END-OF-LIFE EDUCATION EXPERIENCES OF RESPIRATORY THERAPISTS: IMPLICATIONS FOR UNIVERSITY LEADERSHIP

by

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A Dissertation Proposal Submitted to the Faculty in the Educational Leadership Program of Tift College of Education at Mercer University in Partial Fulfillment of the Requirements for the Degree DOCTOR OF PHILOSOPHY

Atlanta, GA 2017
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DEDICATION

This writing is dedicated to my beautiful wife, Clara Smith Zimmerman, and our two children Calder and Olivia. Thank you for sticking by me during the times of stress, exhaustion, and writers block. I love you all very much.

To Grayson and Millie Blue, whose boundless energy and unconditional love never failed to put a smile on my face at 5 a.m.

And to my father, Ralph David Zimmerman, Sr., who was tasked with the burden of teaching me about the phenomenon of death and dying at much too young of an age.

Any man’s death diminishes me,
Because I am involved in mankind;

- John Donne, 1623
ACKNOWLEDGEMENTS

The author would like to thank the members of his dissertation committee for their constant support, direction, and constructive criticism during the course of this dissertation.

First and foremost, I would like to acknowledge the support of my dissertation chair, Dr. Elaine Artman, for all of her patience and support. It has been quite a long journey, and I cannot thank you enough for the encouragement and faith you have shown in me these years. You are a true teacher in every sense of the word, and I am forever in your debt.

I am also grateful to Dr. Carol Isaac, my methodologist, for opening my eyes to the world of qualitative research as seen through the lense of interpretive phenomenological analysis. Your advice was often given not just as a member of my committee, but as that of a fellow clinician. I will be forever grateful to you for your patience and generosity.

I am indebted to Dr. Olivia Boggs for her guidance during this undertaking, and for all of the advice she has given me these last few years. Somehow, you always manage to make your students enjoy learning, although it’s 10 p.m. on a Thursday night at the end of a very long week.

In addition, I would like to acknowledge the support of several colleagues who acted as sounding boards during my research. Drs. Doug Gardenhire and Lynda Goodfellow and Professor Brent Murray. Thanks for pushing me when you knew it was time.
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ABSTRACT

RALPH DAVID ZIMMERMAN, JR.
END-OF-LIFE EDUCATION EXPERIENCES OF RESPIRATORY THERAPISTS: IMPLICATIONS FOR UNIVERSITY LEADERSHIP
Under the direction of ELAINE ARTMAN, Ed.D.

The study addressed the problem of the implications surrounding a lack of end-of-life education in the respiratory therapy curriculum. Respiratory Therapy programs need to integrate therapists’ lived experiences with palliative care into their educational programs in an effort to facilitate an improved level of end-of-life care and teach future therapists how to better deal with the stress associated with witnessing death in the clinical setting (Giordano, 2000).

Using the qualitative approach of interpretive phenomenological analysis, the research was conducted at a large public university. Subjects who had graduated within the past three to 5 years were recruited by email and recorded interviews were transcribed, analyzed, and coded. Superordinate, sub-superordinate, and emergent themes were defined and used to analyze the transcribed interviews.

The researcher identified three superordinate themes that addressed the research question: (a) Needs for the Patient (b) Needs for the Family (c) Needs for the Care Provider. Sub-superordinate themes included Suffering, Time, and Honesty (under needs for the patient); Support, Compassion, and Engagement (under needs for the family); Memorable Experiences, Coping, Stress, and Education (under needs for the care
provider).

Results of the study show that a lack of end-of-life education in the respiratory therapy curriculum can impact therapists, patients, and family members. Practicing respiratory therapists desire more education on how to care for dying patients in order for this impact to be lessened. Recommendations for further study include expanding the size of the study to include other regions of the country and surveying programs to ascertain the amount of end-of-life education students are receiving during their education.
CHAPTER 1
INTRODUCTION

Much of the published work regarding end of life education among healthcare professionals seems to speak to the inadequacy of existing programs (Aulino & Foley, 2001; Field & Cassel, 1997; Giordano, 2009; Schlair et, 2009; Stoller, 2001). Common findings include an overall lack of palliative education, the idea that where it does exist, it may be woefully inadequate, and that allied healthcare professionals would in fact benefit from such training (Carter & Guthrie, 2007; Mallory, 2003; Robinson, 2004; Roberts & Boyle, 2005; Hegedus, Zana & Szabo, 2008). In their study of multidisciplinary end of life training of Pediatric Intensive Care workers, Roberts and Boyle (2005) assess that although allied health workers may be “introduced to this topic as students, they have limited opportunities to put this theoretical knowledge into practice until they have graduated” (p. 57). The authors imply that lack of an adequate curriculum currently places the burden of education on the employing organization through continuing education seminars.

Schwenzer and Wang (2006) found that many factors regarding end of life patient care were significant stressors and could impact the desire and ability of the professional to continue working at a particular facility. Such data would seem important not only to
hospital administrators and human resource professionals, but to the practitioners as well as the patients themselves, all of who are stakeholders in regard to the delivery of appropriate palliative care. Solidifying this line of thought is the finding by Willms and Brewer (2005) that 96% of respiratory therapists surveyed stated that they had personally removed ventilator support as part of the terminal extubation process, and that the respondents claimed to have done so an average of 33 times during the course of their professional career (p. 1047). According to documents released by the National Board for Respiratory Care, end-of-life care is not listed in the matrix for any of the three sets of national board examinations a respiratory therapist must pass in order to become registered (“Clinical Simulation Examination Detailed Content Outline,” 2010, “Entry Level CRT Examination Detailed Content Outline,” 2009, “Therapist Written RRT Examination Detailed Content Outline,” 2010). Only if a therapist chooses to sit for the advanced credential of Neonatal/Pediatric Specialist is the topic addressed in a maximum of two of the 120 examination questions (“Neonatal/Pediatric Specialist Examination Detailed Content Outline,” 2011).

Research Problem

In an effort to help provide improved end-of-life care and teach future practitioners how to better deal with the stress of caring for dying patients, RT programs need to integrate therapists’ lived experiences with palliative care into all degree levels of education (Giordano, 2000).
Research Questions

Major Research Question: What are the lived experiences of respiratory therapy students regarding palliative care situations?

The following sub-questions were used to gather the information necessary to answer the major research question:

1. How do recent RT graduates perceive their ability to perform end-of-life tasks?
2. To what extent are recent RT graduates emotionally affected by a lack of end-of-life education?
3. To what extent do recent RT graduates believe that their ability to perform their jobs effectively is influenced by their experience with end-of-life education?
4. To what extent do recent graduates perceive that the current program adequately addresses the issue of End-of-Life Education?

Theoretical Framework

While only a small amount of published literature is available regarding the psychological affect caring for dying patients may have on respiratory therapists, a number of researchers have concluded that providing such care may result in the creation of both a moral and emotional stress (Giordano, 2000; Schwenzer & Wang, 2006; Willms & Brewer, 2005). The theoretical framework for this study will be based upon Resilience Theory as it applies to the ability of healthcare workers to cope with the various forms of stress and adversity that may accompany providing end-of-life patient care.
Numerous definitions of human resilience may be found in the literature; perhaps one of the most inclusive was written by Egeland, Carlson, & Stroufe in 1993. The authors noted that resilience is “the capacity for successful adaptation, positive functioning or competence…despite high-risk status, chronic stress, or following prolonged or severe trauma” (p. 517). A second notable description of resilience was written by Kaplan (1996) who stated that the process of resilience involves “the presence of protective factors…that help an individual counter and resist the effects of personal vulnerabilities and environmental hazards” (p. 158). Kaplan stated “these protective factors make up the complex of a person’s resilience potential at any given time” (p. 158).

Respiratory therapy practitioners who deal with death on a regular basis are most likely to function in areas such as hospital emergency departments and/or intensive care units, where other forms of job-related stress may be experienced simultaneously (Wunsch, Linde-Zwirble, Harrison, Barnato, Rowan, & Angus, 2009; Gates, Gillespie, & Succop, 2011). Limited control is often available over the situation itself, as even the most valiant resuscitative efforts may result in a negative outcome (American Heart Association, 2011). Research into Resilience Theory has identified a number of response patterns and personal descriptors that may explain why some practitioners are able to persist in the face of moral and/or emotional trauma and continue to perform their jobs effectively over time (Barnard, 1994; Cyrulnik, 2011; McCubbin, Cauble, & Patterson, c1982; Polk, 1997; Southwick & Charney, 2012).
Procedures

The procedures used in this study will be phenomenological in nature and include a series of interviews with students who have graduated from respiratory therapy school within the last five years. The information being examined during this study involves the experiences of respiratory therapists while caring for dying patients in an effort to determine their perception of whether or not their respective educational programs prepared them for participating in end-of-life care and to determine the lived experiences of Respiratory Therapists with regard to participating in end-of-life care.

Semi-structured face-to-face, telephone, or videoconference interviews utilizing open-ended questions will be conducted using with all subjects in order to collect the necessary data. The site chosen for the study is considered to be the number one degree granting institution in the United States (“HSC NEWS - Respiratory care program ranks No. 2 in U.S. survey,” 2004). The Only students graduating with a Bachelor’s degree or an entry-level Master’s degree are being selected in this study in an effort to increase compliance with the 2015 Initiative, which is a move by the accreditation body of the respiratory care profession to limit the number of Associate’s Degree programs after the year 2015 in order to promote the importance of advanced educational degrees in the field. Analysis will occur utilizing Palmer, et al.’s (2010) eight-step protocol for Interpretative Phenomenological Analysis (IPA).

Purpose of the Study

The purpose of this study is to better understand the lived experiences of respiratory therapists who provide end-of-life care to their patients.
Definition of Terms

Respiratory Therapist: a healthcare practitioner who treats and cares for patients “with breathing or other cardiopulmonary disorders” and “under the direction of a physician assume(s) primary responsibility for all respiratory care therapeutic treatments and diagnostic procedures…Therapists also provide complex therapy requiring considerable independent judgment, such as caring for patients on life-support in intensive-care units of hospitals” (United States Department of Labor, 2011).

Inhalation Therapist: Term used to describe the work of a respiratory therapist in the earlier days of the profession (Sellery, 1971).

Palliative Care: an approach that improves the quality of life of patients and their family facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Health Organization, 2011).

End-of-Life Education: education aimed at instilling healthcare providers with the social, physical, and emotional tools necessary to provide proper palliative care to their patients and obtain an understanding of the coping mechanisms associated with caring for the dying (Yale School of Medicine, 2011).

Terminal Extubation: the withdrawal of mechanical ventilatory support from a patient who is expected to die as a result of the removal of support (Truog et al., 2001).

Limitations

In an attempt to diminish any unintended bias that may result from the
researcher’s experience, full disclosure will be made available to all parties. Member checking will also be performed in an effort to mitigate any potential bias by allowing the interviewees to review their statements and suggest revisions if necessary. There are bound to be aspects of the subjects’ feelings toward end-of-life education that may not be revealed during the interview process. The process of analyzing collected data may be unintentionally influenced by the author’s own experiences in the field (both personal and professional). The subjects’ response to interview questions may be influenced to some degree by the presence of the researcher. Experience with end-of-life care, both personal and academic, may vary from one individual to the next or from region to region. The results of this study may not be applicable to all states, as laws impacting end-of-life care vary. The use of telephone interviews will not allow the researcher to pick up on visual cues that may be apparent during face to face and audio/video interviews.

Delimitations
The proposed study will be conducted with the following delimitations:

1. Only respiratory therapists who have graduated in the last five years and are currently working in the field will be interviewed.
2. The participants will be affiliated with respiratory therapy programs, which may affect the ability to transfer findings among other allied health professions.

Significance of the Study
The results of this study may inform program directors on needs within the realm
of end-of-life education. Any information regarding the ability to reduce stress
associated with palliative care may have a positive effect on the attitudes nurses and
allied health professionals have toward their careers, thereby increasing job satisfaction
and length of employment (Schwenzer, 2006).

This study has the potential to affect Respiratory Therapy education programs,
students, and administrators as well as hospital administrators and patients by influencing
attitudes toward the provision of end-of-life education in the respiratory therapy
curriculum. If a definitive link between lack of end-of-life curriculum and negative
impact upon subjective job performance or emotional well-being among respiratory
therapists is shown, program administrators may change in program requirements in an
effort to fill the educational needs of future graduates via curriculum change or on-
campus post-graduate continuing education programs. Considering the link between
emotional burnout and job turnover (du Plooy & Roodt, 2010; Laschinger, Leiter, & Day,
2009; Leiter & Maslach, 2009), hospital administrators may find the results interesting as
well since they regularly hire new graduates. Last, the terminally ill and their families
may be affected by any curriculum change that allows a significant member of their
healthcare team to exhibit better job performance.

Summary

Considering the inadequacy of current levels of end-of-life education among
allied health workers, both educators and hospital administrators should consider the
implications of inadequate levels of training (Barrere, Durkin, & LaCoursiere, 2008; Judy
L. Mallory, 2003; Willms & Brewer, 2005). Much of the research in end-of-life
education involves either physician-or-nurse training programs (Giordano, 2005). Chapter two provides a review of literature in the field of end-of-life education among members of the healthcare team and summarizes research on the topic in order to support the statement of the problem and need for the study.
CHAPTER 2
REVIEW OF THE LITERATURE

This chapter is designed to provide a review of literature in the field of end-of-life education among members of the healthcare team and summarizes research on the topic in order to support the statement of the problem and need for the study. Topics covered include human resilience and resilience theory, which will be the basis for the theoretical framework for the proposed study. A review of resilience as it relates to healthcare practitioners is also included. In addition, a review of moral distress is included, as well as a review of end-of-life research, which includes a review of multiple theories on death and dying. Other topics covered include the role of respiratory therapists in the healthcare setting and end-of-life education in both the allied health and nursing curricula.

Resilience Theory

VanBreda (2001) describes resilience theory as “a multifaceted study that has been addressed by social workers, psychologists, sociologists, educators and many others” (p. 1). The author goes on to state that “the field of resilience…in some aspects is well developed and explored…in others it is still nascent” (p. 2). VanBreda also lists a number of factors researchers have found to be associated with personal resilience over the years, including a sense of coherence, the ability to thrive, hardiness, potency, stamina, and personal causation. The origins of resilience theory appear to lie in the
psychological evaluation of children who were able to remain resilient despite having to overcome a number of adversities in childhood (VanBreda, 2001).

Definition of Resilience

The American Psychological Association (APA) defines resilience as “the process of adapting well in the face of adversity, trauma, tragedy, threats or significant sources of stress” (American Psychological Association, 2015). The APA goes on to state that while resilience is not considered to be a trait that individuals either possess or do not possess, but a combination of “behaviors, thoughts, and actions that can be learned and developed in anyone” and that “research has shown that resilience is ordinary, not extraordinary.” The APA lists the following factors as being associated with resilience (APA, 2015):

1. Having caring and supportive relationships within and outside the family.
2. The capacity to make realistic plans and take steps to carry them out.
3. A positive view of oneself and confidence in your strengths and abilities.
4. Skills in communication and problem solving.
5. The capacity to manage strong feelings and impulses.

Similar factors were described in a 2007 concept analysis of resilience by Earvolino-Ramirez. These include the presence of at least one positive relationship with another person, the presence of an informal social support network, and the ability to have close relationships (p. 75), which describe the importance of supportive relationships. The author further found factors that relate to the impact of a realistic
outlook, such as the presence of healthy expectations/needs and the characteristic of being future-oriented (p. 75). Also listed were a sense of personal worthiness and a belief in his or her self-efficacy (which relates to a positive view of oneself), effective communication, assertiveness, above-average social intelligence, problem-solving ability, and productive critical thinking skills (highlighting the importance of communication and problem-solving skills), and a good-natured temperament accompanied by above-average social intelligence, interpersonal sensitivity, and the ability to manage a range of emotions.

Resilience Among Healthcare Practitioners

As the current generation of healthcare providers continues to age out of workforce at an alarming rate, practicing professionals will begin to face even greater workplace stress due to staff shortages (Lowe, 2013). Recent outbreaks of diseases such as influenza and Severe Acute Respiratory Syndrome (SARS) also act to produce chronic stress among healthcare practitioners (Maunder, et al. 2008).

Resilience Among Nurses

The American Nurse’s Association (ANA) considers both burnout and compassion fatigue to be a risk to the career span of current practicing nurses (ANA, 2010). In a position statement on providing end of life patient care, the ANA stated that these risks could be reduced by the adoption of mechanisms such as social support and physical self-care (ANA, 2010, p. 28). Cope, Jones, and Hendricks (2014) claim that the combined effect of high stress levels in the nursing profession lead to “burnout; high attrition of nurses; and an environment no conducive to retention and or job satisfaction”
The eight themes assigned by the authors in the qualitative study designed to uncover characteristics of resilient nurses included managing self, focusing on the positive, valuing social support, paying it forward, a passion for the profession, the taking on of challenge, experiencing adversity and growing through it, and leadership (p. 3).

In a 2013 review of workplace stressors and the impact they have on nurses, Lowe concludes that increasing pressure on the current system of healthcare in the United States will bring about a necessity for the creation of “caring, healing work environments” aimed at increasing resilience among practicing nurses. Lowe suggested using Watson’s theory of caring as a foundation on which to build a system that would allow nurses to succeed in the face of occupational stress. Watson’s theory considers the importance of the caregiver, or nurse, and the impact one’s well-being has on both their patients and themselves. The author suggests giving special attention to Watson’s three main theoretical components of carative factors, the transpersonal caring relationship, and the caring occasion (Lowe, p. 54). Carative factors are described as those that foster individual well-being, such as faith or spirituality and seeking to be sensitive to the needs of oneself and others. The transpersonal caring relationship involves searching for a wholistic approach that integrates the mind, the body, and the spirit in an effort to create a special relationship between the caregiver and others. A caring occasion can be defined as an opportunity for two human beings to come together in way that allows for the creation of the opportunity for one to care for the other (Lowe, p. 54).
Resilience Among Respiratory Therapists

Little literature exists specific to the analysis of resilience among practicing respiratory therapists. Hill and Nyce (2010), however, claim that tasks as simple as obtaining a change of shift report can be a source of stress among RTs who are caring for critically ill patients. The authors list multiple ways of mitigating the impact of obtaining a change of shift report, such as face to face communication, the use of written support, and communicating in a manner that both problems and intention (p. 49).

Stress Among Healthcare Practitioners

Glasberg, Eriksson, and Norberg (2007) state that stress has been traditionally described as being either physical, psychological, social, or a combination thereof. The authors then examined the role of the conscience in determining the impact of stress on healthcare providers. Regression analysis showed that 39.6% of the variance in stress among those surveyed was due to stress of conscience. Other contributing factors include the field of employment (i.e., internal medicine versus emergency care), the level of perceived support from management, and personal resilience. The researchers concluded that healthcare providers whose job prevents them from listening to their conscience when it warns them against causing pain to others and those who find it necessary to deaden their conscience in order to be efficient in their jobs can suffer from higher levels of job-related stress of conscience (p. 255).

Schwenzer and Wang (2006) studied moral distress among respiratory care practitioners and found that many factors regarding end of life patient care were significant stressors and could impact the desire and ability of the professional to
continue working at a particular facility. Such data would seem important not only to hospital administrators and human resource professionals, but to the practitioners as well as the patients themselves, all of who are stakeholders in regard to the delivery of appropriate palliative care. Solidifying this line of thought is the finding by Willms and Brewer (2005) that 96% of respiratory therapists surveyed stated that they had personally removed ventilator support as part of the terminal extubation process, and that the respondents claimed to have done so an average of 33 times during the course of their professional career (p. 1047).

Research on End-of-Life Care

Research into the end-of-life experience entered the mainstream with the 1969 publishing of Elisabeth Kubler-Ross’ *On Death and Dying* (Parkes, 2013). Since that time the endeavor has grown into an area of study known as thanatology, a field of study tasked with contemplating the process of dying from an interdisciplinary approach (Fonseca & Testoni, 2011). Current research in the field includes a focus on not only understanding the scientific and psychological processes associated with the physical act of dying, but also with the training of those whose job it is to care for terminally-ill patients during their final days (Brady, 2015; Fonseca & Testoni, 2011).

History of End-of-Life Education

According to Chiarella (2006), “Care of the dying has always been a feature of human society” (p. 3). More recently, providing care for patients at the end-of-life is a fundamental expectation society places upon medical professionals (Chiarella, 2006; Kaufman, 2005). A number of healthcare programs, such as those designed to train
physicians, nurses, and physician assistants, have shown interest in increasing the amount of education students receive related to care for the dying (Billings, Engelberg, Curtis, Block, & Sullivan, 2010; Brown-Saltzman, Upadhya, Larner, & Wenger, 2010; Bui, 2012; Feldman & Slavin, Winter 2000; Pulsford, Jackson, O’Brien, Yates, & Duxbury, 2013). Several researchers credit the move toward an increase in end-of-life education for healthcare providers to the early works of Elisabeth Kubler-Ross (Blaylock, 2005; Dugan, 2004; Kuczewski, 2004; Oransky, 2004), while others stress the importance of research performed by the Institute of Medicine (Aulino & Foley, 2001; G. E. Dickinson, 2007; Schwartz et al., 2005).

A 1997 report from the Institute of Medicine found large gaps in the knowledge of care at the end of life among healthcare providers. This knowledge gap was found to be a major barrier to the improvement of services in the healthcare arena. The authors made a total of seven recommendations directed at improving care of terminally ill patients. The first recommendation addressed the expectation that both terminally ill patients and their families should be able to expect and receive adequate end-of-life care. The second recommendation mentioned that all healthcare providers should commit themselves to improving care for the terminally ill in an effort to prevent the pain, suffering, and other symptoms that are often associated with the dying process. The third recommendation suggested that “policy makers, consumer groups, and purchasers of health care…work with health care providers and researchers” to adequately measure and address care of the dying, to relieve the financial burden often associated with end-of-life care, and reform current prescription drug laws the “impede the effective use of opioids
to relieve pain and suffering” (p. 267). The fourth of seven recommendations the Institute of Medicine made in an effort to combat this lack of provider knowledge urged educators and other health professionals to initiate changes in undergraduate, graduate, and continuing education to ensure that future practitioners have the attitudes, knowledge, and skills to care well for dying patients. The fifth recommendation suggested that the field of palliative care should become “if not a medical specialty, at least a defined area of expertise, education and research” (p. 269). Recommendation six stated that researchers should work to “define and implement priorities for strengthening the knowledge base for end-of-life care,” while recommendation seven involved understanding the importance of maintaining a “continuing public discussion” aimed at developing “a better understanding of the modern experience of dying” including the options and obligations faced by patients, family members, and the community at large (p. 269-270). Four years later, Aulino and Foley (2001) claimed “Although education in palliative care has made clear progress, it has yet to be incorporated fully into the fabric of medical education” (p. 475).

Theories on Death and Dying

Dr. Elizabethe Kubler-Ross’ theory of death and dying is considered by many to be the sentinel work on end-of-life care (Blaylock, 2005; Dugan, 2004; Kuczewski, 2004; Oransky, 2004). Kubler-Ross theorizes that every individual, when faced with their own impending mortality, experiences a five-stage process that culminates in the eventual acceptance of their own fate. The five stages consist of Denial and Isolation, Anger, Bargaining, Depression, and Acceptance.
As the basis for gathering data for publication, Kubler-Ross held a series of seminars at the University of Chicago Billings Hospital during which she interviewed “terminally ill patients in the presence of students as a meaningful learning-teaching model” (Kubler-Ross, 1969, p. 7). The majority of seminar participants were medical students, interns and residents, although attending physicians, nurses, inhalation therapists, social workers, and occupational therapists were also in attendance (p. 254). While no specific mention is made of findings regarding the opinions of inhalation therapists, Kubler-Ross states that “nine out of ten physicians reacted with discomfort, annoyance, or overt or covert hostility when approached for their permission to talk to one of their [terminally ill] patients” (p. 249) and that “many nurses felt a great lack of training in this area and had little instruction as to their role in the face of such crisis” (p. 253). With regard to students, Kubler-Ross claims that for some “it took three or more sessions until they became comfortable discussing their own reactions and feelings in front of the group” (p. 258) and that “a great many of the students…signed up because of some unresolved conflicts in their own life regarding the death of a loved or ambivalent figure” (p. 257). As a result of attending the seminar series, the author claims that “a growing respect and appreciation for each other’s role began soon to be experienced, which enabled the group truly to share their problems on an interdisciplinary level” (p. 258).

Some modern thanatologists believe that Kubler-Ross’ five-stage approach to death over-simplifies the process by which humans accept loss (Bisconti, Bergmant, & Boker, 2006; Konigsberg, 2011; Roos, 2012). Konigsberg (2011) posits that the human
capacity for resilience alone is largely responsible for the ability to cope with loss, while Roos states that even Kubler-Ross herself never intended for her five-stage approach as being applicable to the living, but only to those who are dying (Konigsberg, 2011; Roos, 2012). Bisconti, Bergmant, and Boker (2006) saw more diversity in the coping response associated with losing a loved one. They state that “not all intervention strategies will work for all individuals,” and that coping strategies must be “customized to account for this variability” (p. 598).

Exposure of Students to Death During Clinical Education Rotations

Clinical rotations have long been a required component of medical education. Clinical education for most students includes rotations through various parts of the hospital setting, such as the emergency department, the neonatal intensive care unit, and the adult critical care unit (Cullen, DL, 2005; Gwyer, Odom, & Gandy, 2003; Robertson, 1986). The main purpose of clinical education is to expose students to the environment in which they will soon be expected to function autonomously while still under the tutelage of a licensed member of the healthcare team. The critical care clinical rotation provides some students with their first experience dealing with other human beings who are either dying or experiencing a great deal of pain and anxiety (Abbott, 2011; Doucette et al., 2011). Jiminez, Navia-Osoriom and Diaz (2009) found three significant sources of stress among nursing students that were linked to the clinical experience. The authors found that all three sources were capable of producing both physiological and psychological symptoms among students with varying degrees of experience. Dennis (2008) described
a series of contrasting events that were experienced by a student in her death education course:

One of the patients in the hospital was close to death and we [the student and her supervisor] did not want her to be alone. So, I decided to go provide support. It was so peaceful. She exhaled gently and then, in less than a minute, she gently exhaled again. And she was gone…I had another patient who was swinging her arms in the air and screaming ‘Leave me alone; I do not want to go!’ It just so happened (divine intervention) that her pastor stopped by, and he prayed with her. She calmed down, and then she died…Each day when I leave the hospital, I reflect on life itself. We know we are not here to stay, but facing death can be so devastating. It is one thing not knowing about it, but it is another thing to have to come to terms with it (p. 201).

Physiological and Psychological Symptoms Associated with the Care of Dying Patients

According to Melvin (2012), healthcare professionals who provide palliative care for extended periods of time, such as those working in intensive care units and hospice facilities, face both physical and psychological consequences. One example of such a psychological consequence has been termed “professional compassion fatigue” (McCubbin & Figley, 1983). According to Showalter (2010), compassion fatigue is “prevalent across all spectrums of the helping professions” (p. 239). The author reasons the many health professional are “secondary witnesses to trauma on a regular basis,” which leads to the internalization of the emotional pain we see in those we care for (p. 239). Showalter goes on to state that many healthcare service providers suffer from
compassion stress, vicarious traumatization, and secondary post-traumatic stress disorder, and that “Crumpled Kleenex now is found in the pockets of health care professionals, not only in the hands of those we care for” (p. 239).

Function of Respiratory Therapists in the Clinical Setting

According to the United States Bureau of Labor Statistics, the duties of a respiratory therapist include examining patients who suffer from cardiopulmonary disease, consulting with physicians to develop patient care plans, performing pulmonary function tests, treating and monitoring patients, and educating them how to properly care for themselves once discharged from the hospital (Bureau of Labor Statistics, 2015). RTs may carry out these duties in a number of hospital settings, including the emergency department, general care wards, the neonatal intensive care unit, or a variety of other adult-centered acute and sub-acute care environments (American Association for Respiratory Care, 2015). In addition to hospital-based staff, RTs also care for chronically ill patients residing in long term acute care facilities, in the home health setting, and on both ground and air transport teams (American Association for Respiratory Care, 2015). As a part of their duties in both the acute and chronic care settings, RTs are often involved in the withdrawal of care from terminally ill patients (Willms & Brewer, 2005). In a 2004 study of nearly 200 practicing RTs, Winn, Colt, and Colt found a need for more formal end of life education for those who treat critically and terminally ill patients on a regular basis.

Role of Leadership in the Health Science Curriculum

It is predicted that between 2010 and 2020 there will be at least a 19% increase in
the number of respiratory therapists needed in the United States alone (American Association of Respiratory Care, 2005; United States Department of Labor, 2011). A 2015 article published in the journal Nursing Ethics described the relationship between emotional burnout and turnover rates among nurses working in the intensive care unit (Shoorideh, Ashktorab, Yaghmaei, & Alavi Majd, 2015), while numerous studies have described the stressful nature of caring for critically-ill and dying patients (Fiabane, Giorgi, Sguazzin, & Argentero, 2013; Maunder et al., 2008; Melvin, 2012; Pavelková & Bužgová, 2015; Showalter, 2010). As educational leaders, department chairs are often responsible for assuring that the courses offered in their program of study are addressing both the requirements of their governing organization as well as the needs of their students (Venance, LaDonna, & Watling, 2014). Leaders in health science education are also tasked with producing a generation of healthcare providers who are capable to meet the demands of an aging U.S. population (Kacmarek et al., 2009).

Role of Curriculum in End-of-Life Care

A number of disciplines have begun to include some form of education regarding end-of-life care in their formal curriculum (Adesina, DeBellis, & Zannettino, 2014; Anneser, Kunath, Krautheim, & Borasio, 2014; George E. Dickinson, 2013; George E. Dickinson & Paul, 2015; Lanning & Dadig, 2010). Studies have shown that formal, classroom-based education can have a significant impact on preparing healthcare students to provide effective end-of-life care to their patients (Brown-Saltzman et al., 2010; Judy Lynn Mallory, 2002; L. Smith & Hough, 2011; Venkatasalu, Kelleher, & Chun Hua Shao, 2015; Yoshioka, Moriyama, & Ohno, 2014). While the fields of nursing, medicine,
and physician assistant studies have formally adopted end-of-life training into their curricula, respiratory care has yet to do so (Brown-Saltzman et al., 2010; Lanning & Dadig, 2010; Pullis, 2013; Rocker et al., 2005).

End-of-Life Education

Many published works regarding end of life education among allied healthcare workers seems to speak to the inadequacy of existing programs. Common findings include an overall lack of palliative education, the idea that where it does exist, it may be woefully inadequate, and that allied healthcare professionals would in fact benefit from such training. In their study on multidisciplinary end of life training of Pediatric Intensive Care workers, Roberts and Boyle (2005) assess that although allied health workers may be “introduced to this topic as students, they have limited opportunities to put this theoretical knowledge into practice until they have graduated” (p. 57). The authors go on to imply that lack of an adequate curriculum currently places the burden of education on the employing organization through continuing education seminars.

End-of-Life Education Among Physicians

The governing body for Physician Assistant Education addressed the issue of end-of-life education in March of 2010 by requiring all accredited programs to conform to the newly written end-of-life education standards within six months (Lanning & Dadig, 2010). Lanning and Dadig (2010) were able to show an increased understanding of the dying process as a whole as well as a reduction in fears and feelings toward end-of-life situations through the use of a Wiki Internet tool designed to provide instruction on end-of-life issues to second-year students.
Billings, Engelberg, Curtis, Block, and Sullivan (2010) utilized a survey assessment tool in an effort to ascertain students’ perceptions of their experience and preparation with regard to end-of-life care. The authors claim that physicians-in-training are exposed to a “formal,” an “informal,” and a “hidden” end-of-life curriculum. Formal curriculum is described as information taught through text and lectures, informal curriculum is described as education received through the clinical experience, and the hidden curriculum is described as knowledge passed on via the “faculty and residents’ behaviors and institutional constructs” (p. 320). The authors collected data via a national survey of 1,455 fourth-year medical students and utilized linear regression to uncover associations between the three types of curriculum and students’ perceived preparedness to care for the dying, their perceived quality of any end-of-life education they received during their training, and their attitudes toward end-of-life. Results of their study show a positive correlation between formal/informal curricula and student perception of their quality of end-of-life education while a negative correlation appears to exist between the hidden curriculum and student perception of the quality of end-of-life education. The researchers concluded that end-of-life education for medical professionals may best occur through advances in coursework and bedside teaching capable of disavowing the negative messages sometimes conveyed via the hidden curriculum.

End-of-Life Education Among Nurses

According to Mitka (2000), nurses are the healthcare providers who are most likely to be positioned to provide end-of-life care to both patients and families in both the hospital and hospice setting. Dickinson (2007) states that by the mid-1980s 80% of
baccalaureate-level nursing schools provided some type of end-of-life education in their formal curriculum, with 15% offering a semester-long course on the topic. Since that time, organizations such as the End-of-Life Nursing Education Consortium (ELNEC) have continued to push for an increase in formal education regarding end-of-life care among nurses and nursing students (American Association of Colleges of Nursing, n.d.).

The ELNEC project began in 2000 as an international education initiative with the goals of promoting research and educating nurses in order to improve the quality of palliative care delivered to terminally ill patients (American Association of Colleges of Nursing, n.d.). In its current incarnation, ELNEC promotes a “train the trainer” format where nurses interested in the field of providing palliative care to their patients are able to attend seminars and return to their respective facilities and train their colleagues on how to provide the best care for their terminal patients (American Association of Colleges of Nursing, n.d.). Eight core modules are covered during the training process: Palliative Nursing Care; Pain Management; Symptom Management; Ethical Issues; Culture; Communication; Loss, Grief, and Bereavement; and Final Hours. In August 2003, ELNEC was expanded to offer training specific for palliative care in the pediatric population. In 2009 the curriculum was expanded once again to cover both the perinatal and neonatal populations. As of 2015 ELNEC has trained over 19,500 health professionals who have in turn returned to their facility and trained an estimated 585,000 others (American Association of Colleges of Nursing, n.d.). While the primary goal of ELNEC is to improve the delivery of end-of-life patient care, the Loss, Grief, and
Bereavement module does touch on the feeling of loss nurses and other health professionals may experience during the course of their job (American Association of Colleges of Nursing, n.d.).

End-of-Life Education among Respiratory Therapists

Despite a need for formal training in palliative care, little research exists regarding end-of-life education in the field of respiratory care despite (Brown-Saltzman et al., 2010; Collins, Marshall, & Vaughan, 2015; Winn, Colt, & Colt, 2004). A 2004 abstract published in the Journal of the American Association for Respiratory Care addressed the issue by surveying 561 therapists in San Diego County, CA (Winn et al., 2004). Data from the 199 respondents suggests that there was a need at that time for the integration of formal training in end-of-life care into the respiratory therapy curriculum.

An article published in the Internet Journal of Allied Health Sciences and Practice article by Collins, Marshall, and Vaughan (2015) studied the attitudes of undergraduate respiratory therapy students toward death and dying. Students were surveyed on five different occasions as they progressed through both their classroom and clinical experiences. Students received training in end-of-life care in the classroom setting, and results showed that as students progressed through the clinical rotations their death anxiety scores became lower. This is in contrast to a 1990 study by Johannson and Lally that found increased levels of death-related anxiety among nursing students who had completed a formal course in death and dying.

A paper published in the journal Respiratory Care studied the impact of an interdisciplinary program designed to provide practicing respiratory therapists with
training on both ethical and end-of-life issues (Brown-Saltzman et al., 2010).

The program sought to help therapists “be aware of the ethical issues related to end-of-life decision-making and care…understand the elements of bereavement,” and allow them to “practice interactions concerning end-of-life care in the hospital” (p. 859). The intervention was also designed to “address moral distress” and promote “adaptive coping mechanisms” (p. 859). The authors determined that while almost all of the therapists had recently participated in end-of-life care, yet they had received no previous training in end-of-life care. Approximately one-third of the subjects reported experiencing distress when participating in the withdrawal of support from a terminally ill patient. The researchers concluded that “greater emphasis should be placed on death and dying issues during respiratory therapy training” (p. 865).

Summary

This chapter presented a review of literature related to end-of-life education in the healthcare curriculum in an effort to provide an understanding of the subject as it relates specifically to the field of respiratory therapy and respiratory therapy education. The literature describes both the history and the current state of end-of-life education and its place in the healthcare curriculum. Given the limited amount of research available in the field of respiratory care, an overview of end-of-life education in both the medical and nursing curricula was provided as a basis for description. The chapter also described the relationship between educational leadership and end-of-life education, including the responsibility leadership has to provide the next generation of caregivers with the tools
they will need to care for an aging population. Chapter three will provide an
in-depth description of the methodology that will be used to complete this qualitative
study.
CHAPTER 3

METHODOLOGY

Schwenzer and Wang (2006) studied moral distress among respiratory care practitioners and found that many factors regarding end of life patient care were significant stressors and could affect the desire and ability of the professional to continue working at a particular facility. In an effort to help provide improved end-of-life care and teach future practitioners how to cope with the stress of caring for dying patients, respiratory therapy (RT) programs need to integrate therapists’ lived experiences with palliative care into all degree levels of education. The purpose of this study was to better understand the lived experiences of recent respiratory therapy graduates regarding the provision of end-of-life care to their patients. This chapter will describe in depth the research design, population, sample, participants, instrumentation, validation, data collection, institutional review board approval, response rate, data analysis, and reporting of the results associated with the study.

Research Questions

Major Research Question: What are the lived experiences of respiratory therapy students regarding palliative care situations?

The following sub-questions were used to gather the information necessary to answer the major research question:
1. How do recent RT graduates perceive their ability to perform end-of-life tasks?

2. To what extent are recent RT graduates emotionally affected by a lack of end-of-life education?

3. To what extent do recent RT graduates believe that their ability to perform their jobs effectively is influenced by their experience with end-of-life education?

4. To what extent do recent graduates perceive that the current program adequately addresses the issue of End-of-Life Education?

**Research Design**

The proposed research design is a qualitative study of respiratory therapy programs using an interpretative phenomenological approach (IPA) (Larkin, Watts, & Clifton, 2006; Reid, Flowers, & Larkin, 2005; J. A. Smith, 2004, 2007). There are four elements of a qualitative research proposal including epistemology, theoretical perspective, methodology, and methods which outline the procedures (Crotty, 1998). Each element supports the qualitative research design with epistemology being the foundation that supports the theoretical perspective, the methodology, and then the methods.

The epistemology of this study lies within the realm of constructionism, or “that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed out of interaction between human beings and their world, and developed and transmitted within an essentially social context” (Crotty, 1998, p. 42).
Meaning is constructed by humans via engagement with their interpretation of the world. Meaning is not created, but constructed (Crotty, 1998). Husserl, the acknowledged founder of phenomenology, conjured the concept of intentionality or “relatedness” which mirrors constructivism (Crotty, 1998). This foundation sets the stage for useful, if not valid, interpretations where interpretivism, linked to Max Weber’s *Verstehen* or understanding, may be “overwhelmingly oriented towards and uncritical exploration of cultural meaning” (Crotty, 1998, p. 60). The *Verstehen*, or interpretivist approach to the social sciences is historically linked to hermeneutics and phenomenology.

IPA is a particular qualitative approach to research used in psychology that “represents an epistemological position, offers a set of guidelines for conducting research, and describes a corpus of empirical research (Smith, 2004, p. 40). IPA allows the exploration of participants’ lived experiences or phenomenology (Giorgi, 2012), as well as being connected to the researcher’s personal experience, also known as the interpretative or hermeneutic approach (J. A. Smith, 2004). While there are multiple variations of the phenomenological method (Giorgi, 2006), IPA is an approach that is routinely used in both the health professions and psychology (Arroll & Baron, 2013; King et al., 2008; Osborn & Smith, 2008; Robinson & Smith, 2010). The phenomenological movement demands for social scientists to go “Back to the things themselves” and attempt to “lay aside, as best we can, the prevailing understandings of those phenomena and revisit out immediate experience of them, possibilities for new meaning emerge for us or we witness at least an authentication and enhancement of former meaning” (Crotty, 1998, p. 78). Phenomenology is grounded in the philosophy of Heidegger and Merleau-
Ponty, who repeatedly stated that “the world is always already there” (Crotty, 1998, p.44). Heidegger argued for hermeneutic phenomenology by stating that the word itself is comprised of the words “phenomenon” and “logos.” He explained that “logos” is translated as to “show” or to “appear,” which defines the word phenomenology as to “be concerned with the thing as it shows itself” (Smith, 2007, p.7). Hermeneutics originally began with the interpretation of biblical texts but was expanded by Dilthey, Schleiermacher, and Gadamer to include the “hermeneutic circle,” which represents the dynamic circular relationship between the “part and the whole” (Smith, 2007, p.5). In a practical example, to understand the part you must first look to the whole, and vice-versa. As important as the interpretation of different aspects of the object, the hermeneutic circle between the researcher and the object must also be considered. This is where the researcher attempts to bracket their preconceptions and subjectivity throughout the research process.

IPA was used for this study by employing a series of open-ended interview questions directed towards recent RT school graduates and Respiratory Therapy Program Directors/Department Chairs who are connected by the common experience of caring for dying patients. The researcher utilized the process of interpretative phenomenological analysis whereby the essence of the phenomenon was identified using interviews for data analysis.

Population

The population from which a sample was taken to complete this study consisted of respiratory therapy program graduates. Due to the eventual phasing out of the
associate’s degree practitioner as a result of the 2015 initiative, only graduates from bachelor’s level programs were included. The population consisted of students who matriculated from the program that is currently ranked number one in the country according to the American Association for Respiratory Care (Respiratory Care Education Section Bulletin, 2004).

Sample

Recent program graduates were recruited from the alumni list of a Bachelors and Integrated Master’s degree respiratory therapy program at a large urban university that is considered to be the top program in nation according to a survey published by the American Association of Respiratory Care (Respiratory Care Education Section Bulletin, 2004). The chosen site is also the largest multi-degree granting institution of its type in the United States, offering an Associate of Science to Bachelor of Science bridge program, a traditional Bachelor of Science program, an Integrated Master of Science program, and a traditional Master of Science program. Participants were recruited via email invitation (Appendix A) and accepted on in order of response, and the number of participants were added until saturation is reached. In order to reduce the impact of curriculum change over time, only former students who have graduated in the last five years received an email inviting them to participate, along with a consent form and description of the study.

Participants

Participants in the study consisted of the first recent graduates to agree to participate in the study. If there is no positive response from any of the program
graduates, a follow-up request will be sent via email. If there was still no positive response, a third email was sent. The first 5 subjects that agreed to volunteer were interviewed. Recent graduates were chosen in the order in which they agreed to participate. A total of eight subjects were interviewed, as saturation of the subject matter was reached.

Interviews

Semi-structured interviews were conducted with each participant in either a face-to-face, telephone, or video conference format utilizing a set list of the following open-ended questions designed to uncover the essence of the phenomenon being studied:

1. What is your background in respiratory care?
2. What, if anything, have you been taught regarding end of life patient care?
3. Please describe what end of life care means to you.
4. What is your most memorable experience with end-of-life patient care?
5. What, if anything, could have made this experience better for you and/or your patient?
6. Is there anything you would like to add?

All interviews were interactional conversations that ranged from highly structured survey interviews to free-flowing exchanges (Silverman, 1997). Triangulation of data occurred through the use of interview responses, course descriptions, and published curriculum from the educational program the participants attended.
Validity or “Trustworthiness”

Qualitative research validity or “trustworthiness” (Denzin & Lincoln, 2000, p.230) was considered throughout the research process. Tools used to enhance the validity included triangulation of data through the use of peer review and debriefing, clarification of researcher bias, and member checking (Creswell, 1998; Glesne, 1999). Data was collected from multiple subjects in order to fulfill Bogdan and Biklen’s (1998) assertion that doing so will lead to “a fuller understanding of the phenomena” being studied (p. 104). Peer review and debriefing occurred when the researcher reviewed the data with respiratory therapy faculty members who hold an impartial view of the study. Clarification of researcher bias occurred through the use of a written reflection by the researcher in order to “become more reflective and conscious” of how personal beliefs and experiences may impact data analysis (Bogdan & Biklen, 1998, p. 34). Member checking occurred once themes are assigned to the transcribed interviews, when the researcher communicated with the subjects to have them scrutinize the information collected (Lincoln & Guba, 1985, p. 236). In an effort to add further validity to the process, Lincoln and Gupa’s criteria for assessing the soundness of a qualitative study was also followed (Lincoln & Guba, 1985). These criteria include credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). Credibility was judged via the use of peer debriefing and member checking. In order to fulfill this requirement, all interviews were transcribed and made available to an expert in the field who has over 25 years in the field as a clinician, an educator and a program director. After signing a confidentiality agreement, the expert engaged in peer debriefing sessions
with the author after each interview session. Member checking was followed by sending an electronic version of the transcribed interviews for the interviewees to read and evaluate for credibility. Transferability was discerned, to the extent that it can be in naturalistic inquiry, according to whether the author has provided adequate “rich, thick description” of the phenomenon under study. In an effort to produce such description, purposeful sampling was done through the use of serial selection of sample units and selection to the point of redundancy (Lincoln and Guba, 1985, p. 201-202). The data collection process began with 5 subjects and more were added until redundancy is achieved. Dependability was achieved via the use of meticulous documentation of data during the course of the study. All interview sessions were digitally recorded and transcribed. Once the transcribed interview has been coded by the researcher, an inquiry audit will be performed by an expert in the field who will examine both the interview process and the end product in an effort to determine a lack of researcher bias and add to both the dependability and confirmability of the study (Lincoln and Guba, 1985).

Subjectivity Statement

The purpose of a subjectivity statement is to make transparent all experiences the researcher may have had in the field of study. Smith, Flowers, and Larkin stated that while “The lived experience of being a body in the world can never be entirely captured or absorbed, but equally, must not be ignored or overlooked” (p.19). As noted by Bogdan and Biklen (1998), a researcher should “Acknowledge that no matter how much you try you cannot divorce your research and writing from your past experiences, who you are, what you believe, and what you value” (p.34). The authors further state that
“Being a clean slate is neither possible nor desirable,” and that the purpose of subjectivity is to “become more reflective and conscious of how who you are may shape and enrich what you do, not eliminate it” (p.34).

As a researcher engaging in an IPA study of end-of-life experiences of respiratory therapists, I have several life experiences that may have affected my view of end-of-life care. In an effort to bracket these experiences in an effort to reduce their impact as well as make them known to the reader, they will be summarized here, and the following statements will be shared with each participant. I will mitigate bias by using verification procedures described above during analysis of interview transcripts. The chair of a bachelor’s degree granting program with over 20 years’ teaching experience agreed to participate in the peer review process.

I am a middle-aged father of two children who spent six years working as a respiratory therapist in a large urban level one pediatric hospital. During my clinical years, I split my time between the pediatric intensive care unit and the transport team. As a respiratory therapist who practiced in the pediatric critical-care arena, one of my jobs was to manage patient’s ventilator status while they were receiving invasive or non-invasive mechanical ventilation. Many of these children were critically ill, and some suffered from terminal illness. Others had been injured in a manner that left them in a permanent vegetative state. On multiple occasions I cared for a patient who was terminal and was part of the team that engaged in withdrawal of care.

In addition to the exposure I received during the time I spent as a practicing respiratory therapist, I was introduced the end-of-life care at an early age. My father
suffered from terminal atherosclerosis and had his first myocardial infarction when I was nine years old. Over the next five years he spent time both in and out of the hospital recovering from a series of further infarcts. He died when I was fourteen years old. As a husband, I have also been present during the end-of-life episodes of my father-in-law, grandfather-in-law, and grandmother-in-law.

As an educator, I have spent ten years teaching students at both the baccalaureate and master’s degree level in a respiratory therapy program at a large urban state university. Part of my responsibility as an Assistant Clinical Professor and the Director of Clinical Education is to engage the students in the clinical setting and to design curriculum for all clinical courses. While working with students at various facilities, I have had the opportunity to be present during a number of episodes of end-of-life care for neonatal, pediatric, and adult patients. These experiences will be bracketed by the use of verification procedures and rigorous step-by-step data analysis.

Data Collection

Data will be collected via face-to-face, telephone and/or videoconference interviews with recent program graduates depending on which method each participant finds most convenient. Each participant was asked to sign a written statement of informed consent prior to the interview process. The consent stated that no identifying factors will be included in data published with the study. All interviews were audiotaped after permission to do so was granted by the participant, and field notes and memos were hand-written by the researcher during the interview process. A paid transcriptionist who signed a confidentiality statement prior to the transcription process, transcribed
interviews verbatim after being sent digital copies of recorded interviews via a secure online file-sharing service. Subjects were interviewed according to the order in which they responded to a recruitment letter distributed electronically by the researcher. The department chair of the participating institution had the email addresses of alumni on file and shared them with the researcher so that he was able to contact subjects directly via email.

Institutional Review Board Approval

This study was performed under the guidelines of, and with the approval of the Mercer University Institutional Review Board (IRB) in Macon, Georgia. IRB approval was sought once the proposal was successfully defended. Institutional review from which the school the interview subjects received their degree was not necessary, as they are no longer students at the institution.

Data Analysis

According to Smith, Larkin, and Flowers (2009), “The existing literature on analysis in IPA has not prescribed a single ‘method’ for working with the data.” This being said, the authors continue to point out that “the essence of IPA lies in its analytic focus” which results in the characterization of the approach “by a set of common processes and principles” which may be applied in a flexible manner (Smith, Larkin, & Flowers, 2009, p. 79).

Palmer, et al. (2010) created an eight-step protocol to be utilized for the analysis of IPA focus group data. These eight steps were adapted by the author and made relevant to semi-structured interview analysis. The steps recommend that the researcher focus on
objects of concern and experiential claims, positionality, role and relationships, organizations and systems, stories, language, adaptation of emergent themes, and integration of multiple cases. Step one suggests that the researcher focus on objects of concern and experiential claims by recognizing them as they appear in the transcribed data, summarize them, and “sort them into emergent patterns” (Palmer et al., 2010, p.104). Sorting occurred through the use of colored highlighters to label common themes in the transcribed data which was then be further categorized into broader themes. Step two, positionality, involves exploring both the role facilitators play in the data collection process and the perspective of those who are being interviewed. This occurred when the transcribed interviews were re-read through the lens of the subjects’ relationship to the phenomenon of end-of-life care/education in an attempt to “capture [the] participant’s relationship to, or involvement in” the matter (Palmer et al., 2010, p. 108). Step three requires the researcher to examine any references to others in an effort to understand the meanings and expectations of any relationship they may have to the respondent. Background data was collected during the interview process and participants’ references to other individuals contextualized the information collected. Step four is similar to step three in that it requires the researcher to examine references to organizations and systems to better understand the meanings and expectations of any relationship they may have to the respondent. In order to achieve this, transcribed data was reviewed once again in order to determine how the subject described organizations/systems in an effort to discern their meaning as well as any consequences that result from their relationship to the subject. Step five includes the examination of any accounts, or stories, the participant
may tell in an effort to understand what information it is meant to relay. To achieve this the transcribed interviews were re-read with focus on the structure, imagery, and tone of each narrative presented (Palmer et al., 2010, p. 111). Step six actually occurs during steps one through five and involves dissecting the language the subject uses in an effort to discern any patterns present, the context in which language is used, and why that language is being used. This step did not require an actual re-reading of the transcribed material through a different lens, but occurred through the process of grouping similar cases together throughout the analyzation process. Step seven involves a return to the themes assigned in step one in order to adapt them to information discovered in subsequent steps. This process involved reconsideration of all themes assigned during step one in light of any new discoveries that may appear during steps two through six.

Step eight involves the integration of multiple cases in an effort to:

Build up an overall analysis of the topic under investigation” by “pick(ing) out commonalities and differences…revisiting the transcripts to check themes in relation to original claims” and “consider(ing) the analysis in the wider context of existing relevant theories, models and explanations. (Palmer et al., 2010, p. 105)

This was done by returning once again to the major themes associated with the phenomenon of end-of-life in an effort to relate the findings to current theory.

Bracketing and peer review by experts in the field of respiratory therapy occurred in order to reduce the influence of any potential opinions or biases of the researcher.

Data was then hand-coded line-by-line through the use of highlighter pens of various colors and labeled utilizing using written tables, after which codes were collected and
interpreted in an attempt to identify common themes in the data. Interviews were then re-read in light of any new coding in order to search for previously undiscovered supporting information that was pertinent to the study.

Reporting Results

A table was used to summarize the results from each individual interview as well as the themes were found to be common among the participants. Documentation and quotations will be used to add descriptive detail to the narrative descriptions.

Summary

The goal of this study is to use the Interpretive Phenomenological Approach to gain understanding of the lived experiences of respiratory therapy students regarding the issue of palliative care experiences and education. This approach will also be utilized to interview recent program graduates. Semi-structured interviews utilizing open-ended questions, was used to collect data during telephone and/or videoconference interviews with participants. Credibility, transferability, dependability, and confirmability was used to assess the soundness of the study (Lincoln and Gupa, 1985). Data was transcribed, hand-coded, and labeled in an attempt to describe the phenomenon being studied using an interpretive lens. Results were reported using a table to summarize themes found to be common during the analytical process. Chapter four reports the results of the methodology outlined in this chapter.
CHAPTER 4

RESULTS

In an effort to help provide improved end-of-life care and teach future practitioners how to better deal with the stress of caring for dying patients, RT programs need to integrate therapists’ lived experiences with palliative care into all degree levels of education (Giordano, 2000). The purpose of this study was to better understand the lived experiences of respiratory therapists who provide end-of-life care to their patients. The study was guided by the following major research question and accompanying sub-questions:

Major Research Question: What are the lived experiences of respiratory therapy students regarding palliative care situations?

The following sub-questions were used to gather the information necessary to answer the major research question:

1. How do recent RT graduates perceive their ability to perform end-of-life tasks?
2. To what extent are recent RT graduates emotionally affected by a lack of end-of-life education?
3. To what extent do recent RT graduates believe that their ability to perform their jobs effectively is influenced by their experience with end-of-life education?
4. To what extent do recent graduates perceive that the current program adequately addresses the issue of End-of-Life Education?

A constructivist epistemology was used to address the study, and analysis was performed using an adaptation of the Palmer et al. (2010) 8-step approach for IPA that was modified for the analysis of semi-structured interviews. Study participants were asked the following questions during the interview process:

1. What is your background in respiratory care?
2. What, if anything, have you been taught regarding end of life patient care?
3. Please describe what end of life care means to you.
4. What is your most memorable experience with end-of-life patient care?
5. What, if anything, could have made this experience better for you and/or your patient?
6. Is there anything you would like to add?

This chapter reports the data collected and analyzed during the participant interviews. The chapter is organized according to the following sections: Respondents, Method of Analysis, Background in Respiratory Care, Prior End-of-Life Education, Definition of End-of-Life Care, Memorable Experiences Associated with End-of-Life Care, How End-of-Life Care Can Be Improved, and Additional Information Offered by Participants.

Respondents

A total of 8 subjects were interviewed for this study. The first 5 respondents were initially reviewed in order to comply with the recommendation of Creswell (1998, p. 64).
After 5 interviews the researcher suspected that saturation had not been achieved, so two more respondents were interviewed. Saturation was achieved after the 7th interview as redundancy of information had begun to occur during the interview process (Morse, 1989). At that time, one more respondent was interviewed in an effort to confirm saturation. Table 4-1 lists demographic data for the subjects involved. Time in field describes the number of years that have passed since the subject completed their entry-level degree in respiratory therapy, rounded to the nearest whole number.

“Certifications” list the various board certifications the subject currently holds. Area of practice describes the primary field in which the subject is currently employed. All subjects were assigned an alias that was used to protect anonymity.
### Table 1

**Participant Information and Demographics**

<table>
<thead>
<tr>
<th>Subject</th>
<th>Degree</th>
<th>Time in Field</th>
<th>Certifications</th>
<th>Area of Practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tom</td>
<td>BS</td>
<td>3 years</td>
<td>RRT</td>
<td>ICU</td>
</tr>
<tr>
<td>Brian</td>
<td>BS</td>
<td>5 years</td>
<td>RRT-NPS</td>
<td>PICU</td>
</tr>
<tr>
<td>John</td>
<td>MS</td>
<td>2 years</td>
<td>RRT-NPS</td>
<td>ICU</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>COPD Educator</td>
<td>NICU</td>
</tr>
<tr>
<td>Cara</td>
<td>BS</td>
<td>3 years</td>
<td>RRT-NPS</td>
<td>ICU</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>NICU</td>
</tr>
<tr>
<td>Carol</td>
<td>MS</td>
<td>2 years</td>
<td>RRT-NPS</td>
<td>LTAC/Rehabilitation</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>CPFT</td>
</tr>
<tr>
<td>Katie</td>
<td>BS</td>
<td>3 years</td>
<td>RRT-NPS</td>
<td>PICU</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>ACCS</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>NICU</td>
</tr>
<tr>
<td>Mary</td>
<td>BS</td>
<td>2 years</td>
<td>RRT-NPS</td>
<td>ICU</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>AE-C</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>NICU</td>
</tr>
<tr>
<td>Alex</td>
<td>BS</td>
<td>3 years</td>
<td>RRT</td>
<td>ICU</td>
</tr>
<tr>
<td>Average</td>
<td></td>
<td>2.875 years</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Method of Analysis**

Recorded interviews were analyzed according to Palmer’s eight-step protocol for the analysis of IPA focus group data. These eight steps were adapted by the author and made relevant to semi-structured interview analysis. Palmer (2010) suggests that the steps help the researcher focus on objects of concern and experiential claims.
positionality, role and relationships, organizations and systems, stories, language, adaptation of emergent themes, and integration of multiple cases in the following manner:

Step 1. Focus on objects of concern and experiential claims by recognizing them as they appear in the transcribed data, summarize them, and “sort them into emergent patterns” (Palmer et al., 2010, p.104).

Step 2. Explore both the role facilitators play in the data collection process and the perspective of those who are being interviewed (Palmer et al., 2010, p. 108).

Step 3. Examine any references to others in an effort to understand the meanings and expectations of any relationship they may have to the respondent.

Step 4. Examine references to organizations and systems to better understand the meanings and expectations of any relationship they may have to the respondent.

Step 5: Examine any accounts, or stories, the participant may tell in an effort to understand what information it is meant to relay.

Step 6: Dissect the language the subject uses in an effort to discern any patterns present, the context in which language is used, and why that language is being used.

Step 7. Return to the themes assigned in step one in order to adapt them to information discovered in subsequent steps.

Step 8. Integrate multiple cases in an effort to “build up an overall analysis of the topic under investigation” (Palmer et al., 2010, p. 105).
Originally, 24 emergent themes were developed while analyzing the 8 transcripts. Themes with similar meaning were then further grouped into 9 sub-superordinate themes and three superordinate themes which were *Needs for the Patient, Needs for the Family, and Needs for the Care Provider.*
Table 2

*Master Table of Themes*

<table>
<thead>
<tr>
<th>Superordinate Themes</th>
<th>Sub-Superordinate Themes (Interpretation)</th>
<th>Emergent Themes (Codes)</th>
<th>Number of Participants with Sub-Superordinate Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Needs for the Patient</strong></td>
<td>Suffering</td>
<td>Comfort Quality of Life Futility</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Time</td>
<td>Time to Prepare Time to Say Goodbye Educate Early Timeliness of death</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Honesty</td>
<td>What to Expect Discussion Avoidance</td>
<td>6</td>
</tr>
<tr>
<td><strong>Needs for the Family</strong></td>
<td>Support</td>
<td>Support for Family Support for Patient</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Compassion</td>
<td>Calm Environment Respect for Patient</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Engagement</td>
<td>Knowledge of Patient’s Wishes Allowed to Participate</td>
<td>6</td>
</tr>
<tr>
<td><strong>Needs for the Care Provider</strong></td>
<td>Memorable Experiences</td>
<td>Positive Negative Difficult Appreciation</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Coping</td>
<td>Friends Retreats Self-Care Chaplain</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Stress</td>
<td>Burnout Emotional Impact</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Education</td>
<td>Definition of End-of-Life Care Prior End-of-Life Education Need for More</td>
<td>8</td>
</tr>
</tbody>
</table>
Background in Respiratory Care

Subjects’ time in the field, defined as the number of years since graduation rounded to the nearest whole year, averaged 2.75 years and ranged from two to four years (n=8). Two subjects (25%) worked only in pediatrics, while two others (25%) worked only in adult care. Three subjects (37.5%) were employed at a facility that provides the opportunity for them to split their time between adult and neonatal critical care, and one subject (12.5%) was employed at a long-term acute care facility that specializes in rehabilitation.

Two subjects (25%) listed their entry-level degree as a MS in Respiratory Care. Six subjects (75%) listed their entry-level degree as a BS on Respiratory Care. Six subjects (75%) held the Neonatal/Pediatric Specialist credential, while the following credentials were held by one subject each: Adult Critical Care Specialist (12.5%), Certified Asthma Educator (12.5%), Chronic Obstructive Pulmonary Disease Educator (12.5%), and Certified Pulmonary Function Technologist (12.5%). All subjects were Registered Respiratory Therapists, with two (25%) having the RRT as their only certificate.

Needs for the Patient

Needs for the Patient was one of the three superordinate themes that emerged from interview data. Sub-superordinate themes associated with Needs for the Patient include Suffering, Time, and Honesty.
Suffering

All 8 subjects addressed the need to limit patient suffering, whether physical or emotional. Emergent themes included Comfort, Quality of Life, and Futility.

Comfort. Brian noted that the definition of comfort may vary from one patient to another, stating that his definition of end-of-life care included,

Comfort…whatever that means to them, whether it be pain-related, whether it be emotional. We have therapy dogs that will come and play with the kids.
Anything that will comfort them from a pain and emotional standpoint to help them better deal with whatever terminal illness they are suffering from.

Alex addressed the need for pharmacological pain management by “giving them morphine…keeping them comfortable.” No respondent mentioned a situation where they felt that effective pain management was not in place; however, all stated the importance of minimizing pain during end-of-life care. John hoped that his patient’s last memories were “generally good ones…without pain.”

Quality of life. Katie, an RT that works with children, was specifically concerned that both family and physicians might sometimes seek over-aggressive treatment for a terminally ill patient, stating,

I see these kids, these chronically ill children, and their parents are just oblivious to their quality of life. All along they just want the doctors to do more and more and more, and these kids have no quality of life. How long are you going to drag this out? They [the patient] has no sense of consciousness, they’re just a body
here on Earth…Just a brain stem, and they’re not even really here. They don’t talk, they don’t go to school, they don’t laugh. They’re just a body.”

When describing a memorable patient, Tom stated that,

The way they found the patient in the first place was in their own bed of stool…the family wasn’t even taking care of them at home. That’s no way to live. When the patient died, the hospital called the family, and they still didn’t show up.

A total of 4 participants described the lack of quality of life during the course of their interview.

Futility. Five subjects spoke of the psychological impact of providing what they felt was futile care to a terminally ill patient. Most were concerned that such care causes unnecessary pain and discomfort to the patient. Katie declared:

We’re not meant to be on this earth forever. We all have end dates. Don’t think about yourself. Don’t think about what you’re going to do without your kid, or what other people would think if you chose to de-escalate their care. Think about your child that’s lying in the bed suffering, intubated, on an oscillator, being poked, prodded, and suctioned for weeks on end-- and, you know that kid is not going to live. Don’t be selfish.

Tom spoke of a futile situation with a patient who:

Was down [in cardiac arrest] for 45 minutes before EMS got to her house.

Nobody really explained to the husband what the possible outcomes could be.
The next day we coded her 7 times, and he thought she was having a simple heart attack.

Subjects believed that the provision of futile care to such patients led to unnecessary, prolonged suffering that prevented the patient from experiencing what they consider to be an acceptable palliative care environment.

Time

The sub-superordinate theme of Time was consistent throughout all interviews. Emergent themes related to the concept of time include Time to Prepare, Time to Say Goodbye, Educating Early, and the Timeliness of Death.

Time to prepare. A total of 5 participants discussed the need for patients to have time to prepare for their end-of-life experience. Subjects felt that patients who were informed of the terminal nature of their situation during the later stages of their disease process were not given adequate time to prepare themselves emotionally or psychologically for what was ahead. Carol stated that:

A lot of young people don’t really have the opportunity for end-of-life care. They just end up in really bad situations. Usually it’s a trauma or something acute. A situation where there’s no time for a choice. No time to prepare…every doctor needs to [have a conversation regarding end-of-life] as soon as a patient is admitted with a terminal illness. They often have no idea how the course could really go, and they deserve time to prepare, to say goodbye, to make amends.

Brian stated that while his facility “has a pretty good group in place that deals with [end-of-life] situations…we could do a better job working out a plan that allows [the patient]
to spend time with family and friends.” Seven subjects agreed that providing patients with adequate time to prepare for their end-of-life experience allowed them not only to get their personal affairs in order but to also spend time with their families.

Time to say goodbye. Carol noted in her description of a positive end-of-life situation that both the family and the patient “were able to say goodbye.” Tom mentioned a terminally ill patient who “was tired of fighting.” He stated that the patient “told her family. She talked to everyone. She didn’t want to be placed on a ventilator. It was tough because she had been a patient at the hospital for years.” Subjects believed that providing patients with adequate time to say goodbye to family and friends provided them with a sense of control that may allow them to achieve a sense of closure during their end-of-life experience.

Educate early. Tom mentioned a patient who had suffered a severe anoxic brain injury, yet the family:

Wasn’t really aware of the gravity of the situation. Finally, after several days of coding [the patient], the husband signed a do not resuscitate order because someone had taken the time to sit down and talk with him…to explain what was happening.

Carol, who had worked for 2 years in long-term acute care and rehabilitation, stated that at her facility end-of-life situations were:

…handled very calmly. There weren’t many codes, most were withdrawal of care. The doctor came in and spoke with the family. They were upset,
crying…but they knew what was happening. The physician explained step-by-step how we would withdraw care. They [the family] were prepared.

Educating early about what is happening to their family member is an important part regarding the Needs of the Patient.

Timeliness of death. Carol mentioned a memorable situation where the patient and his spouse were close in age to hers, stating that:

We were doing CPR and his wife was screaming…she was about my age and she was just devastated. I mean someone had to physically hold her up. I put myself in her shoes and thought “Oh my gosh, this could be me.” I had to get out of the room quickly. Someone asked me if I was okay and I just broke down crying.

Katie described a case where a three-year-old patient had died suddenly in his father’s arms:

He had an AVM (arterial-venous malformation) and just instantly died right there at home. His dad had come home from work and the little boy met him at the door just after 5 o’clock as usual. He hugged his father and said, “Dad I’m so glad you’re home.” Then he screamed and was gone. It took a while for the ambulance to get there. Hearing the father tell me this was brutal. This kid was way too young to die. I remember I cried on the way home that night.

These situations incurred the participants’ sense of empathy in considering their patients’ families. The emotions flooded them as their perceptions of the time of these deaths were too early.
Honesty

The Third sub-superordinate theme related to the superordinate theme of Needs for the Patient is “Honesty.” Emergent themes related to Honesty include knowing What to Expect in terms of illness and Discussion Avoidance of the terminal illness itself. Six participants described this sub-superordinate theme.

What to expect. Subjects’ opinion varied in regard to how well patients and their families were being prepared by hospital staff to experience end-of-life care. Some felt that their patients were being told how their situation would progress in a straight-forward manner, while others claimed that their facility should be more forthright with both patients and their families. Brian claimed that while his hospital “has a pretty good group in place to deal with [end-of-life] situations,” but that they could always do a better job of addressing the expectations of patient, family, and bedside staff. Cara referred to the uncertainty of expectations, stating that end-of-life care can often “be a lot quicker or a lot longer than anyone expects.” “What to expect” is unpredictable in terms of the Needs of the Patient.

Discussion avoidance. Katie and Carol referred to experiences they were involved in where they felt physicians had avoided discussing the inevitability of death with their patients and patient’s families. Katie referred to multiple situations where staff felt that care was futile but the attending physician was hesitant to discuss the inevitable with family members. She claimed that by postponing the death of a terminally ill patient, physicians caused not only prolonged physical suffering but also delay the healing process for loved ones. Cara mentioned an experience with a terminally ill
cancer patient who she cared for in the emergency department that had never had an end-of-life conversation prior to that day. Instead of being scared or angry, the patient praised the critical care physician for “having a discussion their oncologist should have had long ago.” “Honesty” towards the patient was important for the Needs of the Patient.

Needs for the Family

The second superordinate theme created from the interviews is titled Needs for the Family. Needs for the family consists of three sub-superordinate themes: Support, Compassion, and Engagement.

Support

The sub-superordinate theme of Support relates to the emergent themes of Support for the Family and Support for the Patient. The emergent theme Support for the Family refers to statements made by subjects stressing the importance of giving family members what they need in terms of physical and emotional support, while Support for the Patient relates to the impact patient support mechanisms may have on family members as they prepare to engage in an end-of-life scenario with their loved one. Five participants discussed this sub-superordinate theme.

Support for the family. Maxie, who has worked as a staff therapist in the neonatal intensive care unit, claimed that her current facility utilizes a support group comprised of parents who have lost a child and whose goal is to “speak to other parents and prepare them as they’re going through the whole process.” Maxie stated that parents seem to appreciate the opportunity to receive counsel from others who have been through a similar situation en lieu of speaking with a professional counselor with limited personal
experience. The hospital she referred to is quite large, and Maxie mentioned that only by caring for such a large number of patients is it possible to assemble a viable program of peer-support. Providing support for the family, be it spiritual, emotional, or physical, was seen by those interviewed as an integral aspect of providing adequate end-of-life care.

Brian stressed the importance of:

…having [support systems] in place designed specifically to help parents deal with kids that are suffering from a terminable illness…to help prepare them for what is to come. We have therapy dogs for the kids, but it’s also very important that we support the parents any way we can.

Support for the patient. Subjects referred to clergy as being the primary method of support for patients. Cara and John mentioned that their hospital utilizes a palliative care physician who has received special training related to caring for the physical, psychological, and emotional aspects of terminal illness. Their facility is the only one mentioned by participants that employs a palliative care physician or has a dedicated hospice wing. Other subjects felt that while their facilities attempted to address the supportive needs of patients, there was much room for improvement. Cara claimed that patients were not offered support early enough during the course of their terminal disease process, stating that “there needs to be more support for patients before their final hospital admission.” Brian stated his agreement by noting “we could have done a better job towards the beginning [of offering support to the patient].”
Compassion

The sub-superordinate theme of compassion is supported by the emergent themes Calm Environment and Respect for the Patient. The emergent theme of Calm Environment refers to statements made by the interviewees stressing the importance of the final moments of a patient’s life not being one of chaos and confusion. The theme Respect for the Patient refers to statements stressing the need to show patients the respect they deserve during their final moments.

Calm environment. Subjects noted that a calm environment during end-of-life care is can be a time for positive reflection by both patient and family. Carol, who has experience working with ventilator-dependent patients in a long-term care facility, referred to an instance of end-of-life care that she felt was handled particularly well:

The doctor came in to talk with the family-- of course the family is upset, crying, but they [the family] knew exactly what was happening. [The attending physician] explained step-by-step how we would withdraw care and what would happen. It was calm. Quiet. They were prepared.

Carol mentioned that a calm environment is necessary for family and loved ones to say goodbye to the patient, and often for the patient to do so in return. Carol also commented on a contrasting situation she was involved in as a student, where a patient in his early 20’s experienced an unexpected in-hospital cardiac arrest that resulted in a tremendous flurry of activity while his wife stood by the bed apologizing to his lifeless body for a recent argument that was never settled. Carol detailed the intimate details of the
situation, including how care can create the impression that the team is not showing the patient proper respect:

They had stripped off his gown to do CPR and he had gone to the bathroom. When we were doing CPR you could hear his ribs cracking. I just put myself in her shoes and thought “Gosh, this could be me.” So, I had to get out of there very quickly…someone asked me if I was okay, and I immediately broke down crying in the middle of the hallway.

The provision of a calm environment was viewed by practicing therapists to be both a requirement for healthcare providers to perform their end-of-life tasks and a required component of a peaceful transition for the patient and family.

Respect for the patient. Respect for the patient describes the ability of family and caregivers to provide terminally ill patients with the opportunity to maintain their subjective sense of dignity during end-of-life care. Participants commented on the importance of all parties involved in such care to have an acute awareness of all advance directives the patient may have in place, such as a “Do Not Resuscitate” or “Allow Natural Death” orders. Mary and Alex reflected upon the importance of following these orders as a final opportunity to allow patients the freedom to make their own decisions. Mary commented on one case that frustrated her, as her patient’s parents had “made the kid a DNR and then rescinded the order 4 or 5 times over just a few days.” Alex considered it a sign of respect to “provide pain relieve and spiritual support for terminal cancer patients if that is all they want in the end.” Their opinion was communicated by half of the respondents as a being an important aspect of compassionate care.
Subjects also felt that avoiding prolonged suffering was a form of respect they owed their patients. Katie mentioned two specific patients, one being a young child who was being kept alive by mechanical and pharmacological means to the point that the body was beginning to deteriorate in bed:

So here I am passing this kid around to all his family members…I could just tell [that he was gone]…like the smell, it would just jump onto you. I had to leave my scrubs in the garage that night because the smell was so bad.

Katie also noted that it was the bedside nurse, not the attending physician, who finally discussed the “reality of the situation” with the patient’s mother, prompting the deceleration of care that eventually lead to the child’s death. Providing life-sustaining support to terminally ill patients was perceived by 4 of the 8 interview subjects as a form of “disrespect” in that doing so may be contradictory to the desires of the patient and prolong a terminal state of suffering.

Engagement

The third and final sub-superordinate theme related to Needs of the Family is Engagement. This sub-superordinate theme is supported by the emergent themes Knowledge of Patient’s Wishes and Allowed to Participate.

Knowledge of patient’s wishes. Subjects with a background in pediatric care made no reference to the wishes of the patient, but to those of the parents instead. Brian mentioned the importance of providing pediatric patients with a level of “comfort” that is in line with the expectations of the parents. Four subjects who were involved in adult care mention knowledge of patient’s wishes regarding their end-of-life experience as
being paramount to the provision of adequate care. One mentioned how “from conversations I had [with a quadriplegic patient], he had much rather his family agree to pull the plug. But his parents wouldn’t allow him to make that decision…even though he was an adult.” Another, Tom, told of a terminal patient who “just got tired of fighting…and didn’t want to be on the ventilator any longer.” Tom praised the family for allowing the patient, a grandmother, to make her own decisions regarding her DNR status.

Allowed to participate. The emergent theme “Allowed to Participate” relates to the need of family members to be included in the end-of-life of their loved one. Subjects remarked on the importance of family being allowed to participate in the final days, hours, and moments of patient care. Alex spoke of a situation where the family was very involved with the care of their loved one. He declared the impact was positive to the point that “Although the family was hurting, and it was hard letting her go, the family came out and hugged me. They thanked me, and I didn’t know what to say. It was weird to me, but in a positive way. They were very supportive and friendly.” Cara mentioned that her facility tends to “throw all the rules out the window with terminal patients. Family can come and go around the clock.” Regarding one of her most memorable patients, Cara stated that “The family was aware of her situation and what the patient wanted. And they gave her that. They were all there until the end.”

Needs for the Care Provider

The third superordinate theme created from the interviews is titled Needs for the Care Provider. Needs for the care provider consists of four sub-superordinate themes. These
themes include Memorable Experiences, Coping, Stress and Education. Each theme is addressed below.

Memorable Experiences Associated with End-of-Life Care

All 8 subjects responded without hesitation when asked to describe their most memorable experience providing care to a terminally ill patient. Katie and Cara were unable to limit their most memorable experience to a single patient. Three subjects described their most memorable end-of-life care experience as a positive one, while five subjects described their most memorable experience as negative.

Positive experiences. Among the three respondents who described their most memorable end-of-life patient experience as being positive, common positive experiences included active family participation, the family knowledge of patient’s wishes, and appreciation shown toward caregivers. Tom mentioned that one of his most memorable experiences involved an elderly patient whose family did not want to put them through the painful process of “extreme lifesaving measures.” Cara described a situation where a patient had clearly discussed their end-of-life preferences with family members. The family was unanimous in agreeing that fulfilling those preferences was extremely important, which led to withdrawal of care in what Cara considered a very timely manner. The family was also very “appreciative of the care” the patient received, and that they [the family] were “just super awesome.” Alex’s most memorable experience was with a middle-aged patient suffering from terminal lung cancer. He stated that after she died, “the family came out and hugged me and thanked me. I didn’t know what to
say. It was positive. They were very supportive and friendly. You admired them for being strong in that situation.”

Negative experiences. Katie claimed that her most memorable experience was negative in nature:

Those [unexpected deaths] are the toughest. I cried in my car for a while, and what made it worse was that the kid…a three-year-old…well, my grandfather had died the day before, and when I went to the funeral home to see my grandfather, he was at the same funeral home as my grandfather. When I was talking to the funeral home lady, I saw the little boy’s picture. I cried, and cried, and cried, and was like “why does this little boy’s picture keep showing up? It’s following me from my job.” It’s emotionally draining. It’s hard. Sometimes I wonder why I didn’t just go to work in a candy factory, like Willy Wonka.

These memorable experiences were often associated with cases where the subject felt the situation was handled in a manner that had more of a negative impact on the patient or family than it should have. Carol spoke of a situation where neither the patient nor the family were given much time to accept the situation, so when the end came, “the wife was screaming ‘I’m sorry!’ over and over again.”

Coping

The Centre for Studies on Human Stress (2017) defines *coping* as any mechanism, be it thought or action, that an individual may use to deal with a situation that is perceived as being threatening to said individual. The sub-superordinate theme
Coping is supporting by the emergent themes of Friends, Retreats, Self-Care and Chaplain.

Friends. The emergent theme of using Friends as a coping mechanism was supported in detail by seven of the participants. Brian stated:

I’ve worked hard to build a lot of friendships outside the healthcare setting. As simple as that may sound, what it does for me is allow me to hang out with, you know, 5 people, 8 people, and they’re telling me things that they’re doing completely outside of healthcare and it kind of helps me separate myself from what I do on a daily basis.

Mary mentioned the importance of friendships within the hospital setting:

It’s nice to talk with someone who has had similar experiences, even if you don’t want to talk about it from, like, the religious standpoint. I’ve received peer counseling from people as I’ve been going through [an end-of-life care experience]. I’ve had a couple of people sit me down during a couple of hard cases that we had and sort of talk me through it.

Connection with people with similar experiences provided important ways of “Coping” for those providing patient care.

Retreats. The concept of participating in a staff retreat as an effective coping mechanism was mentioned consistently throughout Brian’s interview. Carol and Katie, who have worked part-time for the same hospital system as Brian, mentioned its importance as well. Brian noted specifically that:
They call them retreats over at [hospital]. It’s basically helping us deal with kids dying in the ICU setting. The last one I went to had to be maybe like a month ago. The hospital tries to dress it up a little bit...they offer massages and all, and try to have it in a relaxing area. But the main topic is how are you coping with end of life care...does it bother you at home? Physicians and staff managers are there, and they want to make sure we’re not getting tired out from seeing it too much.

Other participants did not experience retreats, but indicated a need for more opportunity to “decompress” from their experiences. This includes Katie, who works at a hospital that has an institutional connection with Brian’s facility.

   Self-care. The concept of self-care was not mentioned as a stand-alone coping mechanism, but the importance of self-care was woven throughout multiple interviews. Brian noted the value his facility placed on making sure employees were engaging in appropriate self-care outside of the workplace, so that “we’re not getting tired out from seeing [death] so much.” Katie, who is single, stated that “conversations” with her mother were a strong part of her self-care mechanism. Mary, on the other hand, found emotional relief by talking with her best friend, who also works in healthcare, stating “I feel like talking to people that don’t work in healthcare, they don’t tend to really get where we’re coming from.” Again the need for connection with others supported the Needs for the Care Provider.

   Chaplain. Four subjects described the use of a hospital-based chaplaincy program as a useful coping mechanism. Brian mentioned the important role resident chaplains
play at his current facility, stating that:

They’re here every day around three p.m. for about an hour or two…to talk to the staff about anything that day [or in the past]. They have programs in place specifically geared toward making sure the staff is taking care of themselves and dealing with patients dying. They have a room, I think it’s called a respite room, and you can go there any day to speak with a chaplain.

In contrast, Mary was the one subject to specifically mention avoiding the use of chaplaincy services after losing a patient, stating that:

We do have the chaplains and everything, and I’m sure, like for some people that is helpful because, you know…but I’m just…I’m not a terribly religious person.

It’s not the kind of help that I end up needing a lot of the time.

This indicated that practitioners must seek individualized support that meets their needs as a care provider.

Stress

The National Institute of Mental Health (2017) describes stress as the mechanism by which the brain and body respond to the presence of a demand. While Brian was the only subject to broach the topic directly, the concept was woven throughout all interviews. Then sub-superordinate theme of Stress was supported by the emerging themes of Burnout and Emotional Impact.

Burnout. Brian referenced the use of staff retreats as an effort to prevent caregivers from experiencing unresolved stress that may result in therapists “burning out and leaving the field.” Although none of the other subjects made direct reference to the
idea of burnout as it applies to those who provide care to critically ill and injured patients, reference was made to the phenomenon. Katie alluded to burnout as the reason that some therapists are not able to continue with a career in pediatrics, and declared a need for continuing education in an effort to reduce its effect:

We definitely do need that [end-of-life education] at work. That should be something we address because I think it’s much of the reason people can’t work at children’s hospitals for a very long time. They just can’t…you know…they just can’t deal with having to de-escalate care on children. They burn out.

The concept of burnout was not unfamiliar to the interview subjects, even though they had only been practicing for an average of less than three years. Having seen the long-term impact of providing end-of-life care in their more seasoned colleagues, their statements relayed their belief that stress was an inevitable part of the chosen field.

Emotional Impact. Katie made the following reference to the emotional impact that arises from providing care to dying patients:

I remember [after losing a certain patient] I cried on the way home. I don’t know why…I’ve de-escalated on kids before. I think it was just the story of how this guy came home, hugged his son, and the kid just died right there. That really gives you a greater appreciation for, you know, the work that you do, and how you live your life. Those are the toughest. I cried in my car for a while. It’s emotionally…you know end-of-life care is very emotionally draining. It is. It’s hard.

Brian spoke of one patient in particular he had built a relationship with over time:
I’m not going to say her name, but she had terminal cancer. A six-year-old child who was in and out of the hospital a lot. For some reason, she always ended up in my section so we developed a really close relationship with each other. I would go and color with her, or watch a movie. We even did a few things outside the hospital when she was feeling better, so I was really close to her family as well. Maybe 4 or 5 months ago the patient passed, and it really sticks with me because of the relationship I had built with her. When she was receiving end-of-life care, it was very painful for me…and for other caregivers…from an emotional standpoint.

Discussion of the emotional toll end-of-life care can take on a therapist was not limited to patient care experiences that were deemed “negative” by the interview subjects. Simply functioning in an arena where death is not uncommon was seen as a source of emotional stress, even when the experience was viewed as a positive one by those involved.

Education

The sub-superordinate theme of Education was supported by the emergent themes Definition of End-of-Life Care, Prior End-of-Life Education, and Need for More End-of-Life Education.

Definition of end-of-life care. A common theme among all respondents related to their definition of end-of-life care was the necessity to “provide comfort” to terminally ill patients. One definition spoke of “giving them [the patient] morphine…basically keeping them comfortable.” Both physical and emotional comfort were addressed by a majority of the subjects. All 8 respondents referred to the “control of pain and suffering”
in their definition of end-of-life care. While physical comfort was mentioned solely as pharmacological intervention, emotional comfort was described in various ways. John described the provision of comfort as an effort to ensure that patients’ “last memories are generally good ones…without pain and any sort of general sadness.” Cara felt that comfort as making sure both patients were without “unbearable” physical pain and were allowed to say goodbye to family members. Brian, who works in pediatrics, described end-of-life care as a combination of “the things we have in place for [pediatric] patients and even specifically for parents…that address how to deal with kids that are suffering from a terminal illness…preparing the parents and preparing the patient for what is about to come.” Brian was the only subject to mention the use of therapy dogs in the treatment of terminally ill patients.

Part of their definition of end-of-life care that was common among respondents was the provision of emotional care toward family members. Both Brian and Cara mentioned providing emotional support for the patient’s family members. Brian stated that his facility provided specific support “for parents of kids with a terminal illness” designed to help them communicate effectively with their child.

Prior end-of-life education. All 8 subjects noted that they had received some form of end-of-life education during the course of their formal education. Three subjects stated that this formal education was brief and focused around the common theme of cultural differences toward the processes of death and dying. According to Carol, “the only end-of-life care teaching…was in school. What I remember from that is mostly how different cultures deal with death and dying.” Katie stated that her coursework “went
through different scenarios and different cultural practices…what you do in a given situation and how you would want your family to treat you if you were the patient.” Only Brian stated that his employer offered ongoing support and education for those who worked in the critical care arena that was specifically designed to address both personal and professional issues associated with the provision of end-of-life care. Brian referred to the events as “retreats” and stated that:

They offer them every three or four months in the PICU area they send out like an email. You have to get accepted to go to the retreat…only 15 or so people can go. They offer massages, feed you, and do a few other things to pamper you a little bit. But again, the main idea is to have a few physicians there along with nurse management and respiratory management, and it’s all geared around how you and the other staff are dealing with your patients dying…we see these things on a daily basis and they want to make sure we’re not getting burned out from seeing it so much.

Except for the focus on “cultural education,” only one of the participants described any of their institutions of higher education discussing end-of-life issues pertaining to the Needs for the Care Provider in any detail.

Need for more end-of-life education. Brian was the only one of the eight subjects interviewed for the study mentioned the opportunity to participate in any form of end-of-life educational experience since graduating from college. Brian, who works in pediatrics, noted that the unit he works in offers several “retreats” each year where staff can meet with clergy, physicians, counselors, and other staff members in an off-campus
setting to receive education on topics such as pain control, death and dying, and self-care for the provider. The remaining subjects noted a need for more end-of-life education at both the undergraduate and practitioner levels as well as in other care settings. Carol stated:

There needs to be more education [on end-of-life care] in primary care offices and regular outpatient offices, not just in acute hospital settings. Because obviously by the time you get to the hospital, something’s really going on and you’re not prepared to hear all that.

While the noted lack of continuing education for practicing therapists was of concern to the 7 of the 8 interview subjects, Brian’s experience with palliative care retreats represented a novel approach to filling the void. Overall there seemed to be a lack of end-of-life education at both the undergraduate level and continuing education level.
CHAPTER 5

DISCUSSION, CONCLUSIONS, AND IMPLICATIONS

The purpose of this study was to better understand the lived experiences of respiratory therapists who provide end-of-life care to their patients. The following research questions were used in an order to fulfill that purpose:

Major Research Question: What are the lived experiences of respiratory therapy students regarding palliative care situations?

The following sub-questions were used to gather the information necessary to answer the major research question:

1. How do recent RT graduates perceive their ability to perform end-of-life tasks?
2. To what extent are recent RT graduates emotionally affected by a lack of end-of-life education?
3. To what extent do recent RT graduates believe that their ability to perform their jobs effectively is influenced by their experience with end-of-life education?
4. To what extent do recent graduates perceive that the current program adequately addresses the issue of End-of-Life Education?

The theoretical framework for this study was based upon Resilience Theory as it applies to the ability of healthcare workers to cope with the various forms of stress and
adversity that accompany the provision of end-of-life care. A phenomenological approach was utilized that included a series of interviews with practicing therapists who had graduated from respiratory therapy school within the last 5 years. Interviews were transcribed and analyzed, producing total of three superordinate themes were described and supported by 10 sub-superordinate and 28 emergent themes.

Summary of Major Findings

A total of 8 interviews were recorded and transcribed in order to address the research question. During the coding process, three superordinate and 10 sub-superordinate themes were assigned. The 10 sub-superordinate themes gave rise to a total of 29 emergent themes.

Needs for the Patient

The sub-superordinate themes associated with Needs for the Patient include the concepts of Suffering, Time, and Honesty.

Suffering. Emergent themes associated with the concept of suffering included comfort, quality of life, and futility. Respondents noted the ability to minimize pain (thereby maximizing patient comfort) during end-of-life care. Seemingly as important as physical comfort was the concept of quality of life. The majority of therapists interviewed stated that providing mechanical support with the goal of extending the lifespan of a terminally ill patient with no hope for an improvement in their subjective quality of life was paramount to doing harm. Similarly, interviewees stated that participating in futile care was a source of job-related stress and lead to feelings of stress
and discontent with their role as a critical care provider. Such feelings regarding the negative impact of prolonging patient suffering are in line with the findings of previous studies in other professions such as nursing and medicine (Dzeng et al, 2016; Choe, Kang, and Park, 2015; Meltzer and Huckabay, 2004).

Time. Emergent themes associated with the concept of time included time to prepare, time to say goodbye, educate early, and the timeliness of death. Subjects use of the word was associated with a perceived lack of time for both families and patients to accept the concept of incurable disease and prepare themselves for the terminal phase of the process. Therapists also noted that a number of physicians found it difficult to discuss terminal care with the patients, and that discussion avoidance was the source of great concern. By avoiding conversations regarding terminal illness with terminally ill patients, subjects felt that both patient and family were being robbed of the most precious, yet fleeting gift they have during end-of-life: time. These findings are consistent with those of other researchers both domestic and international (Evans et al, 2014; Walczak et al, 2014; Aline et al, 2015).

Honesty. Emergent themes associated with the concept of honesty included what to expect and discussion avoidance. Respondents felt that physicians and physician-extenders were doing a disservice to both the patient and their family by failing to prepare them for the progression of their disease. Some felt that discussion avoidance was a form of dishonesty that could lead patients and their families to believe that they had more time left than modern science suggested. Also of concern was the act of using all means necessary to keep the patient’s heart beating and lungs working when therapists
felt the patient would never regain consciousness or achieve what some may consider an acceptable quality of life. The impact of futile care on provider burnout is well-documented in the literature (Meltzer and Huckabay, 2004; Ferrell, 2006; Wilson, Goetmeller, Bevan, and McCord, 2013).

Needs for the Family

The sub-superordinate themes associated with Needs for the Family include Support, Compassion, and Engagement.

Support. Emergent themes associated with the concept of Support include support for the family and support for the patient. Cara and Tom both stated that their current facility employed a palliative care physician who specialized in providing end-of-life care to patients in need. Such physicians are experienced with the conversations surrounding end-of-life care and how to offer support through such mechanisms as social work and spiritual support (Sheetz, 2008; Bui, 2012; Bui 2013; Ihrig, 2015).

Respondents who worked at a facility that did not employ a physician or physician-extender who specialized in palliative care either felt that the hospital either lacked effective resources, or if resources were available, that patients and their families were not aware. These findings are in line with existing literature on the effectiveness of palliative care teams (Seow, 2016; Walker, Mayo, Kamir, and Kearney, 2013).

Compassion. Emergent themes associated with the concept of compassion include the provision of a calm environment and respect for the patient. In one example, Carol referred to a case where the patient’s spouse was present during a chaotic period when the patient had unexpectedly entered cardiac arrest. She showed concern for the
spouse but also detailed the stressful impact the situation had on her own ability to provide proper care to the patient.

Engagement. Emergent themes associated with the concept of engagement include the knowledge of patient’s wishes and the family being allowed to participate in the end-of-life experience. Both themes were considered by respondents to be integral to the family’s ability to have a positive experience during end-of-life care.

Needs for the Care Provider

The sub-superordinate themes associated with Needs for the Care Provider include Memorable Experiences, Coping, Stress, and Education.

Memorable experiences. Emergent themes associated with the concept of memorable experiences include positive experiences, negative experiences, difficult experiences, and appreciation. All interviewees immediately recalled their most memorable experience when prompted to do so. Seven of 8 (88%) claimed to have more than one memorable experience. Experiences were divided into two major groups: those that were positive and those that were negative. Respondents described positive experiences as those where patients received appropriate care in a timely manner and were given as much notice as possible regarding their timeliness of their condition.

Coping. Emergent themes associated with the concept of coping include friends, retreats, self-care, and chaplains. While multiple subjects stated that they intentionally associate with friends who do not work in healthcare as part of their coping process, Brian was the only respondent to describe in detail the use of organized staff retreats as a mechanism of coping with the stress associated with the provision of end-of-life care.
Self-care was a common theme among those interviewed, and was represented by such efforts as exercise, talking with friends and family, and other sources practitioners may access outside of the clinical setting. While chaplains were mentioned numerous times as an available coping mechanism, respondents stated that they personally did not seek advice or guidance from members of the clergy.

Stress. Emergent themes associated with the concept of stress include burnout and leaving the field. While all subjects had been practicing therapists for an average of 2.875 years (Table 1), all were aware of the potential for unmanaged work-related stress to result in practitioners leaving the field of healthcare in order to seek employment in a less stressful field.

Education. Emergent themes associated with the concept of education include the definition of end-of-life care, prior end-of-life education, and the need for more education on end-of-life care. While no two subjects had identical definitions of what end-of-life care meant to them, there were similarities among all. Subjects used the terms “palliative,” “terminal,” and “comfortable” when espousing their personal definitions. Other common terms include “preparing the patient” and “preparing the family.” All subjects stated that the concept of palliative care and end-of-life had been touched on during their undergraduate experience, only one subject, Brian, claimed to have had any formal educational exposure since graduating. Brian’s facility offered staff retreats aimed at helping care providers better understand and deal with the stress associated with their job. All 8 interviewees felt that there was much room for improvement claimed
they saw a need for more end-of-life education both during their undergraduate experience and during their time in the workforce.

Discussion of Findings

Findings in the study were centered around the superordinate headings of Needs for the Patient, Needs for the Family, and Needs for the Care Giver.

Findings Associated with Needs for the Patient

Findings associated with the needs for the patient were centered around the concepts of suffering, time, and honesty. The therapists who were interviewed for this study felt that it was their duty, as well as the duty of the rest of the healthcare team, to minimize patient suffering at all costs. Failure to do so was perceived by the therapists as failure to provide adequate care and resulted in considerable stress for those involved. Honesty was seen to be a requirement of proper end-of-life care in that it allowed patients time to prepare themselves for their end-of-life experience. Healthcare providers who avoided conversations regarding end-of-life care were seen by the RTs as doing the patient a disservice in that their actions, or lack thereof, were preventing patients from making effective use of the time they had left. These findings are in line with those of Erichsen, Danielsson, and Friedrichsen (2010), whose phenomenological study concluded that honesty was a positive quality that nurses and other caregivers should exhibit whenever possible.

Findings Associated with Needs for the Family

Findings associated with needs for the family were centered around the concepts of support, compassion, and engagement. The concept of support is diatomic, in that it
can refer to a support system for the patient or a support system for family members themselves. The respiratory therapists interviewed for this study felt that both systems were relevant to the provision of adequate patient care. Perhaps nowhere is this concept as apparent as it is in the field of pediatrics. Brian, who works in pediatrics, made frequent reference to his patient’s parents. He stated that he sometimes felt as though he were caring for three patients at a time: the patient, the patient’s mother, and the patient’s father. Failure to provide support for the family, be it from a spiritual, psychological, or emotional standpoint, was seen as a failure.

This study also found that therapists see compassion toward the patient an integral part of successful end-of-life care. Therapists saw lack of compassion as a stressor for the family, which in turn caused them to experience a sort of “stress by proxy.” The same may be said for the idea of family engagement. These findings are in line with those of Kirby, Broom, Good, Wootton, and Adams (2014) who found that special attention should be paid to the role of family during key moments of palliative care in an effort to comply with the “current movement toward the family as the ‘unit of care’ at the end of life” (p. 338).

Findings Associated with Needs for the Care Provider

Findings associated with needs for the care provider include memorable experiences, coping, stress, and education. Therapists interviewed for this study considered both positive and negative end-of-life experiences to be “memorable.” Provider descriptions of positive end-of-life experiences were in line with what Meier and Montross (2016) would consider “a good death.” Meier and Montross’ study
identified 11 core themes associated with the concept: preferences for a specific dying process; pain-free status; religiosity/spirituality; emotional well-being; life completion; treatment preferences; dignity; family; quality of life; relationship with healthcare provider; and “other.” Negative patient care experiences were considered to be a source of stress for the practicing therapists, and could be mitigated by such coping mechanisms as time with friend and family, participating in staff retreats, or seeking spiritual guidance. These methods of coping are similar to those found in a 2010 study by Von Rueden, et al in the *Journal of Trauma Nursing*.

The burden of emotional stress was considered by 5 subjects to be “a part of the job.” Minimizing the short-term impact of stress was viewed as a goal among the respondents, however the idea of long-term stress was rarely mentioned. This could be due to the relatively young age of those interviewed, in that they have not yet reached a point in their lives where they begin to look ahead to the mid-point, or end, of their career. All 8 subjects who were interviewed for this study considered their current level of end-of-life education to be less than optimal. All 8 also described a need for more end-of-life education during the course of their undergraduate or graduate studies, as well as during the span of their career.

**Conclusion and Recommendation for Future Research**

The regularity with which respiratory therapists participate in end-of-life care is a proven source of work-related stress (Giordano, 2000). Using an interpretative phenomenological analysis approach, this study analyzed a series of interviews with recent respiratory therapy graduates in an effort to realize their lived experiences with the
phenomenon of providing end-of-life care. Subjects responses were categorized into the superordinate themes of needs for the patient, needs for the family, and needs for the care provider. Perceived shortcomings in any of these three thematic areas can be a source of stress for the practicing therapist. Program directors, departmental chairs, and others involved in designing the educational curriculum for future practitioners should consider incorporating coursework aimed at addressing these sources of stress in an effort to mitigate their impact on future therapists. Failure to do so could negatively impact their ability to remain a productive member of the workforce as the effects of such long-term stressors may lead to practitioner burnout, increased turnover rates, and less effective patient care. Recommendations for further study in this area include a curriculum survey to discern where, if at all, end-of-life education is occurring among degree-granting institutions and surveying hospital-based department educator in an effort to determine if end-of-life care is part of the orientation curriculum for new hires.
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Kaufman, S. R. (c2005). *And a time to die: how American hospitals shape the end of life.*


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APPENDIX A:

RECRUITMENT EMAIL
Dear Respiratory Therapist,

My name is Chip Zimmerman, and I am currently working on my Ph.D. in Educational Leadership at Mercer University under the supervision of Dr. Elaine Artman. As part of my research, I am asking for your participation in an interview designed to determine the impact of end-of-life education on practicing respiratory therapists. The interview session should last for approximately 30 minutes and can occur face-to-face, via video conference (Skype or FaceTime), or on the telephone. Rest assured that there are no perceived risks associated with participating in the interview process, and should you decide to participate, any and all information that you share will be held in the strictest confidence. No identifying information will be released at any time. Please also note that participation in this study is completely voluntary. If you decide to participate, you may stop the interview process at any time without loss of benefits or penalty.

If you are interested in sharing your thoughts and experiences on end-of-life education, please respond via email to chip@gsu.edu and I will contact you to arrange a time and date. If you have any questions or concerns regarding the solicitation of your participation in this study, or in the interview process itself, please feel free to contact Chip Zimmerman at chip@gsu.edu or Dr. Elaine Artman at artman_em@mercer.edu.

Thank you for your time.
APPENDIX B:

MERCER IRB APPROVAL
05-May-2016

Mr. Ralph Zimmerman
Mercer University
Tift College of Education
3001 Mercer University Dr
Atlanta, GA 30314

RE: End-of-Life Education Experiences of Respiratory Therapists: Implications for University Leadership (H1604136)

Dear Mr. Zimmerman:

Your application entitled: End-of-Life Education Experiences of Respiratory Therapists: Implications for University Leadership (H1604136) was reviewed by this Institutional Review Board for Human Subjects Research in accordance with Federal Regulations 21 CFR 56.110(a) and 45 CFR 46.110(b) (for expedited review) and was approved under Category 6, 7 per 45 CFR 60364.

Your application was approved for one year of study on 05-May-2016. The protocol expires 04-May-2017. If the study continues beyond one year, it must be re-evaluated by the IRB Committee.

Item(s) Approved:

New application for qualitative research design that will utilize an interpretative phenomenological approach via interviews and use of audio and/or videos

Please complete the survey for the IRB and the Office of Research Compliance. To access the survey, click on the following link: https://www.surveymonkey.com/s/K7CTIBR

"Mercer University has adopted and agrees to conduct its clinical research studies in accordance with the International Conference on Harmonization’s (ICH) Guidelines for Good Clinical Practice."

Respectfully,

Ava Chambliss-Richardson, M.Ed., CIP, CIM
Member
Institutional Review Board
Mercer University IRB & Office of Research Compliance
Phone (478) 301-4101
Fax (478) 301-2329
ORC_Mercer@Mercer.Edu

1501 Mercer University Dr. | Macon, Georgia 31207-0001
(478) 301-4101 | FAX (478) 301-2329
Title of Project: End-of-life education experiences of respiratory therapists: Implications for university leadership

Investigator Name: Chip Zimmerman
E-Mail Contact Information: chip@gsu.com

You are invited to participate in an online survey for a research project conducted through Mercer University. Mercer University’s IRB requires investigators to provide informed consent to the research participants.

The purpose of this study is to better understand the lived experiences of respiratory therapists who provide end-of-life care to their patients. Your participation in the study will contribute to a better understanding of end-of-life education. You must be at least 18 years old to participate.

If you agree to participate
The interviews will take approximately 45-75 minutes of your time. The individual interview will be via a meeting, phone or WebEx at your convenience. You will not be compensated.

Risks/Benefits/Confidentiality of Data
There are no known risks which could cause you to feel uncomfortable or anxious. There will be no costs for participating. Although your participation in this research may not benefit you personally, it will help us understand how respiratory therapists perceive end-of-life education. Your name and e-mail address will be kept during the data collection phase for tracking purposes only. All identifying information will be removed during data analysis including names and e-mail addresses.

Participation or Withdrawal
Your decision to participate or decline participation in this study is voluntary. You may decline to answer any question and you have the right to withdraw from participation at any time. Withdrawal will not affect your relationship with Mercer University in any way.

Contacts
If you have any questions about the study contact the investigator Chip Zimmerman at (404) 273-5403 or chip@gsu.com. Mercer University’s Institutional Review Board (IRB) reviewed study #111604136 and approved it on 05-May-2016.

Questions about your rights as a research participant
If you have questions about your rights or are dissatisfied at any time with any part of this study, you can contact, anonymously if you wish, the Institutional Review Board by phone at (478) 301-4101 or email at ORC_Research@Mercer.edu.

Participant Signature: ___________________________  Date: _____________

Investigator Signature: ___________________________ Date: _____________