of hours invested in Professionalism during the 3 year residency</b>		
0-9	113	54%
10-19	32	15%
20-29	10	5%
30+	56	27%
<b>Number of directors reporting yes to teaching topics below</b>		
How to provide care and communication that features respect, compassion, and empathy	156	74%
How to refer to and use other health care resources and personnel	159	75%
How to stay current in one's knowledge and skills to care for patients at end-of-life	89	42%
<b>Formally evaluate residents' competence in topics</b>		
Yes	103	49%
No	95	45%

Note: percentages may not equal 100% due to rounding and due to non-responses for specific survey items

between the amount of teaching time and perceived quality of education in end-of-life care received by the directors during their residency program ( $r_s = .306$ ,  $p = .001$ ).

A one-way ANOVA was used to determine if there were differences in the number of topics covered in the end-of-life curriculum by the number of full time faculty members in the residency program. Results indicated that there were no significant differences in the number of teaching topics covered by the number of faculty members [ $F(3,200) = .085$ ,  $p = .968$ ].

Chi Square tests was used to determine if there were differences in the number of topics covered by such variables as the type of program (academic/university sponsored vs. community based) and the residency directors' history of their spouse or loved one experiencing a life-threatening illness. Results of the analysis indicated there was no statistically significant difference in the number of topics covered by the type of program ( $X^2(1, 202) = .034$ ,  $p = .854$ ) or by the residency directors' history of their spouse or loved one experiencing a life-threatening illness (yes vs. no) ( $X^2(1, 201) = 1.208$ ,  $p = .272$ ).

T-tests were used to determine if selected dependent variables differed in a statistically significant way by the number teaching topics covered (0-12 and 13-17). Those dependent variables included a) number of barriers identified by the director, b) level of outcome expectations of the directors, and c) the perceived quality of education received by the directors during their residency program. Results of these analyses determined that there were no statically significant differences by number of barriers identified by the director ( $t = 1.233$ ,  $df = 180.780$ ,  $p = .219$ ), by the level of outcome expectations of the directors ( $t = -.618$ ,  $df = 197$ ,  $p = .537$ ), and by the perceived quality

of education received by the directors during their residency program ( $t = -1.196$ ,  $df = 197$ ,  $p = .233$ ).

### **Teaching Techniques Used by Residency Faculty**

Residency directors were asked to identify the various teaching techniques used to teach end-of-life care topics within their residency program. The top three teaching techniques were: 1) teaching by attending physicians during rounds (90%), 2) classroom/conference style teaching (83%), and, 3) teaching by preceptor(s) during outpatient clinic (57%). The least prevalent teaching technique was audio recordings of patient encounters (4%). Participants were invited to select “Other” and write in teaching techniques that were not on the list. The most common write in responses were “OSCE debrief,” “direct observation,” “Team-HPM feedback with family,” “bedside curriculum,” “formal involvement of palliative care team on ICU rounds,” and “palliative care rounds” (Table 20).

### **Evaluation of residents’ skill competence**

The residency directors were asked to identify how they evaluate the residents’ skill competence within their residency program. The most prevalent evaluation method was preceptors give verbal feedback (59%). The least prevalent evaluation method was formal evaluations with audio-taped encounters (2%). It is important to note that 30% of programs did not formally evaluate residents’ skill competence in caring for patients at the end-of-life (Table 21).

Table 20

**Teaching techniques used to teach end-of-life care topics**

<b>Item</b>	<b>N</b>	<b>(%)</b>
Teaching by attending physicians during rounds	189	(90)
Classroom/conference style teaching	176	(83)
Teaching by preceptor(s) during outpatient clinic	121	(57)
Role play	83	(39)
Use of standardized patients	61	(29)
Web-based instruction	31	(15)
Chart reviews with residents	28	(13)
Video recordings of patient encounters	24	(11)
Other	20	(9)
Audio recordings of patient encounters	9	(4)

Respondents were asked to check all items that applied to the residency program; therefore, percentages do not equal 100%.

Table 21

**Evaluate residents' skill competence in caring for patients at the end-of-life**

<b>Item</b>	<b>N</b>	<b>(%)</b>
Preceptors give verbal feedback	125	(59)
Attendings fill out written or electronic evaluations	96	(46)
Preceptors fill out written or electronic evaluations	74	(35)
Do not formally evaluate residents' competence	64	(30)
Observed structured clinical evaluations (OSCE)	41	(19)
Formal evaluations with video-taped encounters	21	(10)
Other	9	(5)
Formal evaluations with audio-taped encounters	4	(2)

Note: percentages may not equal 100% due to rounding and due to non-responses for specific survey items

## **Outcome Expectations**

Residency directors were asked to assess the likely impact on the quality of patient care if their residents performed specific actions with the patients who had life-threatening illness. The majority of directors strongly believed that quality of care to patients would be improved if residents performed the end-of-life care skills listed on the survey. The lowest outcome expectation in the scale was that 68% of directors believed the quality of care would be improved if residents would “*evaluate the quality of care provided by surveying patients and their family members.*” The highest outcome expectation belief was that 94% of directors believed that patient care would improve if residents were to “*integrate palliative care and/or hospice care within treatment options for patients nearing end-of-life*” (Table 22).

Independent samples t-tests were used to determine if outcome expectations differed by selected variables including type of program (academic/university sponsored vs. community based), residency directors’ gender, and number of barriers identified by the director. Results of these analyses indicated that outcome expectations did not differ in a statistically significant way by any of the selected variables.

Pearson correlation analyses were used to determine if there were significant associations between outcome expectations and variables such as the number of years the director has been practicing medicine after residency and the number of barriers identified by the director. Results indicated there were no statistically significant correlations between outcome expectations and the selected variables.

Table 22

**Outcome Expectations**

<b>If your residents were to perform the actions below, how likely is it that each action will actually improve the quality of care provided to patients with a life-threatening illness?</b>	Unlikely		Likely	
	N	(%)	N	(%)
Communicate with the patient and his/her family members to establish patient-centered goals of care for patients nearing the end-of-life	2	(1)	197	(93)
Review patient's preferences for end-of-life care on a regular basis and update documentation	4	(2)	191	(91)
Ensure that patient's wishes for end-of-life care are followed	2	(1)	195	(92)
Discuss advance care planning options with the patient and family members	3	(1)	194	(92)
Integrate palliative care and/or hospice care within treatment options for patients nearing end-of-life.	2	(1)	199	(94)
Actively communicate with and/or seek guidance from health care professionals in other disciplines (e.g. nurses, pharmacists, ethicists, mental health)	6	(3)	178	(84)
Evaluate the quality of care provided by surveying patients and their family members.	17	(8)	144	(68)

Note: percentages may not equal 100% due to rounding and due to non-responses for specific survey items



## Barriers

Slightly more than 1 in 4 directors (27%) believed that there were no barriers to investing more teaching time in end-of-life care. The top three barriers reported by directors were: 1) insufficient time in the residency teaching schedule (46%), 2) lack of faculty members certified in Hospice and Palliative Medicine (26%) and, 3) and lack of rotation sites/lack of preceptors with needed expertise (15%). Directors were invited to select “other” and write in their perceived barriers. Some of the barriers provided by the directors included “difficulty fitting the curriculum into an already packed curriculum,” “high number of existing required rotations,” “completing priorities for selective time,” and “lack of faculty expertise in this area” (Table 23).

Independent samples t-tests were used to determine if number of barriers differed by selected independent variables including type of program (academic/university sponsored vs. community based), presence or absence of a program policy that required residents to learn end-of-life education knowledge and skills, and the presence/absence of a formal end-of-life curriculum. Directors from programs that did not require residents to learn end-of-life education knowledge and skills reported significantly more barriers than directors from programs that did require residents to learn end-of-life education ( $t = -2.939$ ,  $df = 108.098$ ,  $p = .004$ ). Similarly, directors from programs that had a formal curriculum had reported significantly fewer barriers than directors from programs that did not have a formal curriculum ( $t = 2.389$ ,  $df = 205$ ,  $p = .018$ ).

Pearson correlation analyses were used to determine if there was a significant correlation between the number of barriers and selected variables such as perceived quality of education in end-of-life care received by the director during their residency and

Table 23

**Barriers making it challenging for residency to invest more time in teaching end-of-life care topics to residents**

Item	N	(%)
Lack of faculty time/insufficient time in the residency teaching schedule	96	(46)
There are no barriers to investing more teaching time in this topical area	56	(27)
Lack of faculty members certified in Hospice and Palliative Medicine	55	(26)
Lack of rotation sites/lack of preceptors with needed expertise	32	(15)
Our residency program needs to focus on topics that are heavily tested on the board exam	18	(9)
Lack of teaching materials	17	(8)
Other	16	(8)
Residents already feel well prepared in this topical area	13	(6)
End-of-life care training is not required by our accrediting body	8	(4)
Residency faculty would be opposed to investing more time in this topical area	4	(2)

Respondents were asked to check all items that applied to the residency program; therefore, percentages do not equal 100%.

number of full time faculty members. Results indicated there were no statistically significant relationships between the number of barrier and the selected variables.

Spearman Rho correlation analyses were used to determine if there was a significant correlation between the number of barriers and selected variables such as number of years the director has been practicing medicine after residency and time spent covering end-of-life topics. Results indicated there were no statistically significant relationships between the number of barrier and the selected variables.

### **Hypothesis Testing**

Although many of the research hypotheses have been addressed in the results within this chapter, Table 24 provides a detailed depiction of each hypothesis, the statistical test that was used to test the hypothesis, and the results of the statistical testing.

Table 24

**Hypothesis Testing**

<b>Hypothesis</b>	<b>Test Used</b>	<b>Test Statistic</b>
1.1: There will be no statistically significant difference in the presence/absence of a formal end-of-life curriculum by the type of program (i.e. university versus community). (Accepted)	Chi Square	$\chi^2 (1, 202) = .115, p = .735$
1.2: There will be no statistically significant difference in the number of faculty members by the presence/absence of a formal end-of-life curriculum in the residency program. (Accepted)	Independent t-test	$t = -1.289, df = 186, p = .199$
1.3: There will be no statistically significant difference in the number of barriers identified by the directors by the presence/absence of a formal end-of-life curriculum in the residency program (failed to reject)	Independent t-test	$t = 2.389, df = 205, p = .018$
1.4: There will be no statistically significant difference in the outcome expectations of directors by the presence/absence of a formal end-of-life curriculum in the residency program. (accepted)	Independent t-test	$t = -.043, df = 201, p = .966$
1.5: There will be no statistically significant difference in the perceived quality of education received by the directors by the presence/absence of a formal end-of-life curriculum (failed to reject)	Independent t-test	$t = -3.387, df = 175.653, p = .001$
2.1: There will be no statistically significant difference in residency programs PAPM stage of readiness by type of residency program (i.e., university sponsored versus community based). (Accepted)	Chi Square	$\chi^2 (2, 201) = .098, p = .952$

Table 24 continued- Hypothesis Testing

2.2: There will be no statistically significant difference in the number of full-time faculty members of the residency program by the residency program's PAPM stage of readiness to implement a curriculum. (Accepted)	One-way ANOVA	F (4,183) = 1.403, p = .235
2.3: There will be no statistically significant difference in the number of barriers identified by the director by the residency program's PAPM stage of readiness to implement a curriculum (failed to reject)	One-way ANOVA	F (4,202) = 2.658, p = .034
2.4: There will be no statistically significant difference in the outcome expectations of directors by the PAPM stage of readiness to implement a curriculum	One-way ANOVA	F (4,198) = .430, p = .787
2.5: There will be no statistically significant difference in the perceived quality of education received by the directors by the PAPM stage of readiness to implement a curriculum (failed to reject)	One-way ANOVA	F (4,197) = 3.970, p = .004
3.1: The majority of residency programs provide training for less than half (i.e. 9 or less) of the topics listed within their end-of-life curriculum (fail to reject)	Descriptive Statistics	
3.2: There will be no statistically significant difference in the number of faculty members by the number of end-of-life topics(0-12 vs. 13-17) covered in a curriculum (accepted)	Independent T-test	t = -.254, df = 184, p = .800

Table 24 continued- Hypothesis Testing

<p>3.3: There will be no statistically significant difference in the residency type (i.e., university sponsored versus community based) by the number of end-of-life topics covered in a curriculum (accepted)</p>	<p>Chi Square</p>	<p><math>X^2 (1, 202) = .034, p = .854</math></p>
<p>3.4: There will be no statistically significant difference in the number of barriers identified by the director by the number of end-of-life teaching topics (0-12 vs. 13-17) covered in a curriculum (accepted)</p>	<p>Independent T-test</p>	<p><math>t = 1.233, df = 180.780, p = .219</math></p>
<p>3.5: There will be no statistically significant difference in the outcome expectations of the directors by the number of end-of-life teaching topics(0-12 vs. 13-17) covered in a curriculum (accepted)</p>	<p>Independent T-test</p>	<p><math>t = -.618, df = 197, p = .537</math></p>
<p>3.6:There will be no statistically significant difference in the perceived quality of education received by the directors by the number of end-of-life teaching topics(0-12 vs. 13-17) covered in a curriculum (accepted)</p>	<p>Independent T-test</p>	<p><math>t = -.603, df = 197, p = .547</math></p>
<p>3.7: There will be no statistically significant difference in the residency directors' history of their spouses or loved ones experiencing a life-threatening illness by the number of end-of-life topics(0-12 vs. 13-17)covered in a curriculum (accepted)</p>	<p>Chi-Square</p>	<p><math>X^2 (1, 201) = 1.208, p = .272</math></p>
<p>4.1: The majority of residency programs provide 15 hours or less of instruction in end-of-life topics in their curricula (failed to reject)</p>	<p>Descriptive Statistics</p>	

Table 24 continued- Hypothesis Testing

4.2: There will be no statistically significant difference in time reported covering end-of-life topics by residency type (i.e., university sponsored versus community based) (accepted)	Mann-Whitney U	(U (175) = 3286, Z = -1.49, p = .136)
4.3: There will be no statistically significant difference in the number of faculty members and the time reported covering end-of-life topics (accepted)	Spearman Rho correlation	$r_s (191) = -.016, p = .833$
4.4: There will be no statistically significant difference in the number of barriers identified by the director by the amount of time reported covering end-of-life topics (accepted)	Spearman Rho correlation	$r_s (178) = -.109, p = .146$
4.5: There will be no statistically significant difference in the outcome expectations of the directors by the amount of time reported covering end-of-life topics (accepted)	Spearman Rho correlation	$r_s (178) = .075, p = .330$
4.6: There will be no statistically significant difference in the perceived quality of education received by the directors by the amount of time reported covering end-of-life topics (failed to reject)	Spearman Rho correlation	$r_s (178) = .306, p = .001$
4.7: There will be no statistically significant difference in the residency directors' history of their spouse or loved one experiencing a life-threatening illness by the time reported covering end-of-life topics (accepted)	Mann-Whitney U	(U (175) = 3365, Z = -.431, p = .667)

Table 24 continued- Hypothesis Testing

4.8: There will be no statistically significant difference in the number of years the director has been practicing medicine after residency by the amount of time reported covering end-of-life topics (accepted)	Spearman Rho correlation	$r_s (178) = -.087, p = .255$
5.1: The majority of residency programs use at least five of the teaching techniques listed within their end-of-life curriculum (accepted)	Descriptive Statistics	
6.1: There will be no statistically significant difference in the outcome expectations of the director by residency type (i.e., university sponsored versus community based). (accepted)	Independent t-test	$t = -1.137, df = 201, p = .257$
6.2: There will be no statistically significant difference in outcome expectations of the director by residency directors' gender (accepted)	Independent t-test	$t = -1.743, df = 202, p = .083$
6.3: There will be no statistically significant difference in the outcome expectations of the director by the number of years the director has been practicing medicine after residency (accepted)	Pearson correlation	$r (203) = -.063, p = .375$
6.4: There will be no statistically significant difference in the outcome expectations of the director by the residency directors' history of their spouse or loved one experiencing a life-threatening illness (accepted)	Independent t-test	$t = -.922, df = 201, p = .358$



Table 24 continued- Hypothesis Testing

6.5: There will be no statistically significant difference in the outcome expectations of the director by the number of barriers identified by the director (accepted)	Pearson correlation	$r (206) = -.055, p = .431$
6.6: There will be no statistically significant difference in the outcome expectations of the director by the presence of a formal end-of-life curriculum (accepted)	Independent t-test	$t = -.043, df = 201, p = .966$
6.7: There will be no statistically significant difference in the outcome expectations of the director by the perceived quality of education received by the directors (accepted)	Pearson correlation	$r (206) = .045, p = .524$
7.1: There will be no statistically significant difference in the number of barriers identified by the director by residency type (i.e., university sponsored versus community based). (accepted)	Independent t-test	$t = .720, df = 204, p = .473$
7.2: There will be no statistically significant difference in the number of barriers identified by the director by the number of faculty members (accepted)	Pearson correlation	$r (191) = -.058, p = .425$
7.3: There will be no statistically significant difference in the number of barriers identified by the director by the number of years the director has been practicing medicine after residency (accepted)	Pearson correlation	$r (203) = -.070, p = .322$

Table 24 continued- Hypothesis Testing

7.4: There will be no statistically significant difference in the number of barriers identified by the director by the time reported covering end-of-life topics (accepted)	Spearman Rho correlation	$r_s (178) = -.109, p = .146$
7.5: There will be no statistically significant difference in the number of barriers identified by the director by the internal medicine residency program's policy regarding requiring residents learn end-of-life education (failed to reject)	Independent t-test	$t = -2.939, df = 108.098, p = .004$
7.6: There will be no statistically significant difference in the number of barriers identified by the director by the presence/absence of a formal end-of-life curriculum (failed to reject)	Independent t-test	$t = 2.355, df = 205, p = .019$
8.1: There will be no statistically significant difference in the number of years the director has been practicing medicine after residency by whether the residency formally evaluates residents' end-of-life communication skills (accepted)	Independent t-test	$t = -1.138, df = 195, p = .256$
8.2: There will be no statistically significant difference in whether the residency formally evaluates residents' end-of-life communication skills by residency type (i.e., university sponsored versus community based). (accepted)	Chi Square	$\chi^2 (1, 199) = 3.368, p = .066$
8.3: There will be no statistically significant difference in the number of barriers identified by the director by whether the residency formally evaluates residents' end-of-life communication skills (failed to reject)	Independent t-test	$t = -3.706, df = 179.819, p = .000$

Table 24 continued- Hypothesis Testing

8.4: There will be no statistically significant difference in the outcome expectations of the directors by whether the residency formally evaluates residents' end-of-life communication skills (accepted)	Independent t-test	t = 1.211, df = 196, p = .227
8.5: There will be no statistically significant difference in the perceived quality of education received by the directors by whether the residency formally evaluates residents' end-of-life communication skills (failed to reject)	Independent t-test	t = 3.395, df = 196, p = .001
8.6: There will be no statistically significant relationship in the number of faculty members by whether the residency formally evaluates residents' end-of-life communication skills (failed to reject)	Independent t-test	t = 2.065, df = 171.234, p = .040

## Summary

The purpose of the current study was to determine the current status of end-of-life curriculum in US internal medicine residency training programs. This chapter presented the results of the surveys completed by residency directors.

Results indicated that 63% of residency programs either did not have a formal end-of-life curriculum in place or had just recently implemented one. Only 36% of programs reported having formal end-of-life curriculum in place for more than three years. Additionally, 11% of programs are undecided about implementing an end-of-life curriculum. Many programs reported spending nine or less hours of instruction during the entire residency in multiple end-of-life topical areas such as communication (46%), ethical issues (50%), socio-cultural issues (71%), patient care (56%), and professionalism (54%). Residency directors also reported that programs do not formally evaluate residents' competence in areas such as ethical issues (55%), socio-cultural issues (77%), and patient care (60%).

Residency directors were asked if their residents were to perform specific skills if it would improve the quality of care provided to the patients at the end-of-life. Almost all of the directors surveyed agreed that performing specific tasks such as integrating palliative care and/or hospice care within treatment options for patients nearing end-of-life and communicating with the patient and his/her family members to establish patient-centered goals of care for patients nearing the end-of-life would increase the likelihood providing better care at the end-of-life.

The three most prevalent teaching techniques used to teach end-of-life topics were teaching by attending during rounds, classroom/conference style teaching, and teaching

by preceptors during outpatient clinics. The most common method used to evaluate residents' skill competence in caring for patients at end-of-life was verbal feedback by preceptors.

Over a quarter (27%) of the directors reported having no barriers to investing more teaching time in end-of-life care. The most common barriers indicated were lack of time in the teaching schedule (46%), lack of faculty members certified in Hospice and Palliative Medicine (26%), and lack of rotation sites/lack of preceptors with needed experience (15%).

## **CHAPTER 5**

### **CONCLUSIONS**

This chapter contains the following sections 1) summary, 2) discussion, 3) recommendations for future research, and 4) conclusions.

#### **Summary**

This study answered the following research questions:

1. What percentage of internal medicine residency programs in the United States has a formal end-of-life curriculum?
2. In what stage of PAPM readiness are residency programs regarding implementing a formal end-of-life curriculum?
3. What end-of-life topics are taught as part of residency programs' end-of-life curriculum?
4. How much time is invested in residency programs' end-of-life teaching?
5. What teaching techniques do residency faculty members use to teach end-of-life topics to residents?
6. Do residency directors believe that having their residents perform recommended end-of-life skills will result in improved end-of-life care to patients?
7. What barriers do residency directors identify to teaching end-of-life topics to residents?
8. How do residency programs evaluate residents' competence in providing end-of-life care?

## **Discussion**

Physicians play a very important role in the lives of patients, especially those patients who are living with life-threatening or terminal illnesses. When treatment becomes futile and curative approaches give way to palliative and hospice care, patients and their family members rely on physicians to help guide them through this challenging stage of life. Those physicians who are well trained in end-of-life care would seem to have advantages in helping patients at this stage of life compared to physicians who are not well trained. Although end-of-life training of physicians has improved over the years, deficiencies still remain (Institutes of Medicine, 2014). The results of the current study demonstrated that US internal medicine residency programs still have much room for improvement in the area of end-of-life education.

As the incidence of chronic disease continues to increase and the American population continues to age, internal medicine physicians are likely to encounter greater numbers of patients who will be living for years with life-threatening illnesses. Although the demand for quality end-of-life medical care is already present among internal medicine patients, this demand will continue to grow. However, more than 1 in 3 internal medicine programs in the current study (36%) reported that they did not have an end-of-life curriculum.

### *Potential Consequences of Being Under Prepared in End-of-Life Education*

A lack of education and training can have deleterious consequences for both physicians and their patients. For example, newly qualified practicing physicians from multiple specialties who received little to no formal teaching about end-of-life care reported that they learned from “trial and error” or “while doing the job” (Gibbins,

McCoubrie, & Forbes, 2011). Although young professionals in all fields certainly learn from real-world experience, learning by trial and error while providing medical care to physically vulnerable patients is certainly less than desirable. The better option is that physicians would receive high quality training during residency.

### *The Importance of the Skill of Communication*

One of the more important skills that should be taught during residency is how to communicate with patients and their family members about end-of-life issues. Unless death occurs suddenly, most patients living with life-threatening illness eventually reach a point where continued curative style treatments and interventions are no longer beneficial. It is at these junctures in medical decision-making that physicians' communication skills become paramount.

Communication has been listed as one of recommended skill domains for internal medicine physicians (Curtis et al, 2001). It is also a recommended skill domain in end-of-life care training for residency programs (Weissman & Block, 2002). Patients and their family members highly value good communication skills in physicians. During the end-of-life stage, patients and their family members ranked "effective communication with physicians" as their top priority (Virdun, Lockett, Davidson & Phillips, 2015).

Although highly important and highly valued by patients, the results of the current study demonstrated that nearly half of US internal medicine residency programs reported 9 hours or less of instruction in end-of-life communication skills during the 3 year residency period. Likewise, nearly 50% of residency programs did not formally evaluate residents' competence to effectively communicate with patients about common end-of-life topics.



Weak training and evaluation during residency training can certainly lead to a variety of problems. For example, miscommunication and misunderstandings between patients and physicians about prognoses and care options are common at end-of-life (Jenkins et al., 2011). Lack of training and weak evaluation can cause physicians to avoid end-of-life conversations with patients, communicate euphemistically, be overly optimistic, or delay discussions until patients are close to death (Wright et al., 2008).

Physicians' difficulty in communicating with patients and their family members about end-of-life topics has been noted in several research studies. Cardiologists and primary care physicians often do not discuss options with patients with heart failure, partly out of a fear of destroying hope (Shah et al., 2013). Similarly, interviews with physicians whose patients died in the hospital revealed that 86% of the physicians reported knowing that death was imminent for these patients, yet only 11% reported personally speaking with these patients about the possibility of dying (Sullivan et al., 2007). Likewise, a survey of 206 family members who provided care to loved ones at home at the end-of-life stage found that nearly 20% of these patients were never told by health care providers that their illness was incurable or that hospice care was an available option (Cherlin et al., 2005).

Having difficulty talking to patients and their family members about death or avoiding such conversations is likely rooted in the avoidance of death seen in American culture, especially in the culture of medicine (Tucker, 2009). In the culture of medicine, death is often viewed as failure (Gawande, 2014) and dying patients are not considered "good teaching cases" (Sullivan et al., 2003). Such negative attitudes toward death and dying learned in medical school and residency can shape future practice patterns that tend

to devalue the provision of end-of-life care, even though the public increasingly states their desire for such humane medical care at the end of life (Fins & Nilson, 2000).

An example of these attitudes toward end-of-life education can be found in a qualitative study with new, experienced, and retired family medicine physicians (Corker, 2012). The investigator reported that the physicians' end-of-life training could be categorized in three ways: 1) unimportance of death 2) avoidance of death and, 3) discomfort with death among senior physicians. If faculty members and attending physicians view dying patients as poor teaching cases and/or are death avoiding, those attitudes are likely to be transmitted to the next generation of physicians. Improved training in end-of-life care can help physicians identify and address their own attitudes, beliefs, and values surrounding death and dying and their role in perpetrating a medical culture that avoids death. If we expect physicians to provide excellent care and communication to patients who are in the process of dying, then we must equip them with necessary knowledge and skills to do so.

Communication skills can be taught effectively to physicians at various points in their education with minimal extra effort and costs. Such teaching methods during residency training may include direct observation by attending physicians, critique and evaluation of video recordings of physician/patient encounters in the outpatient setting, role play with guided practice, and debriefing sessions after videotaped encounters with standardized patients. For example, the use of role modeling by attending physicians and palliative care team, tutorials, and case-based debriefing sessions created significant improvements in physicians' ability to deliver bad news to patients, increased confidence in conducting family conferences, and increased confidence discussing healthcare proxies

with patients (Seoane et al, 2012). Another way to increase communication training is to include a brief course blended into a two-day retreat that would include lecture, group discussion, and role-play formats. Such a course led to significant improvements in internal medicine residents' ability to deliver bad news to patients (Alexander et al., 2006). Another method of improving communication that has been successful in the past is practice sessions within a small group format that involved simulated patient encounters. This occurred during a two-day retreat and helped residency faculty members increase their comfort level, confidence, and skill in teaching communication skills to residents (Back et al., 2009).

#### *The Importance of Teaching Techniques*

All professional educators know that the techniques and methods used to teach adult learners play a significant role in learning outcomes. The results of the current study indicated that the most common teaching techniques in end-of-life training among US internal medicine programs were the traditional teaching methods found in graduate medical education: verbal teaching by attending physicians during rounds, lecture style teaching during conferences, and teaching by preceptors during outpatient clinic.

Didactic lecture-style teaching is typically passive and lacks the interactivity and learner engagement needed change learner behavior. For example, past research has demonstrated that didactic style teaching commonly found in conference style teaching was not enough to increase physician's skills in conducting DNR discussions with patients (Furman et al., 2006).

Another challenge for residency directors and faculty members in residency programs is that the content of the experiential curriculum is dependent on the pathology

encountered in patients. Therefore, one of the weaknesses in relying on clinical rotations, particularly inpatient rotations, is that the lessons learned by residents are contingent on the diagnoses of those patients who are hospitalized. If the resident sees few patients at the end-of-life stage during that rotation, he/she may not receive adequate exposure in end-of-life topics. This weakness points to the importance of including supplemental end-of-life readings, discussions, and on-line modules during mandatory inpatient rotations in intensive care units and oncology.

In contrast to reliance on traditional teaching methods, the Institute of Medicine (2014) recommends the use of a variety of teaching techniques such as simulations, experiential learning, role playing, team-building exercises, interdisciplinary seminars, use of social media, journal or research clubs, and other nontraditional or supplemental methods of learning. Incorporating different teaching techniques during rounds led by attending physicians may also improve learning and comprehension. Teaching techniques such as broadening (asking “what if” questions), targeting (directing questions at specific team members), up the ladder sequencing (asking the same question to medical student, intern, and then resident) and student as teacher (senior learner trains a junior learner) were found effective and helped facilitate learning among multiple levels of trainees during rounds at a Massachusetts teaching hospital (Certain, Guarino, & Greenwald, 2011).

### *The Importance of Advocacy*

One way to ensure that end-of-life topics are taught to all residents is to advocate that the Accreditation Council for Graduate Medical Education and the corresponding Residency Review Committee for internal medicine programs develop specific curricular

requirements and guidelines for end-of-life topics. Currently, the Liaison Committee on Medical Education (2013) states that “the curriculum of a medical education program must cover all organ systems, and include the important aspects of preventive, acute, chronic, continuing, rehabilitative, and end-of-life care” (p. 10). Although this standard mentions end-of-life care, the requirements are vague and open to interpretation. At present, neither the Accreditation Council for Graduate Medical Education nor the Residency Review Committee for internal medicine residency programs has specific curricular guidelines for end-of-life care. Furthermore, the American Medical Association does not have specific curricular guidelines for end-of-life care.

This lack of emphasis on end-of-life curricular content is also found on the medical licensure exam and the specialty board certification examination. There are few questions on end-of-life topics on the current US Medical Licensing Examination (United States Medical Licensing Examination, 2013). A “blueprint” which provides an overview of 15 areas for the three step examination of licensure does include a few items related to terminal phases of illness, but overall, the content of the exam is lacking in the end-of-life care domain. This is also true of the board certification exam for internal medicine. At present, test items related to hospice and palliative medicine make up only 3% of the total exam items (ABIM, 2013c). Currently, hospice and palliative medicine items make up only 2% of the oncology board exams (ABIM, 2013a). For cardiology certification, hospice and palliative medicine makes up only 1.5% of the total examination and is found within a “miscellaneous” portion (ABIM, 2013b). Based on these statistics, it is easy to see why end-of-life education is a minor priority in residency training.

### *Using Interdisciplinary Teaching and Collaboration to Overcome Barriers*

To increase the amount and quality of education in end-of-life topical areas, internal medicine residency directors would have to overcome some potential barriers. In the current study, directors reported that if they were to attempt to increase education in end-of-life they would face barriers such as insufficient time in the schedule, lack of faculty members certified in Hospice and Palliative Medicine, and lack of rotation sites. Similar barriers were reported by faculty members who were considering the implementation of end-of-life and palliative care education into internal medicine clerkships (Shaheen, Denton, Stratton, Hoellein, & Chretien, 2014). Likewise, lack of funding, lack of time, and busy schedules were also top barriers to implementing end-of-life teaching in an oncology nursing curriculum (Coyne et al, 2007).

There is little debate that internal medicine residency programs are challenged to meet the curricular requirements for continued reaccreditation and to prepare residents for passing their licensure exam. Since lack of time and lack of faculty members are formidable barriers, it would be wise for internal medicine residency programs to build bridges of collaboration with professionals in related disciplines who can help provide teaching in end-of-life topics. For example, residency programs could reach out to local colleges and universities that have professors of Thanatology (i.e. death and dying). These professors could be invited to assist with the development and implementation of end-of-life curricula.

The Institute of Medicine (2014) recommends such an approach. More specifically, the IOM recommends that residency programs use an interdisciplinary approach by exposing residents to the teaching and expertise of nurses, social workers,

death and dying educators, psychologists, and chaplains. Furthermore, exposing residents to an interdisciplinary team approach prepares them to serve as members of interdisciplinary teams in the future.

In the real world of medical practice, an interdisciplinary approach is common and yields significant benefits. For example, a survey of almost 1,200 hospice and palliative care social workers found that most reported being part of an interdisciplinary care team and were actively engaged in communication regarding the patients' psychosocial needs at the end-of-life stage (Weisenfluh & Csikai, 2013). Moreover, hospitals that used chaplaincy services found a 4% lower rate of hospital-based mortality and a 6% higher rate of hospice enrollment among terminally ill patients (Flannelly et al, 2012). Such an interdisciplinary team approach could increase the amount of end-of-life instruction for residents and help overcome some of the primary barriers reported by residency directors.

### **Future Research**

Based on the findings of this study, the investigator would offer the following recommendations for future research:

1. Investigate why governing bodies such as the ACGME, LCME, and AMA do not have specific curricular content recommendations, goals, and learning objectives in end-of-life topics.
2. Investigate other primary care residency programs (i.e. family medicine, pediatrics) to evaluate the current status of end-of-life education.
3. Investigate practicing physicians' self-efficacy, attitudes, perceptions, and practices regarding end-of-life care after residency.

## **Conclusions**

Internal medicine physicians play an important role in treating patients at the end-of-life. With the help of a well-trained, interdisciplinary healthcare team, communication and medical care at the end-of-life can be a much more positive experience for patients and their families. Although there have been improvements over the years in end-of-life training, internal medicine residency programs in the United States still need more improvement.



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APPENDIX A  
Survey Instrument

## The National Study of Internal Medicine Residency Directors

**PART A: Directions.** Listed below are questions about how your residency program may be educating residents about end-of-life care issues (see cover letter for definition). Please mark the answers that best describe your residency program and how you educate residents about end-of-life issues. Thank you.

1. Which of the following statements best describes your residency program's current status regarding having a formal end-of-life care education curriculum? (i.e., by "formal" we mean a required rotation in end-of-life care, including hospice or palliative care and/or a structured conference curriculum). (Please check only one)
  - I am unaware if our residency program has a formal end-of-life care curriculum.
  - Our faculty has never seriously thought about implementing a formal end-of-life care curriculum.
  - We are currently undecided about implementing a formal end-of-life care curriculum.
  - After discussing this, our faculty decided not to implement a formal end-of-life care curriculum.
  - We recently decided to implement a formal end-of-life care curriculum for our residency program.
  - We implemented a formal end-of-life care curriculum in the last three years.
  - We have had a formal end-of-life care curriculum for more than three years.
  
2. Which of the barriers below make it challenging for your residency program to invest more time in teaching end-of-life care topics to your residents? (Check all that apply)
  - There are no barriers to investing more teaching time in this topical area
  - Lack of faculty time/insufficient time in the residency teaching schedule
  - Lack of faculty members certified in Hospice and Palliative Medicine
  - Lack of teaching materials
  - Lack of rotation sites/lack of preceptors with needed expertise
  - Residency faculty would be opposed to investing more time in this topical area
  - End-of-life care training is not required by our accrediting body
  - Our residency program needs to focus on topics that are heavily tested on the board exam
  - Residents already feel well prepared in this topical area
  - Other (please specify) \_\_\_\_\_
  
3. Would it be helpful to residency Program Directors if your accrediting body were to develop specific curricular requirements and skill competencies in the area of end-of-life education? → YES NO NOT SURE

**PART B: Directions.** Please indicate your level of agreement with each of the following statements.

	Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
1. End-of-life care topics are not a curricular priority for preparing residents for success in their future practice.					
2. In general, medical schools prepare students/future residents very well to handle end-of-life care and communication with patients and their family members.					
3. More instructional time in end-of-life care topics is not needed in our residency program.					
4. The vast majority of our residents graduate with a high degree of competence to handle end-of-life care and communication with patients & family members.					
5. Medical school prepared <u>me</u> well to handle end-of-life care & communication for my patients and their families.					
6. My residency prepared <u>me</u> well to handle end-of-life care & communication for my patients and their families.					



**PART C: Directions.** Listed below are specific topics/skills common to end-of-life-care curricula. For each topical category on the left, please estimate how many hours of education your residents receive in that category. For each topic/skill listed in the next column, please put an “X” in the box if the topic/skill is taught in your residency program. Finally, in the far right column, please indicate whether your residency program formally evaluates residents’ competence in that topic/skill (e.g. written evaluations, formal feedback from attendings).

<b>Categories/Time:</b> About how many hours are invested in teaching each category below? (e.g. rotations, conferences, office hours, standardized patients etc.)	<b>Topics/Skills:</b> Does your residency program teach each topic below? If “YES,” please put an X in the box	<b>If topic is taught, put an X in the box.</b>	<b>Evaluate:</b> Do you formally evaluate residents’ competence in these topics?
<p><b><u>Communication</u></b></p> <p>Estimated # of hours invested in this topical area during the 3 year residency?</p> <p>Hours = _____</p>	How to discuss prognosis with patient and family members		<p>YES</p> <p>NO</p>
	How to establish patient centered goals of care for seriously ill patients		
	How to deliver bad news in a sensitive way to patients and family members		
	How to make a referral for hospice or palliative care and discuss it with patient and family members		
<p><b><u>Ethical Issues</u></b></p> <p>Estimated # of hours invested in this topical area during the 3 year residency?</p> <p>Hours = _____</p>	How to discuss advance care planning with patients and family members (e.g. advance directives)		<p>YES</p> <p>NO</p>
	How to explain to the patient and family members that future treatment is likely to have little benefit or extend length of life		
	How to discuss the withdrawal of life sustaining treatments (e.g. ventilator, artificial nutrition and hydration, etc.)		
<p><b><u>Socio-Cultural Aspects</u></b></p> <p>Estimated # of hours invested in this topical area during the 3 year residency?</p> <p>Hours = _____</p>	Knowledge of bereavement, grief, and mourning		<p>YES</p> <p>NO</p>
	Knowledge of psychological aspects of dying for the patient and family members		
	Knowledge of religious and cultural aspects of dying		
<p><b><u>Patient Care</u></b></p> <p>Estimated # of hours invested in this topical area during the 3 year residency?</p> <p>Hours = _____</p>	How to provide symptom management in the final months/weeks of life		<p>YES</p> <p>NO</p>
	How to manage pain in the final months/weeks of life		
	How to manage nutrition in the final months/weeks of life		
	How to manage hydration in the final months/weeks of life		
<p><b><u>Professionalism</u></b></p> <p>Estimated # of hours invested in this topical area during the 3 year residency?</p> <p>Hours = _____</p>	How to provide care and communication that features respect, compassion, and empathy		<p>YES</p> <p>NO</p>
	How to refer to and use other health care resources and personnel (e.g. hospice, palliative care, long term acute care).		
	How to stay current in one’s knowledge and skills to care for patients at end-of-life		

**PART D: Directions.** Please mark the answers that best describe your residency program. Thank You!

1. Which of the following teaching techniques are used by residency faculty members to teach your end-of-life care topics? (*Check all that apply*)

Teaching by preceptor(s) during outpatient clinic       Teaching by attendings during rounds  
 Role play       Use of standardized patients  
 Web-based instruction       Chart reviews with residents  
 Audio recordings of patient encounters       Video recordings of patient encounters  
 Classroom/conference style teaching       Other, (please specify) \_\_\_\_\_

2. How does your program evaluate residents' skill competence in caring for patients at the end-of-life stage? (*Check all that apply*)

We do **not** formally evaluate residents' competence in end-of-life communication and clinical skills.  
 Preceptors give **verbal** feedback.  
 Preceptors fill out written or electronic evaluations based on residents' outpatient performance.  
 Attending physicians complete written or electronic evaluations based on inpatient performance.  
 Formal evaluation of **video-taped** encounters with patients and/or standardized patients.  
 Formal evaluation of **audio-taped** encounters with patients and/or standardized patients.  
 Observed structured clinical evaluation (OSCE) for end-of-life communication/counseling skills.  
 Other (please specify): \_\_\_\_\_

3. How does your program evaluate/assess residents' cognitive knowledge of how to care for patients at the end-of-life stage? (*Check all that apply*)

We do **not** formally evaluate residents' knowledge in this topical area.  
 Residency faculty members provide informal feedback regarding residents' knowledge.  
 We formally assess residents' knowledge via written and/or on-line assessments/exams.  
 Other (please specify): \_\_\_\_\_

4. If your residents were to regularly perform the actions below with patients that have a life-threatening illness, how likely is it that each action would actually improve the quality of care provided to these patients? (Put an "X" in the column that best matches your opinion)

How likely is it that each action below will actually improve the quality of care for patients with life-threatening illness?	Very Unlikely	Unlikely	Not Sure	Likely	Very Likely
Communicate with the patient and his/her family members to establish patient-centered goals of care for patients nearing the end-of-life					
Review patient's preferences for end-of-life care on a regular basis and update documentation					
Ensure that patient's wishes for end-of-life care are followed					
Discuss advance care planning options with the patient and family members					
Integrate palliative care and/or hospice care within treatment options for patients nearing end-of-life.					
Actively communicate with and/or seek guidance from health care professionals in other disciplines (e.g. nurses, pharmacists, ethicists, mental health)					
Evaluate the quality of care provided by surveying patients and their family members.					

Please turn page



**PART E: Directions** - Listed below are questions about demographic factors. Please provide the requested information. Thank you.

**Residency Program Information**

1. Residency Location: (*circle one*)    Urban                      Suburban                      Rural
2. Residency Type: (*circle one*)        Academic/University sponsored        Community based program
3. How many *graduates per year* have you **averaged** for the **past three years**? \_\_\_\_\_ graduates per year
4. How many **full-time** equivalent (FTE) **physician faculty members** are employed by the residency program?  
\_\_\_\_\_ FTE faculty
5. Does your residency program have a **required rotation, elective rotation or no rotation** in each of the following?
  - a. Hospice care .....    \_\_\_ Required    \_\_\_ Elective    \_\_\_ No rotation
  - b. Palliative care .....    \_\_\_ Required    \_\_\_ Elective    \_\_\_ No rotation
6. Does your residency program have a **structured conference curriculum** in end-of-life care? (i.e. learning objectives, organized and regularly scheduled topics) .....    Yes    No

**Demographic & Background Information: The following information pertains to you.**

1. Degree: (*circle all that apply*)    M.D.    D.O.    PhD    Other: \_\_\_\_\_
2. Sex:        Male                      Female
3. Race/Ethnicity:    White    African American    Hispanic    Asian    Other (*please specify*) \_\_\_\_\_
4. Age: \_\_\_\_\_ years old.
5. If you are **NOT** a director, what is your title: \_\_\_\_\_
6. If you **ARE** the director, how many **years** have you been **the director** of this program? \_\_\_\_\_ years
7. If you **ARE** the director, number of **years** you have been practicing medicine **AFTER** residency? \_\_\_\_\_ years
8. What percent of your professional time is spent seeing patients? \_\_\_\_\_ % of my time.    \_\_\_ Not applicable
9. If you **ARE** a clinician, where do you spend most of your time? (*please check one*):  
 \_\_\_\_\_ I am not a clinician  
 \_\_\_\_\_ Inpatient setting/hospital  
 \_\_\_\_\_ Outpatient clinic/private practice  
 \_\_\_\_\_ Outpatient clinic affiliated with the residency program  
 \_\_\_\_\_ Other (*please specify*): \_\_\_\_\_
10. If you are the director, in the past year, how many patients have you referred to palliative care services? \_\_\_\_\_
11. Have you ever experienced a life-threatening illness? (e.g. cancer) .....    \_\_\_ Yes    \_\_\_ No
12. Has your spouse or another family member ever experienced a life-threatening illness?.....    \_\_\_ Yes    \_\_\_ No
13. Has your spouse or another family member ever used hospice or palliative care services? ..    \_\_\_ Yes    \_\_\_ No

*Thank you for completing the survey! Please return it within 7 days in the self-addressed, postage paid envelope that we provided to you. Thank you.*

APPENDIX B

Cover Letter of First Mailing

Date  
Name  
Address  
City, State, Zip

Dr. Name:

Greetings from the University of Toledo in Ohio! You have been selected to participate in an important national study of US internal medicine residency programs. The purpose of this study is to gather information about how residency programs' teach end-of-life care topics (i.e. communicating with and providing medical care to patients who are near the end of life).

**We need your help.** Please complete the enclosed survey and **return it to us within 10 days.** Your responses on the survey are very important! By responding, you will help advance the field of internal medicine residency training. *If you participate, we will also send you a detailed and comprehensive report of the results.*

Enclosed is a survey on light blue paper. The survey takes approximately **10 minutes** to complete. As a token of our appreciation, we have **enclosed a \$2 bill for your time.** Although it's not much, perhaps you can purchase a coffee or cold drink "on us." To make the process even more convenient, we have enclosed a self-addressed, stamped envelope.

Your survey responses are **totally confidential.** Only aggregate data from all participating residency programs will be reported. Your completion of the survey represents your informed consent for participation. If you decide not to participate, there will be no penalty or any loss of benefits to which you would be otherwise entitled.

Should you have any question regarding this study, please contact Derek Cegelka by e-mail at [Derek.Cegelka@rockets.utoledo.edu](mailto:Derek.Cegelka@rockets.utoledo.edu) or by phone at (XXX) XXX-XXXX. If you have questions regarding your rights as a research participant, please contact the Chairperson of the SBE Institutional Review Board at (419) 530-2844.

Thank you for your professional courtesy.

Sincerely,

Ragheb Assaly, MD  
Program Director  
University of Toledo Medical  
Center

Timothy Jordan, PhD  
Professor  
University of Toledo

Derek Cegelka, MPH, CHES  
Doctoral Student  
University of Toledo

APPENDIX C

Cover Letter of Second Mailing

Date  
Name  
Address  
City, State, Zip

*Re: 2<sup>nd</sup> Request for Survey - National Study of Internal Medicine Residency Directors*

Dear Name:

**We need your help!** A couple weeks ago, we mailed to you a letter, survey on light blue paper, and two \$1 bills. In that letter, we asked you to complete a survey regarding your residency program's curriculum and training methods in end-of-life care.

We have not yet received your completed survey. Perhaps you never received our first mailing. Perhaps you misplaced the original survey or thought it was too late to complete the survey. It is **not too late.**

For your convenience, we have enclosed another copy of the survey. We have also enclosed a second postage paid envelope. Completing the survey requires approximately **9 minutes.**

If you would be so kind, please complete the enclosed survey as soon as possible. You may also return the survey by FAX @ 419-530-4759 (Attention Dr. Timothy Jordan).

Should you have any question regarding this study, please contact Derek Cegelka by e-mail at [Derek.Cegelka@rockets.utoledo.edu](mailto:Derek.Cegelka@rockets.utoledo.edu) or by phone at (XXX) XXX-XXXX

Thank you for completing and returning the survey. We really appreciate your help!

Sincerely,

Rahgeb Assaly, MD  
Internal Medicine Director  
University of Toledo Medical  
Center

Derek Cegelka, MPH,  
CHES  
Doctoral Student  
University of Toledo

Timothy Jordan, PhD  
Professor of Public Health  
University of Toledo

APPENDIX D

Cover Letter of Third Mailing



Date  
Name  
Address  
City, State, Zip

***Third Request for Survey - National Study of Internal Medicine Residency Directors***

Dear Name:

Greetings from the University of Toledo in Ohio! Over the past month, we have attempted to contact you by mail on two previous occasions. The previous two mailings included a survey (on blue paper) and a postage paid return envelope. The first mailing also included two \$1.00 bills as a token of our appreciation for completing the survey.

***Unfortunately, we have yet to receive your completed survey.***

**We really need your help!** You were one of the internal medicine residency directors selected to participate in this very important study. The goal of this national study is to identify what US internal residency programs are teaching regarding end-of-life topics.

Your ideas and perceptions are very important to us! It is not too late to complete and return the survey to us. The survey takes approximately **9 minutes** to complete. Please return the survey in one of the postage paid envelopes that were included in our first two mailings. ***Thank you!***

**NOTE:** If it is easier for you to complete this survey online, please type this URL into your web browser:

**<http://tinyurl.com/ptfxfrf>**

Should you have any question regarding this study, please contact Derek Cegelka:

Email: Derek.Cegelka@rockets.utoledo.edu      Phone: (XXX) XXX-XXXX

Sincerely,

Rahgeb Assaly, MD  
Internal Medicine Director  
University of Toledo Medical  
Center

Derek Cegelka, MPH,  
CHES  
Doctoral Student  
University of Toledo

Timothy Jordan, PhD  
Professor of Public Health  
University of Toledo