A Thesis

entitled

Toward a Nursing Theory for Providing Transcendent End-of-life

Care to Patients and Their Families.

by

Spencer H. Rizk

Submitted to the Graduate Faculty as partial fulfillment of the requirements

for the Master of Science Degree in Nursing - Family Nurse Practitioner.

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May 2018

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An Abstract of

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Death is an unavoidable aspect of life which often requires end-of-life care in a healthcare setting. End-of-life care could be optimized with a holistic approach to care which includes supporting both the patient and their loved ones throughout the dying process as well as into the immediate post-death period.

To understand perceptions of the families who had experienced a loss of a loved one, a one-time focus group was held. Using Colaizzi's (1978) process of descriptive phenomenological data analysis, the researchers discovered themes based on focus group discussions. Themes included education of patient, family, and caregivers; emotional, cultural and spiritual support for both patient and family; empathy; time; both physiological and environmental comfort for the patient; and effective communication for both the patient and family. All of these themes were necessary for obtaining transcendent end-of-life care.

For Peggy Sue, everything I do, I do for you.

For Dad, for teaching me how to be a man and constantly supporting my goals.

For Lion, for keeping me smiling, confident, and mostly sane throughout this entire process.

For Keith, for inspiring me to always follow my dreams.

For Ann, in hopes all that is learned by this project may make you proud of your favorite nephew.

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# Chapter One

## Introduction

From the minute we are born, there is an unknown, semi-modifiable countdown which begins to signal our deaths. Everyone is aware they will one-day die. The reality of the not knowing the when or how in which death will occur forces most humans to instead attempt to prevent both morbidities and mortalities through modifying their lifestyle and thus lowering their risk factors that hasten death.

Entire lives and careers are dedicated to postponing death while caring for the living. Yet each day that passes, death is one day closer, unwavering. It is inevitable and unavoidable. Leaving loved ones behind creates sadness and shakes even the most stoic of individuals. Depending on the individual and their spiritual beliefs, often the unknown timeframe, possibility of pain, damage to family and relationships after death, all lead to fear. These beliefs and views on death and dying have changed over the years and now, arguably more than ever, there is an increased focus for improved end-of-life quality of care.

Individual views on the dying process vary based on a multitude of factors including, but not limited to, their culture, geography, educational level, and history of involvement in the dying process. The dying process is one which has been in constant reform over the ages (Banjar, 2017). Beginning in the early 20$^{th}$ century, death was seen as a natural unavoidable occurrence but this ideology rapidly evolved. By the 1960's the "tame death outlook" evolved into a newer approach focused on avoidance of death and extension of life (Banjar, 2017).

Thoughts surrounding the dying process evolved at this time due to technology advancement with an increased focus on prevention. Additionally, there were new practices in place to physically mask the reality that death had occurred through funeral homes and embalming services. By the 1990's there was an increased focus on avoidance of death versus prevention or acceptance that it would, or had occurred. Many individuals during this time chose to ignore the possibility that death may occur and this led to an advancement in life preserving methods like: increased ICU utilization, technological advancements, increased research funding and completion, private funerals, closed caskets, and unrealistic expectations of care (Banjar, 2017). Thoughts on the dying process have since evolved into what they are today. People now live with hopes of life elongation through emphasis on health care advancements and extreme measures in the critical care to extend life such as, longer time on ventilators, untested or risky procedures, among other expensive tests deemed unnecessary to terminal outcome by the healthcare staff. Palliative care may begin in the critical care setting in order to provide the patient with contentment as early as possible. Ethical dilemmas pertaining to death and dying exist across the U.S. including physician assisted suicide, and euthanasia. Both of these dilemmas discussed in an effort to ease fears of dying and decrease time of discomfort before death and give individuals feelings of increased control over their death? (Banjar, 2017).

Humans have always desired to live long lives and when dying, desire to have the most peaceful death as possible (Banjar, 2017). New focus on end-of-life care bundles (predetermined groups of various interventions provided to ICU staff to help improve end-of-life care), are becoming increasingly important as family members are expecting

vast improvements in caring for their loved ones in their final moments. For example, family members are monitoring the status of their loved one to assure he or she is experiencing minimal pain, increased comfort, and increased attention and care from staff. Family for this study is described as all those viewed as having significance to the patient regardless of blood relation such as close friends or neighbors likely to be present at end-of-life.

Patients and families may benefit by enhancing interventions and caring services performed during and after end-of-life care. These benefits include achieving overall contentment with the dying process through multi-faceted care addressing concerns with optimal pre- and post-death care, acceptance, adequate understanding of the process, personal needs, needs of the family, and optimization of comfort and serenity. To guide nurses in their nursing care of the dying, there are currently only basic protocols and standards of care. Therefore, development of a middle-range theory to guide nursing actions during and after end-of-life is necessary for optimization of care.

**Purpose**

The purpose of this study is to develop a middle-range theory based on healthcare to improve the overall experience of the end-of life process for a patient and his or her family.

**Significance of the study**

Currently, few studies exist on the effect of end-of-life healthcare interventions on a patient or the value in the effects these interventions have on the patient's family. Healthcare, for this study, is defined as an interdisciplinary team including various health-related disciplines such as nursing, social work, palliative care, and medicine. The

completion of this thesis, in addition to a supporting study with the intention to utilize conclusions to produce a middle-range theory, has the potential to both fill in knowledge gaps needed for care of the family of one who is dying as well as positively affecting the end-of-life experiences for potentially, millions of individuals.

## Chapter Two

## Theorectical Framework

Ruland and Moore's middle-range nursing Peaceful End-of-Life Theory will be used to guide the development of this theory (Ruland & Moore, 1998). Ruland and Moore's nursing theory addresses an all-encompassing approach to end-of-life care (Gunther, 2010). Both theorists were experienced in caring for the dying patient and advocated heavily for advancements in healthcare during this difficult but, important, time in an individual's life. Ruland and Moore (1998) advanced their theory based on 5 different concepts including: absence of pain, experience of comfort, experience of dignity and respect, being at peace, and closeness to significant others. Each category encompasses a different aspect of the dying process and does not fail to include post death which many other theorists frequently do such as: Katharine Kolcaba's Theory of Comfort (2003) and Kristen M. Swanson's Theory of Caring (1998). Kolcaba's Theory of Comfort (2003) does address caring interventions for patient as does Swanson's Theory of Caring, but neither specifically include care for the patient and family after death has occurred. This is not unusual for nursing theorists, but it is a gap in knowledge this thesis intends to fill.

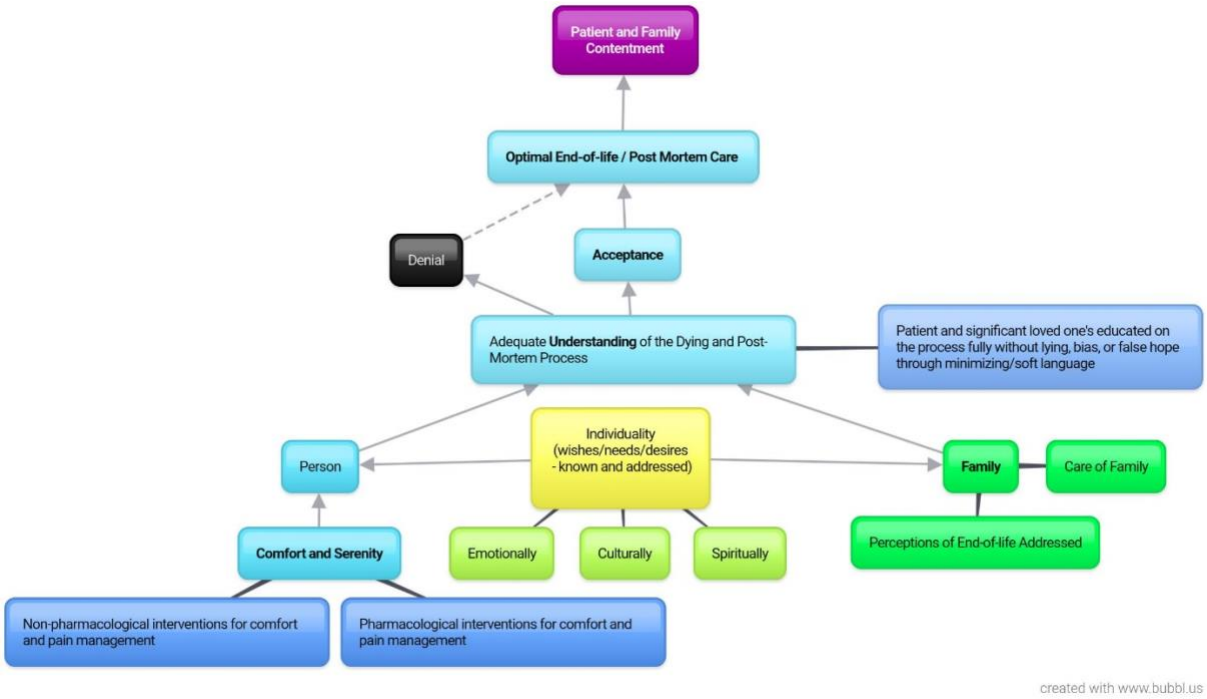
Ruland & Moore spoke with multiple coworkers and friends and discovered that there was a lack of direction and management of complex care during end-of-life. To correct this gap in care, Ruland & Moore's theory on Peaceful End-of-Life was developed. Ruland and Moore continually edited and revised their theory in order to fit the evolving healthcare field. Eventually the culmination of this work became known as, the Peaceful End-of-Life, middle range nursing theory, (Higgins & Hansen, 2010).

Ruland and Moore's theory of Peaceful End-of-Life encouraged additional research into pre and post death healthcare. The theory, however, did not specifically discuss the patient and family's views on end-of-life care interventions, and the effects of such interventions on all those involved. This research study is being completed to identify specific methods of improving end-of-life care for patients and their families, based on personal perceptions, and to expand upon areas not discussed in Ruland and Moore's theory.

**Research question**

Based on the perceptions of the families of past loved ones, which healthcare interventions made a positive [and] or negative impact on their overall end-of-life experience?

*Figure 1*. Concept map constructed pre-study based on health care literature




(Rizk, 2017)

**Concept Map**

Overall the goal of this research study is to find methods to increase a patient and their family's overall contentment with the dying process. Contentment should include optimization in end-of-life care and post mortem care.

Acceptance of death before dying is a common goal in patient care at end-of-life. (Hinton, 1999). Acceptance is defined by the English Oxford Dictionary as willingness to tolerate a difficult situation (Acceptance, n.d.). Acceptance and awareness of death are both crucial to an ideal end-of-life situation. Each individual and his or her family have the ability to accept death, but this ability is something that may need fostered by the healthcare team in order to assist the patient and family in reaching it.

In the concept map (Figure 1), it is easily visualized that denial is a counterproductive detour on the journey to acceptance and thus overall contentment. Ideally, the patient would move from acceptance to contentment but due to the worldwide phenomenon of fearing death increasing in the last century, this is often not that case (Banjar, 2017). However, this is not to say that interventions should cease when acceptance is not likely to be achieved. There is a dotted line connecting denial to optimal end-of-life care because interventions are designed to make end-of-life care as ideal for the patient, family and significant others, as possible. However, in times in which acceptance is unattainable due to certain conditions for example, lack of time before death, or sudden terminal diagnosis; acceptance may be difficult or even unrealistic and interventions may continue to achieve as many goals of end-of-life care as possible.

Adequate understanding of the dying and post-mortem process is crucial to attainment of overall contentment with end-of-life care. Patients and their families should feel adequately educated on the process, and continually feel they have an effective understanding of the end-of-life experience. Often family members will state they feel they were lied to or the truth was omitted or "smoothed" over in an effort to reduce their sadness at end-of-life and this may be true (Jin, 2016). This type of "soft language" has riddled healthcare and is counterproductive to adequate understanding by the patient and their family. In order to progress to acceptance, the patient and their families must be educated fully on the dying process and what to expect, even if this education could cause emotional distress. Ruland & Moore agree and discuss educating without bias as crucial to maintaining dignity and respect of the patient and their families. It is ethical to treat the patient as an individual deserving equal attention and to not allow their illness to change

the language in which staff would educate, especially if this were to include falsehoods (Consales, 2013).

Person and Family are interrelated and demonstrated by double sided arrows connecting the two concepts. Between these concepts is Individuality which includes spiritual, cultural, and emotionally competent care. These aspects of care are important to address from each individual's perspective in order to achieve overall contentment. Ideally each individual would have their needs, wishes, and desires known and addressed by the healthcare team.

Each concept is further divided into specific areas that need to be met to attain overall contentment. As discussed briefly above, person is divided into two important aspects of end of life care necessary to be addressed, individuality and Comfort. Individuality includes addressing factors such as: wishes, needs, and desires in order to provide a holistic approach to care in supporting the emotional, cultural, and spiritual needs of the individual. Comfort measures would include both pharmacologic and non-pharmacologic approaches to care. These multi factorial aspects of care need to be addressed in order for the patient to achieve contentment. Spiritual, emotional, and cultural needs are viewed as important by multiple theorists and healthcare professionals in end-of-life care (Sampson, 20114). Ruland & Moore believed emotional and spiritual support to be the most important to achieving peace, one of their theory's major concepts (2013). Ruland & Moore believed meeting the patient's wishes, needs, and desires, as crucial to the patient's dignity and respect. Each individual patient is "respected and valued as a human being" (Ruland & Moore, 1998, p.172). These factors of care were gathered and labeled by Ruland & Moore as personal worth. Personal worth includes

autonomy and respect for persons, which includes meeting all the possible patient's needs, wishes, and desires during end-of-life care.

Family is separate in both distinction and color within the map, from person, because sadly, not all dying individuals will have families present. When present, the family's contentment in the dying process should be seen as a separate, yet related, effort to achieving overall contentment by all parties. The relation is demonstrated by also being connected with an arrow to aspects important to all individuals involved and that is meeting their spiritual, cultural, and emotional needs. This is achieved by making their wishes, and desires known and addressing them appropriately. Ruland & Moore discussed family involvement and care at end-of-life under the term closeness (2013). Ruland & Moore identified that families should not only witness, but participate in care for their loved one. Ideally this involvement would promote opportunities for each party to feel close to one another before imminent death. Similar to the needs of the individual, it is important to tend to the family's grief, worries, and questions surrounding care which may differ from the patient but should be addressed or discussed regardless (Ruland & Moore, 1998).

Comfort is a term heavily discussed by Ruland and Moore and includes: preventing, monitoring and relieving physical discomfort, facilitating rest and relaxation, preventing complications, monitoring and administering pain relief, applying pharmacological and nonpharmacological interventions to aide care (2013). The goal of comfort is to reduce the pain of the patient to a level which can be perceived as tolerable or comfortable (Jin, 2013).

## Review of the Literature

**Contentment.** To be content, is defined by the Oxford English Dictionary simply as, having one's desires met; not disturbed by the desire for more, something different, pleased (content, adj.2 and n.4, 2017). In turn contentment can be seen as a "state of overall happiness and satisfaction" (contentment, n, 2017). Ruland and Moore included the word contentment in their definition of peace - "a feeling of calmness, harmony, and contentment, free of anxiety, restlessness, worries, and fear" (Ruland & Moore, 2001). Contentment was not explicitly defined by Ruland and Moore but was encompassed by the definition of peace per the theorist's experiences with the term in their respective practice's.

Considering all definitions, for this research study contentment in end-of-life care is defined as, the overall satisfaction of expectations and lack of additional achievable desires at end of life by both the patient and their family. This can also be elaborated upon as having hope and feeling at peace with the inevitable outcomes. Hope at end-of-life should not be of living but of achieving a peaceful, meaningful death (Copp, 2001). Patients would ideally feel their life had meaning, their memories will be retained in the families around them and feel reasonably comfortable throughout the time of their end-of-life care.

**Optimal end-of-life care.** To be optimal, end-of-life care should begin with pre-death care and then extend past death and focus on both the patient and their families' care. Optimization of end-of-life care is dependent on multiple other factors such as: acceptance vs. denial, adequate understanding of the end-of-life process, family, care of family, perceptions of end-of-life, individuality, spiritual and cultural needs, patient

involvement, comfort and serenity, and pharmacological and non-pharmacological interventions.

Rogers poised that each aspect of a patient's health is modifiable and each person is able to be cared for through multiple interventions until they achieve overall wellness which Rogers held as the highest goal of her theory (Rogers, 1994). In an interview with Jacqueline Fawcett in 1987, Rogers mentioned how the Science of Unitary Human Beings is exactly that, "a science…humans exist as modifiable energy fields, infinite, ever changing, innovative...everything we observe is part of this process" (1989). One of Rogers's theoretical concepts is that of an energy field, inspired by scientists including Albert Einstein, Harold Burr, and Filmer Northrop. Rogers dictated that humans are made of energy fields which are infinite, constantly changing, evolving, and affecting its surrounding. Energy is neither created nor destroyed so the inclusion of post death in her theory is supported by the idea that humans even after death possess an energy to them which should be nurtured in similar fashion to a living person (Rogers, 1994).

Watson also discussed her inclusion of post death in her theory of Transpersonal Caring (1989). Watson's 10 Curative Factors include a wide array of broad "goals" but these "goals" of care are also helpful in guiding this research study, utilizing a humanistic-altruistic system of values, instilling faith or hope when appropriate, trusting relationship development, support and protection, gratification of human need, and recognizing and including caring for existential-phenomenological forces (Jesse, 2010). Existential and phenomenological forces are complex terms but can be simplified as addressing the way a human sees themselves compared to the world, their existence, and addresses an individual's thoughts, consciousness or self-awareness (Watson, 1989).

The focus on end-of-life care outcomes for patients and lesser focus on the families of these patients has led to multiple studies on how to improve the end-of-life care experience. In a survey asking suggestions on improving end-of-life care, over 1400 critical care nurses replied with similar themes (Beckstrand, Callister, & Kirchoff, 2006). Main suggestions included: not allowing the patient to be alone at time of death, managing pain and discomfort, knowing advanced directives and other patients' wishes ahead of time, promoting cessation of invasive or traumatic treatments earlier when diagnosis is terminal, and increased education for all involved in the care process (Beckstrand et al., 2006). Barriers to the process were found to be nursing time constraints, poor staffing, communication challenges, and physician treatment preference. Out of all of the barriers, time was the most significant barrier discussed by the critical care nurses, even some going as far to say that due to the time restraints in the ICU, a dignified or "good death experience" was unlikely in the critical care setting. Overall, the researchers concluded that a system of implementation using findings obtained from experienced critical care nurses could increase the quality of end-of-life care (Beckstrand et al., 2006).

Another study by Sampson, Finlay, and Byrne (2014) gathered primarily from the patient's perspective attempted to determine what areas of care the patients felt made a positive influence on the palliative care they received while battling a terminal diagnosis. Free text responses (N=594) were systematically analyzed and themes emerged demonstrating areas of care viewed as most important to patients in end-of-life care. Overall, the emotional experience of care, including interventions dealing with autonomy, connectedness, and relationships, seemed to make the largest impact on

patient reports of care satisfaction. Sampson (2014) found emotional care to be more important to the individual themselves which was odd because similar studies conducted from the caregiver's perspective, place the importance of care in physical symptom relief like pain management. The centralization of the emotional aspect as important to care has implications for end-of-life care in that there needs to be increased emotional interventions of care alongside the traditional interventions like pain management (2014).

When terminal patients are asked, what would they want most in care, they often include answers with some form of the following: relief of pain and symptoms, a sense of control, open discussions with physicians, time to strengthen relationships with families, and avoidance of burdening families (Jin, 2013). If care interventions are based from these responses, the interventions should include a checklist of items such as: regularly assessing symptoms like pain, comfort, ease of breathing, and agitation. There should also be an offer of spiritual care if needed and a consideration for where death is going to occur such as at home, hospice, hospital, or another location.

Overall, optimal end-of-life care is a combination of the achievement of multiple factors performed by all those involved in the end-of-life situation. These achievements in care then proceed onward and their success is determined by the patient and family's overall contentment.

***Acceptance vs. denial.*** Death is disconcerting to most human beings which is frequently the reason repression or denial can be viewed as a natural or functionally necessary emotion but acceptance would be the ideal (Zimmerman, 2007). Copp (2002) conducted a study to examine the use of denial and acceptance as interdependent and fluctuating coping mechanisms of patients and their families. Twelve hospice patients

and their families were studied through interviews to determine the presence of both denial and acceptance at time of dying along with factors contributing to the extent of each. Acceptance by dying patients and their families has not only been seen by caregivers as an important aspect of care but has even been viewed as “morally imperative” (Copp, 2002). Dying individuals were found to use denial and acceptance as a means of coping and to varying degrees which is why it is important to move towards an open awareness culture of death in the healthcare setting. Acceptance should always be seen as the ideal in end-of-life care but denial should be addressed as equally important to some patient’s mental stability. Educating health care teams on proper communication at end-of-life may be able to provide patients with increased opportunities to openly communicate and help ease them to awareness and acceptance of death (Copp, 2002).

In a study by Zimmerman (2007), death and denial were looked at in two separate ways, as a psychological coping mechanism during the dying process, and as an obstacle to palliative care. Denial was determined to be a normal aspect of the dying process in an acute presence but often becomes maladaptive if the presence of denial continues and obstructs care (Zimmerman, 2007). Denial from both the family and patient led to obstructions in: open discussions of dying, ability to die comfortably at home, accomplishing advanced care planning, symptom management, and stopping treatments determined as futile by the healthcare team (Zimmerman, 2007). The overall goal should be to eliminate denial as early as possible in order to aid the patient and family in reaching complete contentment in end-of-life care. Interventions to prevent maladaptive denial are limitless and should begin immediately at diagnosis of terminal

illness. Such interventions include: early palliative care consults, pastoral care presence if accepted or requested, family involvement in the care process, avoidance of soft language (Euphemistic language used to conceal truth of a situation), by medical providers, frequent offers of emotional support, and psychiatric referral if maladaptive denial is suspected by any member of the care team etc. (Zimmerman, 2007).

***Adequate understanding.*** Education in end-of-life care is not a new topic for discussion but the focus on the importance of proper end-of-life education and discussions pertaining to care, has increased in recent years due to society's views changing on the dying experience (Jin, 2013). Clinicians in Chicago attempted to discover methods to improve care in the ICU. These clinicians felt there needed to be a conversation on Quality vs. Quantity at end-of-life. It is natural for humans to choose 1 month of extra life if available then to first consider what the quality of life that one month of extra life may be because they do not fully understand the potential ramifications of either decision. If patients were fully educated on their disease states and the likely outcomes of the future without "soft language" or "smoothing," outcomes of patient and family satisfaction with end-of-life care could improve because patient's may choose to continue or discontinue their care based on this proper education. The desire to extend life is often strong near death and if it is not for the patient, it may still be for their families. Jin (2013) completed a study to determine if an addition of a short training course in palliative care for professionals who encounter death, but may not be palliative care providers, improved outcomes at end-of-life. After completion, the results demonstrated that this type of training course can improve outcomes at end-of-life for the medical team, the patient, and their families (Jin, 2013). Increasing the understanding and

education of the dying process for all of those involved is imperative to successfully meeting all goals for care.

***Family.***

*Care of family.* Family involvement in the death and dying process of a loved one is vital to the family's overall contentment (Bloomer, Endacott, Ranse, & Coombs, 2017). The type and amount of involvement will vary depending on the specific patient and cultural background of those involved, but a thorough assessment and compassionate approach is necessary for all parties involved. Twenty-one adult critical care nurses participated in a study in Australia and New Zealand used a qualitative approach to determine how to communicate better with families during the dying process (Bloomer et al., 2017). One conclusion from the study is that family communication during treatment withdrawal and the dying process is a complex and multifaceted nursing activity that is known to contribute to family satisfaction with care (Bloomer et al., 2017). There is need for familial support and ongoing education opportunities in an effort to develop the art of communication in end-of-life care.

End of life care and aspects of care which can increase the experience for the family have been a focus of multiple studies across the world in the last few years (Cronin, Arnstein, and Flanagan, 2017). Previously the focus of care was mainly on the patient, but lately there has been an increased focus on how caring for the family of the patient can make the overall experience better for all of those involved. In a qualitative descriptive study for understanding of an individual, with a terminal diagnosis of less than 2 weeks, in a gynecology-oncology unit, four major themes emerged (Cronin et al., 2015). An awareness of nursing vigilance directed at the family provides a sense of being

cared for; nursing presence enhances mutual connectedness and appreciation, when death is imminent; family members want to understand the process, be included in the discussions, and be validated once decisions are made; and, attention to the environment of care provides peace and relaxation at a difficult time (Cronin et al., 2015). These four themes demonstrate the importance of caring for all involved in the process, not just the patient, at the end of life. Vital to the information gathered by Cronin et al (2015), is the fact that approaching family members near imminent death to assess their feelings on the process is not only acceptable, but welcomed (Cronin et al., 2015).

*Perceptions of end-of-life.* A study, interested in ways to improved end of life care in an ICU focused on how ICU nurses handle death of a patient in regards to their care for family during end-of-life (Bloomer et al., 2013). The study included identifying specific organizational or environmental factors, and any additional factors that may assist or desist in caring for patients in a compassionate manner (2013). The qualitative study was completed through utilization of two focus groups and discovered major themes which contributed to nurse's views of what needed to be improved to care effectively for patients. These themes included: Time, Place, Presence, and Culture. These major themes were then further differentiated into smaller subcategories of care such as: time with patient families, prolonging time till death, support after death, ICU design, working with families, nursing cultural competence, and adequate facilities provided for visiting family members. Overall, ICU nurses do attempt to ensure an experience of a "good death" even when met with restraints due to location, time, staffing, etc. (Bloomer et al.pg 27, 2013). Kisvetrová, Joanovič, Vévoda, & Školoudík discovered that ICU nurses often feel there is a point in care in which what they feel

“needs” to be done in order to meet their employers’ expectations becomes blurred with what they feel they “want” to do to better care for the patient. Kisvetrová purposed this is related to a lack of nurse education in care for patients and families during end-of-life. Kisvetrová then supports this logic by discovering that a useful skill in this area is being underutilized, assisting the patient and family to discuss feelings around death and what it may mean to them (Kisvetrová, Joanovič, Vévoda, & Školoudík. 2017). This skill is likely underused due to the lack of education in end-of-life care and the unequal focus on physical symptom management. The researchers concluded that there needs to be an increasing amount of education specific to end-of-life care with a focus on families and the emotional/spiritual aspect needed to fully accommodate all needs in such a crucial time (Bloomer et al., 2013).

In the acute care setting, nurses and physicians base their family support on what is communicated instead of what is understood. Coombs, Tang, and Long-Sutehall (2016) conducted a two-part study which illuminated an important aspect of family care at end-of-life - bereaved family member’s observations. Families are more observant of physiological deterioration than originally known (Coombs et al., 2016). Families of ICU patients not only pay attention but actually notice the trajectory of death due to mindfully watching for changes in cardiac monitors as well changes in their relative’s looks and sounds. Changes in treatment or interventions from any of the care staff also led the families to form conclusions on the research studied deterioration of the patient. Thus, families are often active participants in the end-of-life process and need to be treated as such. Healthcare professionals should clarify what families are paying attention to so they

can focus on educating and supporting aspects of care. Thus, making the entire process as therapeutic as possible for all those involved (Coombs et al., 2016).

***Individuality.***

*Emotional needs.* End-of-life is a difficult time for all of those involved and the emotional health of the patient and their families is crucial for overall wellbeing (Sampson, 2014). There are multiple facets of emotional health, one of those being Hope. "Hope is often linked to the future and is a significant factor for patients dealing with adversity, such as a terminal illness" (Broadhurst, pg. 18, 2015). Broadhurst discovered seven key themes that increased hope and emotional wellbeing: disease status; positive personal relationships; positive character traits; quality of life; setting and achieving goals; spirituality/religion; and hope after death (Broadhurst, 2015). Meeting the emotional needs of the patient is necessary to assist the patient to overall contentment. Each patient will require individualized care based on their emotional health throughout the end-of-life process (Kisvetrová, 2017).

*Cultural needs.* End-of-life patients are "highly vulnerable when their cultural needs are unmet" (Boucher, pg. 996, 2017). Cultural diversity should always be taken into account when caring for these individuals and their families. Ethnic habits, religious beliefs, and language are all aspects of cultural competency important for the health care team to address appropriately (Boucher, 2017). The modern health care system is evolving just as rapidly as the nation is diversifying. Cultural differences need to be considered if end-of-life care is to be delivered in an accessible, interdisciplinary fashion across healthcare settings to relieve distress among vulnerable and diverse populations (Boucher, 2017).

*Spiritual needs.* Martha Rogers believed that we must attend to spiritual-mysteriousness and dimensions of each individual's life experiences (1997). Both Rogers and Watson highlighted the importance of caring for the soul of the patient to achieve ideal outcomes. Watson defined her goal of care as health, "unity and harmony within the mind, body, and soul, congruence between self as perceived and the self-experiences" (1989). Rogers diversely poorly defined health, and instead chose to use the term wellness as the ideal allowing her to incorporate a larger number of factors into her idea of wellness such as spiritual, cultural, and emotional wellbeing (1997). Each of these intelligent and respected theorists chose to include a focus on spiritual and cultural needs of a patient in care.

Spirituality and cultural needs are grouped with other emotional needs like connectedness and relationships during end-of-life care. Previously discussed, Sampson (2014) discovered that the emotional aspect of care to be the most important to the patient at end-of-life. It is thus quintessential to make sure all spiritual and cultural needs are met for ideal care.

Despite the evidence of these interventions, the spiritual and emotional aspects of care are often lost or less frequently used when compared to classic physical relief based interventions like pain medication and positioning (Kisvetrová et al., 2017). Based out of Czech, Kisvetrová led a cross sectional study which desired to determine the frequency in which nurses performed certain interventions at end-of-life (2017). Kisvetrová found that nurses reported increased use of activities which focused on the physical comfort of end-of-life patients such as, monitoring pain, assisting with basic care, and frequent rest periods. Additionally, nurses with higher education levels were more likely to perform

interventions surrounding psychological peace and spiritual ease such as, offering culturally appropriate foods, obtaining spiritual support for patient and family, communicating willingness to discuss death, assisting in finding a shared meaning of death by patient and family, and making sure the environment meets patients' needs and desires (Kisvetrová et al., 2017). Overall nurses lacked in performing activities focused on communication with the patient and their families. Discussing death and hospice care was a specific venture which nurses lacked in performing in the study (Kisvetrová et al., 2017)

*Patient involvement.* Planning for death is a crucial aspect of the dying process the individual should have input in end-of-life decisions (Trankle, 2014). Proper planning for death through goal initiation and attainment, patient input in decision making, communication amongst all parties, existential (spiritual) considerations, conflict avoidance, and emotional pressures are all themes identified as important to the patient's involvement in the end-of-life process. Not all situations allow for decision making the patient's life, in cases of sudden death. However, in every situation, there should be effort to obtain involvement from most of the participating parties, and if possible the patient themselves. This is in an effort to increase the efficacy of care and maximize the control the patient's feel they have in the end-of-life process (Trankle, 2014).

Many physicians mentioned how they felt that it was important to help the patient feel their life was meaningful. Finding life meaningful can increase their sense of self-worth, especially if the patient is lacking in this area. The goal for assisting the patient is to allow the patient to have their needs met, both physical as well as emotional and spiritual before death (Trankle, 2014).

***Comfort and serenity.***

*Pharmacological & Non-pharmacological interventions.* Care interventions are extremely important at end of life due to the often-debilitating levels of pain experienced by terminal patients. One idea posed by Clark, Curry, and Byfield (2015) is the use of a care bundle provided to nurses caring for end of life patients. These care bundles are education packs for nurses which include multiple assessment techniques, standard pain management orders, and standardized comfort measures of both pharmacological and non-pharmacological interventions. These care bundles are often widely utilized and consist of evidenced based practices known to be beneficial to the patient (Clark et al. 2015). Some of these interventions include: monitoring the patient for anxiety, staying physically close to the patient, making sure nurse staffing is adequate so the nurse can spend the time needed with the patient, family and significant others , monitoring pain, postponing activates when the patient is fatigued, medicating by alternate routes when swallowing problems develop, providing frequent rest periods, respecting privacy, frequently assessing the environment, and monitoring for deterioration of physical or mental capabilities (Clark et al. 2015). Nurses utilized an end-of-life care bundle and then were administered a follow up survey to determine whether their knowledge or comfortability in caring for patients at end-of-life had improved. In order to determine how to improve end-of-life care, it is significant to know if these bundles hold some type of clinical worth.

Similar to Clark, Trankle identified symptom management as one of 13 factors previously discussed factors to achieving a “good death” (2014). Trankle also discovered

that peace and comfort were overwhelming goals for symptom control and each are variable and patient dependent (Trankle, 2014).

**Summary of Literature**

Overall the literature supports a multi-faceted approach to end-of-life care including pre- and post-mortem care for the patient and their families. Patient and family contentment in end-of-life care is the overall goal of this research study with contentment defined as the overall satisfaction of expectations.

Contentment at end-of life includes both pre-death care of the patient and family while extending the nursing care past death to the family. Contentment at end-of-life care for the patient is dependent on multiple factors such as: acceptance, adequate understanding, family and patient involvement in decision-making, care of family, individuality, comfort and serenity.

Conclusions from both Beckstrand (2014) and Sampson (2013), illuminated the importance of an emotional aspect of care in end-of-life. Each study actually found emotional aspects of care to be even more important to both the family and caregivers when compared to physical aspects such as pain management. Hope was also a specific aspect of emotional health discovered to be vital to patient care (Broadhurst, 2015). Besides emotional needs, cultural and spiritual needs were also identified as important to achieving overall contentment.

Acceptance of impending death is ideal but both acceptance and denial are defense mechanisms utilized by patients and families as interdependent coping mechanisms vital to end-of-life contentment (Copp, 2002). Acceptance should be viewed

as the goal but denial should be appreciated as a venture to protect self-esteem and emotional instability (Copp, 2002). When denial of death is present, the healthcare team should remain diligent to assisting both the family and patient towards acceptance through open communication and honest discussions of personal expectations (Zimmerman, 2007).

Families and patients require an adequate and thorough understanding of the end-of-life process in order to reach contentment (Jin, 2013). This adequate understanding should include hope that even though death may be the final outcome for the patient, healthcare personnel will continue to provide appropriate care to the family and their loved one (Broadhurst & Harrington, 2015). The idea is not to protect the patient from the truth, it is to illuminate the truth and then, though intervention, improve the situation to the highest possible degree.

Efficacy of care and control by the patient and/or the family in end-of-life progression can assist the patient and family to find contentment (Trankle, 2014). Including each individual as an active participant in the care assist the patient to feel their life was meaningful (Trankle, 2014; Rogers, 1997; Watson, 1979). Physiological interventions for comfort, and emotional care through appropriate spiritual and cultural interventions should take the forefront in patient care. Symptom management at end-of-life assists in not only providing comfort for the patient, but assists in the emotional care for both the patient and family members (Clark et al., 2015).

Attention needs to be placed on the care of family members as well as care of the patients, giving them a sense of being cared for (Cronin et al., 2015). The decisions made by the patient and family are ones that should be supported as the family members will

need to live with the memories once the patient has died. (Cronin et al., 2015). Nursing presence enhances mutual connectedness and appreciation. When death is imminent family members want to understand the process, be included in the discussions, and be supported once decisions are made (Cronin et al., 2015). Care for the family can result in the family and patient sharing in contentment.

Evidence supports a focus on the emotional aspects of care interventions. Overall, the patient and family should be thoroughly educated, and then encouraged to make informed decisions regarding the healthcare they receive, thus achieving total contentment with the end-of-life process.

# Chapter Three

# Methods

## Study Design.

This research was a qualitative study to determine the lived experiences of familes who have had a loved one at end-of-life who passed away. The study was to determine which healthcare interventions made a positive and/or negative impact on the families who experienced end-of-life experiences with their loved ones.

## Sample Criteria.

After the Institutional Review Board (IRB) approval was obtained, individuals who met inclusionary parameters were recruited through a snowball effect. This type of sampling allows the researcher to gain access to a specific, targeted population that is the focus of the study.

All individuals included in the study needed to have lost a loved one in a health care setting including but not limited to a hospice or hospital facility. They also needed to be above the age of 18 and able to speak English.

Individuals were excluded from the study if they were not physically present during the dying process at any point or the loved one of discussion had died less than 6 months ago.

## Data Collection.

The researchers conducted a focus group with semi-structured questions which were modifiable depending on the discussion generated within the group. Both the student investigator, and his chair led the discussions related to the end-of-life experiences. Questions were asked purposefully asked in a non-judgmental manner. The

focus group was digitally recorded and electronically transcribed. The transcription was reviewed to insure errors in transcribing were corrected and no true identifiers were present.

**Focus Group.**

Upon entrance to the focus group, all participants were provided with a packet of information including the invitation to participate with signed consent form, community resources, and a demographics sheet questionnaire. The informed consent was read with an emphasis on reminder that they did not have to answer any questions that they did not wish to do so and that they were free to withdraw from the study at any time throughout the approximately 1 1/2 hour session. After consenting to participate, each person was asked to select a name to use from a selection of randomized nametags located on the conference table. Then they were asked by the student investigator to complete the demographic information and place both the signed consent and demographics sheet in an envelope with their chosen name on the outside.

As the focus group began, the student investigator instructed the participants not to use personal names, agency names, or any identifying information in their remarks; instead use only the names they selected when identifying themselves. Participants were informed during the consenting process that the session was audiotaped. In addition, when the audiotape started, a consent statement was read once more: "By participating in this focus group and signing a consent agreement you are consenting to participate in this research study. Names and other such identifying information will not be collected in order to help maintain the confidentiality of each participant. Anyone who does not want to participate may freely leave the room at any time."

At the conclusion of the focus group, participants were thanked for their participation and after a summary was provided by the leaders, an open forum style discussion was opened for any questions or final statements. Participants were then reminded of resources available to them if they required additional emotional support during their grieving process.

**Data Analysis.**

At the completion of the focus group, the tape recording of the group session was digitally transcribed and reviewed. Next, the researchers identified themes using Colaizzi's (1978) phenomenological analysis method. Qualitative research proposes to discover perceptions of individual experiences with a specific phenomenon and allow others to re-examine meanings behind a certain event. Allowing for individuals an unbiased and open way to provide examples of their end-of-life experiences as they lived them is the basis for discovering important data that may not be discovered by qualitative methods.

Themes were discovered through transcription analysis and categorized and compared with influences from phenomenological literature by Colaizzi (1978). Analysis began by both the Graduate Student Researcher and Thesis Chair reviewing transcriptions and separately highlighting responses each viewed as significant to the study. Next these highlighted responses were color coded to match other text demonstrating a similar theme. For example, if a participant discussed or mentioned the word comfort in their response, this text would be coded pink so that the amount of text discussing comfort could be easily interpreted, combined, and deduced. Through this abstraction, meanings of statements were further compared and interpreted based on

Colaizzi's (1978) hierarchy as seen in Appendix A. After themes were identified, statements on the interconnectivity were made along with statements for each theme, theme group, and categories. Efforts were made to describe phenomena as accurately and without bias as possible to reveal the essential structure. Conclusions were drawn from the interconnectivity of the data deduced in order to confirm whether the final statement reflected the lived experience of the participants.

**Sample.**

The study sample consisted of 3 males and 5 females. The age range was between 26 and 75 years of age with the mean age of 48 years. All but one of the group participants were married. Only 2 of the participants had lost a loved one less than 2 years ago, with the remainder having lost their loved one between 2 and 3 years ago.

**Results.**

Exploration of the end-of-life experience was unique to each participant but there was some uniformity in responses and general thoughts and feeling surrounding each loved one's death. These responses could be separated into categories of relevant themes.

The themes established before the study, based from literature review were significantly different but did share some similarities with those which emerged from the focus group. The focus group responses were more appropriate terms for what participants viewed as important to end-of-life care.

**Support.**

Support was not just an aspect of care for the loved one but possibly even more so, for the family. The participants of the focus group were split evenly when discussing

whether they felt supported in their respective end of life experiences. There were three types of support discussed: spiritual, cultural, and emotional. When participants of the focus group had positive experiences in these support categories it did make a positive effect on the overall situation.

Related to emotional support Nicole mentioned pertaining to her Mother's passing that "the hospice personal was amazing, very supportive. I think they worked harder at supporting the family than they did almost supporting her because they knew she was passing and we were going to be the ones left behind.". Amelia, regarding the passing of her aunt, responded that, "Hospice made it very well known that they were available to the family at anytime and we could reach out to them".

When there was the perception that emotional support was lacking, it left a lasting negative feeling about the experience. John commented that "I don't feel like we were treated right because they all told us that they weren't real worried about our feelings and us seeing our father. They were more worried about telling us that he was passing". Emily added, regarding both grandparents deaths, "I don't recall either facility offering emotional support. . .The family was there for each other but I don't think either healthcare facility offered any emotional support".

Culturally little was discussed by this focus group. Amelia did feel that since her husband's grandfather was a veteran, the healthcare team went above and beyond the call of duty when they asked if we "wanted the color guard to come in and present . . .his wife, with a flag" and military pins".

In regards to spiritual support, almost all participants mentioned that their spiritual needs were exceeded and if they were not, that the support in this area was desired.

Amelia mentioned a positive experience where her friend's father's nurses came into the room shortly after he had passed and together "knowing that my friend and her father were Christians we all prayed over his father and I thought that was very neat". Eric had a similar experience where the nurse stayed in the room for the prayer and he felt this "was nice to have someone so involved in the closure". Nicole shared the importance of providing requested spiritual care in sharing, "The chaplain came and spoke with my dad all the time. He was angry with God. The chaplains made an effort to try to help him". When spiritual care is requested and it is not provided, it is remembered by the family as evidenced by Amelia's disappointment by saying, "For my husband's grandmother, no one came in and she had wanted somebody to come in and it was requested. They never showed up".

**Education.**

Education proved to be a common theme of discussion. Participants of the focus group not only discussed education provided to the patient but also to the family and the importance of proper staff education on how to care for end-of-life patients. Providing education to the dying patients was important for the patient understanding what was happening to them. Nicole commented that "with my mom they made a point of speaking to her so she understood. And granted the medications made her forget a lot, but periodically they would remind her again - and I didn't have to, or my dad didn't have to, so that way she understood. When she would start to question why she wasn't feeling better, they would remind her in a caring way, or at least as caring as you can, that she wasn't going to get better. Speaking positively about the experience, John added,

“With my dad they made sure they came in and told him, [name of patient] do you know you’re dying? Because we couldn’t tell him”.

The information provided to the family seemed to vary with the receipent of the information as well as the provider of the information. For example, Nicole commented that “both Hospice programs we used gave me books”. Eric similarly commented, “My grandfather when he was in Hospice. I believe it was the nurse practitioner who came in and kept us very involved in his plan of care. It made me feel real sure that he was being taken care of”. In contrast, Emily expressed fear and frustration in not understanding by stating, “when I walked into the room and I heard the gurgly breathing, I knew she [grandmother] was basically drowning. I had no idea what was happening. I knew that it was getting toward the end, so they [hospital personnel] may have informed some family members, and they may have relied on those family members to tell the rest of us. But I was not informed”.

The request for information also pertained to what occurs after the loved one passed as shared by Emily, “I would have liked knowing what the process was because I’m going to have to deal with it someday. And I don’t know what to do with them [once they passed]. I’m sure I could Google how to take care of him. I’m unaware of the process”. Tom shared similarly when stating, “If they had said look we don’t know how far she’s [mother] going to be able to go, but in the future, this is going to happen, she could die. You don’t really wanna be told something like your parents are gonna die but it would just be nice if you knew the process so you think about the Funeral Home and you call the Funeral Home and are prepared. It would be easier to know what to do because it’s tough”.

The timing of the information also seemed to matter as expressed by Eric, “It’s hard to educate about the death process and the grieving process. But I have never dealt with death until my grandmother, and I guess I would have appreciated something like a card in the room that had ways to deal with this death like hugging a family member, or having a support system, or a moment of prayer, or like sharing memories of the loved one that was dying. It could also have on the card contact information if I needed to reach out. I think that would have been really helpful. ‘cause I feel like when my grandmother passed we didn’t know where to go from there. As Emily added, “With being educated before the passing. There is a lot of stress that goes into the actual passing that I don’t know how much I would actually retain and after the passing. I don’t know if the grief would be so overwhelming to retain the information”.

There were times when staff did not appear too knowledgable about the end-of-life experiences, thus causing the group to consider staff education. Nicole pondered that, “maybe they don’t know how to provide the right kind of care to the patients and their families, so maybe there is a lack of Education because they’re used to working at saving lives not helping end of life”. John added that he felt that “Some nurses care more then other nurses. Some nurses are there for a job and some nurses are there because they care about people and getting them well”. Olivia agreed in stating, “I think that in a hospital setting they are more into saving lives instead of being educated as to how to help people with end of life”.

**Empathy.**

The nurses spoke about several experiences that captured the meaning of the theme of “empathy”. Definitions of empathy vary, but the one used in this paper is “the

ability to acknowledge, understand, and emotionally resonate with a person's feelings and situation" (Soto-Rubio & Sinclair, 2018, p. 1430). Empathy can be described as a hypothetical warmth in a person, lack of empathy can be seen as the opposite, cold or indifferent. There were several examples of the participants relating to having cold experiences. Olivia shared, "When my mom passed I felt they were very cold . . . not very caring with her or with the family". John also mentioned having had "cold" experiences with nursing professionals who were not supportive and "weren't very kind to the family. It was very hard at the time… not very caring with her or with the family". Amelia, when discussing her grandmother's death in the hospice setting stated a more positive end-of-life experience can be had if the "staff would treat everybody as if that person was their family member and try to put yourself in their shoes."

**Time.**

"Time" was directly mentioned over 30 times within the focus group, and multiple other times in a different manner. Time was mentioned in regard to the time healthcare staff spent with family and also the amount of time family was allowed to spend with their loved ones. Timing of information was also mentioned, as described earlier, in regards to providing information.

Time healthcare providers spent with the family and patient was important to the family. Eric felt that his loved one wasn't checkd on enough. Eric when speaking about staff said, "I didn't see them very often. I would have liked them to come in and check up on him [grandfather], turn him and make sure he was comfortable". Eric, on a positive note when speaking about his Grandmother's passing mentions that the nurse, "was in there all the time and was checking up on us".

The amount of time that family was permitted to be with the loved one was important to the family's experiences. Nicole shared, "They let me sit with her [mother] whenever I wanted to, . . . stay with her as long as we wanted, everything was on our time. Nicole additionally commented that, "The one bad thing about that was that I don't think they gave us the right time span - like they told him he was dying, but let everybody believe we had time to say goodbye". The time issue extended after the death occurred also. John had a poor experience when his father died because the time he was allowed to spend with his father after death seemed rushed but other participants experienced the opposite. Emily commented that, "when my grand father passed at the hospice facility we were allotted at that time how much we needed to made it to say our final goodbyes. And I found that even more comforting".

**Communication.**

Open, honest, unbiased communication was desired by the focus group as a whole. Olivia shared a story about a time after her newborn daughter passed away where "The communication in the hospital wasn't very good. The nurse thought that I already knew. And I didn't. And she was saying things to me that she thought I already knew that she was gone".

Surprisingly participants actually didn't have a problem with false hope and actually felt the opposite. Nicole demonstrated this when discussing how the healthcare staff handled her Mother's terminal prognosis, "They would remind her in a caring way. . . that she wasn't going to get better. So, then there was no false hope lingering".

The most powerful statement on communication came from Emily who professed, "I think everyone can agree that there is a language barrier between the health care

professional and the patient's loved ones. Listening to the health care providers talk, it's almost a foreign language. When the doctor came in, it almost felt rushed . . . I think the doctor felt that he did his job when he spoke to the family members in healthcare, and they got the jest, but I'm still sitting there, wondering what this doctor was talking about. And as soon as the family members were done talking to him, he was out the door onto his next patient". Olivia added that, "if you don't have somebody in your family in the medical field, a lot of times they don't explain things and the only way you know is if you have a medical person in the family to explain it to you".

**Comfort.**

The theme of "comfort" was definitely an aspect of care discussed. Comfort can be both an environmental issue or a physical issue. Eric was distressed with his Grandfather's care in hospice because "the setup of the room with him kind of being in a corner where he couldn't watch TV there. He had bad eyesight and he was all the way across the room, and then older generations don't really watch TV so just having him by a window would have helped also but he was clear across the room [from both the TV and a window] …I would have liked them to come in . . .and make sure he was comfortable."

Regarding physiological pain, there were mixed comments. On a positive note, Tom expressed that, "for my mom they did everything they could to keep her comfortable so she didn't have any pain and my dad too". Nicole commented that, "They worked hard to get her pain under control. It never was but they would do anything. . . . and let me give her whatever to try and do my best to keep her comfortable". In contrast, Olivia expressed, "My mom was dying they didn't keep her painfree at all. She was in a

lot of pain and crying all the time that she was in a lot of pain and they didn't do anything to address the pain".

**Transcendent.**

Transcendent is defined as surpassing the ordinary or expected (OED, 2018). Multiple participants of the focus group mentioned they felt supported and positive about the end-of-life experience when the health care team performed actions that were beyond what was expected of them – based on what is regularly performed by their counterparts, especially in regard to supporting the family and patient throughout the end-of-life experience. Transcendent care or going above and beyond really is more focused on simple acts than grand gestures. An example was shared when Emily stated that "It's the simplest acts that make the world of difference. . . The simplest acts are those things that you remember". Emily, continued discussing that the nursing staff "gave us a separate room and allowed the whole family to be in there while she was passing, I know there are restrictions on how many people should be in there but the fact that we were all there able to give our love and support means a lot". She also shared that, "It's the simplest acts that make the world of difference . . . The simplest acts are those things that you remember". Eric shared that after his grandmother passed, "We were all sitting there crying, no one knew what to say until somebody said to share memories. And honestly that made the world of difference. And I would like other families to have that, have that closure".

# Chapter 4

## Discussion

Before the focus group was conducted and the concept map (Figure 1) was constructed, the ultimate goal of the student researcher was for both the patient and the family to have attain *contentment* with the end-of-life process. *Contentment* was not a term nor a theme which was discussed by any member of the focus group. However, after the study, the theme emerged not of the ultimate goal of *contentment* but of end-of-life care which is *Transcendent.*

Other findings obtained from the focus group particpations were often different than the expected outcomes obtained from the healthcare literature. For example, *optimal end-of-life care, adequate understanding of the dying and post-mortem process, individuality, person and family* were discussed in the focus group but not explicitly but within through other words and as part of other aspects of care. *Adequate understanding of the end-of-life process* was better expressed by the focus group participants using the word education repeatedly and was a main focus of the participant's experiences. *Denial versus acceptance*, and *false hope* were not discussed at all unless prompted. Aspects of the term *Individuality* were discussed including cultural, emotional, and spiritual care but more of a support measure and not as related to the original expectant term of individuality from the research. *Person* and *Family* were connected yet separate themes originally but with the focus group it was found that the family members combined these together when describing different aspects of care. *Comfort* was discussed but the statements of the participants were based on outcomes of interventions not usually on the intervention itself, which was different that the research literature. Additionally, quite

surprisingly, *denial vs. acceptance, false hope, serenity, and specific physiological and non-physiological aspects of pain and comfort relief,* were barely or not specifically discussed at all.

**New concept map**.

After analytical review of transcribed responses the following themes, and categories within those themes, were exposed revealing that end-of-life care can be *Transcendent* by focusing end-of-life interventions on education, support (culturally, spiritually, and emotionally), Empathy, Time, Comfort (environmentally, physiologically), and communication, as seen in Figure 2.

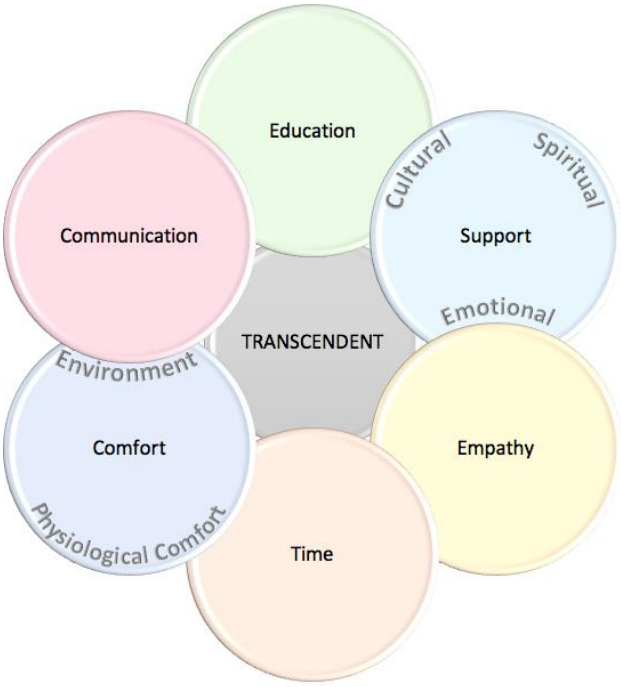



*Figure 2*. Post study concept map based on themes which surfaced in focus group.

Transcendent was found to be the ideal term to define what participants believed was the ideal type of end-of-life care. When the positive aspects of care were discussed

participants, including Eric, repeatedly mentioned satisfaction with care when the nurse "went above and beyond". This current finding is new as no evidence of the goal of end-of-life care being described as *Transcendent,* could be found in the literature. Appropriately then *Transcendent* became the center of the new revised concept map seen in Figure 2.

Education was a theme which was expected to be demonstrated and was supported by previous literature. "Education is an aspect of care for the dying needed to fulfill lack of knowledge … ideally help patients and their families feel they have greater control" (Clark, 2015) Participants in the focus group repeatedly mentioned they desired to be better educated by staff on all aspects of care including pre- and post- death care. Participants even offered suggestions for improved education. Eric and Amelia agreed in that a physical resource like a book or pamphlet on different aspects of care would be very helpful. Interestingly education was discussed also in the aspect of who is educated being a limitation to Transcendent end-of-life care. Often healthcare staff will only educate immediate family but multiple participants agreed some type of education either physical or otherwise should be available to more distant relatives also as they have to experience the disheartening situation as well. Consales (2014) also supported the importance of education in end-of-life care.

Support was a theme which emerged with three separate categories including emotional, cultural, and spiritual support. These were originally included under individuality but moved beneath support with evidence from the focus group. Participants in the focus group repeatedly mentioned words related to cultural, spiritual, and emotional care at the same time they used the word "support." Research is split on what

term better defines these categories of care but overall research supports their inclusion and importance to end of life care. These were not new findings as Hadders (2014) describes the necessity for end-of-life care to be, “culturally, and spiritually competent,” Tan (2013), even found “emotional support” to be one of the most important aspects of care even over physical aspects of comfort which was visualized by the researchers in transcriptions of the participants responses.

Empathy was not an expected finding but it is not a new finding as additional literature does support its importance to end-of-life care. Combs (2016) discusses the importance of giving families time as important to improving end-of-life care but also delineates by saying, for the time to be effective, it must be “impregnated with empathy”. Nurses and all medical professionals should not come off as, “closed off”, or calloused. Healcare professionals can give patients and families all the time in the world but if providing time is seen as an inconvienance by the receiver it is not going to improve the situation and may even worsen it. Understanding and sharing an understanding of what the family is going through provides a “closeness” which improves outcomes for all those involved in the “end-of-life situation”.

Supported by various literature, time was expected, and proved to be important aspect to end-of-life care. Eric had a lengthy response describing a situation in which he felt the nurse was absent for hours and not readily checking in on his grandfather. Other participants agreed when Eric discussed a solution to his situation as more frequent, and lengthier visits from healthcare staff. Ruland & Moore (2001), supports the importance of time in end-of-life care by mentioning that nurses should be, “attentive to patient’s expressed needs, and wishes, and preferences”.

Comfort was a term which was expected to be a theme originally based on literature but the categories within it were somewhat unexpected. Based on the literature, Trankle (2014) put greater importance on pharmacological pain interventions vs. non pharmacological but the focus group responses separated comfort into just two categories, measures which relieve physiological pain which of course may include pharmacological medications, and non-pharmacological methods. However, there was an unexpected importance given to the environment the patient is in directly contributing to their overall comfort. Eric discusses a situation in which his grandfather's comfort was hindered because the room he was in at a hospice facility which did not allow him to watch TV, view outside, or get around easily. These all were a hindrance to the full ability to be comfortable in end-of-life. Ruland & Moore (2001) did include environment in their concept map under comfort but did not put as large of an emphasis on its importance as the focus group responses indicate.

Similar to comfort, proper communication was expected to be an important aspect to end-of-life care but the focus group failed to show participants had struggled false hope or biased medical information. Literature review demonstrated the common occurrence of health care staff providing false hope to patients and families (Broadhurst, 2016). However, the topic never was broached by the focus group participants until prompted with a question if they had experienced false hope. Participants did report failed communication in their negative end-of-life experiences but the main complaints discovered involved the language barrier between healthcare staff and patients/loved ones. Literature like Broadhurst (2016) discusses false hope and ways to improve the openness of communication but it fails to highlight the importance of making sure loved

ones and patients understand what is being communicated to them by using language appropriate for their level of education and specific situation.

**Limitations.**

The themes and conclusions drawn from the study could possibly be unique to just this one focus group. By only conducting one focus group, information is limited especially due a lack of diversity within the chosen group. The majority of the participants in this group were Caucasians who identified as Christian. A more culturally diverse pool of study participants could also reveal new and important themes not discovered in this study. Another limitation could be the sampling method as this type of sampling has the capability to produce more diverse results depending on how it snowballs but in this particular case, limited the participants to a less diverse group of individuals.

**Implications for Future Research.**

The literature and results from this focus group show a clear importance in improved end-of-life care for patients and their loved ones. Future research is necessary to improve the diversity of the study, reduce the limitations which occurred and to improve end-of-life care effectively. Additional focus groups that includes diverse populations, has the potential to achieve the goals of providing caring and compassion end-of-life care.

**Implications for Future Practice.**

End-of-life care is currently flawed. Interventions at end-of-life are not efficient in improving care and there is little education in place to improve this (Jin, 2003). The study results discussed demonstrate that practice needs to change.

Improvements in education of healthcare providers is needed so that there is an awareness of how to properly care for patients and their families at end-of-life. After this support is provided health care staff will be aware of the importance of cultural, social, and emotional support. In addition staff and administration will understand the importance of increasing the time allotted for patient care. Empathy is a difficult aspect to teach but it should be reviewed in an effort to help healthcare staff at minimum, be more aware of the way they are interpreted by the patient and the patient's loved ones. Comfort measures need to be addressed, including consideration of the environment as well as other physiological methods for improving comfort such as medication, positioning, and the healthcare providers support. Lastly, healthcare providers need to make an increased effort to communicate effectively for both the patient and the family.

Communication needs to be at an appropriate educational level for the entire family. Additionally, since the situation of having a dying loved one is both emotional and stressful, the information may need to be repeated, or handouts provided, to ensure that the family understands the information.

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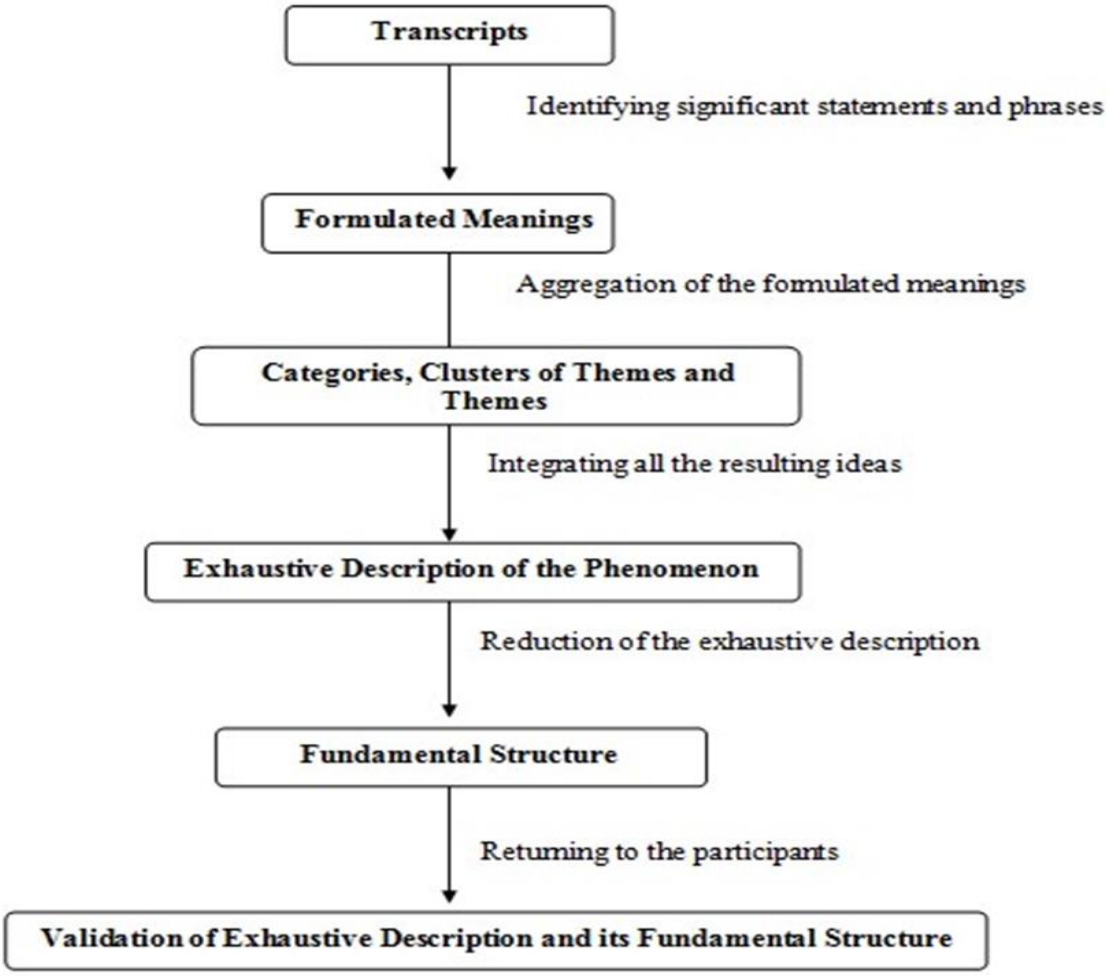
## Appendix A

**Colaizzi's Phenological analysis hierarchy (Shin, Kyung, Kim, Hye & Young, 2004).**