

KENNEDY TERMINAL ULCER: A RETROSPECTIVE CHART REVIEW OF  
ULCERS IN THE HOSPICE SETTING AND EDUCATING PROVIDERS AND  
NURSES ON THE IMPORTANCE OF SKIN CHANGES AT LIFE'S END

by

Anna Victoria Nesovic

A Scholarly Project submitted in partial fulfillment  
of the requirements for the degree

of

Doctor of Nursing Practice

in

Family and Individual

MONTANA STATE UNIVERSITY  
Bozeman, Montana

April 2016

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## DEDICATION

I would like to dedicate this paper to my Grandmother, Aurelia Frances Gatzemeier. She received her nursing degree from St. Joseph's Hospital School of Nursing in Joliet, Illinois. She served during World War II as a registered nurse. She continued her professional work by volunteering and supporting emergency services, in rural Montana. She was one of the strongest nurses I have ever met.

Even in her last years she continued to care for those around her. She was very knowledgeable and always completing nursing assessments on those around her. She has been a great inspiration in my life.

## ACKNOWLEDGEMENTS

I first would like to thank my DNP committee chair, Dr. Karen Zulkowski. I truly appreciate her continued guidance through this entire journey and helping set the foundation for this project. I am also thankful to Dr. Donna Williams as she stepped up and agreed to co-chair my project and brought a unique perspective. Also, I am beyond thankful to my outstanding committee members Dr. Karen Kennedy-Evans and Karrin Sax. Thank you for your encouragement, time and support during this process.

I am also grateful to the facilities that allowed me to complete my project. I am truly appreciative to them as this project could not have been completed without their support. I also would like to acknowledge Emily and Brian Tesar for their assistance and help with the statistical analysis portion of the project.

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## ABSTRACT

The geriatric population is growing in the United States and caring for geriatrics can be complex. This population is at an increased risk for skin injury. There are some skin changes that are seen specifically at the end of life. One of the ulcers that can be seen at the end of life is the Kennedy Terminal Ulcer (KTU). This type of ulcer is a result of hypoperfusion to the skin. Currently, there is a limited amount of literature available on the KTU. Also, some nurses and providers are unaware of this type of ulcer. The purpose of this study was to gather data on pressure ulcer prevalence, characteristics and location in hospice patients. Sacral/coccyx ulcers identified after hospice admission were used as a proxy for the KTU to gather data on the average length of life after ulcer onset and prevalence. A retrospective chart review at a local hospice home was completed to gather data on pressure ulcers and the KTU over an 18 month period. Three education sessions were also completed using the cognitive load theory to educate nurses and providers on the disease process and implications of the KTU. The pressure ulcer prevalence in a hospice setting was found to be 27.8%. The majority of pressure ulcers were stage 2 (43%). The coccyx (45%), buttock (18%) and heels (16%) were the most common areas for pressure ulcer development in this setting. The average length of life was 17.7 days and the median was 9.5 days after sacral/coccyx ulcer onset. The estimated prevalence in this sample of the KTU was 6.1%. During the education sessions only 61.5% of participants had previously heard of the KTU. The education session showed a significant difference in participant's knowledge in unavoidable pressure ulcers, pathophysiology of the KTU and usual presentation of the KTU. Being aware of the skin changes that occur at the end of life is important for providers and nurses. It gives them the opportunity to educate the family and patient about the disease process and implications. There is a need for further research on skin changes at life's end.

## CHAPTER ONE

## INTRODUCTION

Background and Significance

The United States (US) population is aging and healthcare providers need to be able to care for the complexity of geriatrics. By the year 2030, approximately 20% of the US population will be older adults and by 2050 the geriatric population is going to more than double compared to the population in 2010 (Centers for Disease Control and Prevention [CDC], 2013). It is estimated that the US greater than 85 year old population will triple to 14.6 million in 2040 from 6 million in 2013 (Department of Health and Human Services [HHS], 2014a). This is due to the general population living longer and also the aging of the baby boomer generation (HHS, 2014a).

The elderly usually live with a chronic illness and also can have multiple comorbidities (CDC, 2013). This population is at a higher risk for having severe illness, poor mobility, malnutrition and incontinence which increase their risk of developing a pressure ulcer. In Healthy People 2020 Older Adult Objectives, there is a goal to reduce the rate of pressure ulcer-related hospitalizations among older adults (CDC, 2013).

Pressure ulcer prevention is of utmost importance. Pressure ulcers decrease the quality of life in several different aspects. Development of a pressure ulcer can be painful and costly to the person and health care system (Gorecki et al., 2009). Approximately 2.5 million people develop a pressure ulcer per year and the average cost is \$9.1-\$11.6 billion per year in the US (HSS, 2014b). The individual cost per pressure

ulcer ranges from \$20,900 to \$151,700 (HSS, 2014b). Pressure ulcers can take a long time to heal and increase the person's risk of developing an infection (Russo, Steiner, & Spector, 2008). The person's life is impacted in a physical, psychological, emotional, spiritual, social and financial way (Gorecki et al., 2009; Langemo, 2005).

The Centers for Medicare and Medicaid Services [CMS] (2012) mandated that long-term care facilities publically report pressure ulcer prevalence in their facility. If long-term care facilities do not submit the required quality information they will receive a 2% point reduction in their Annual Payment Update (CMS, 2012). CMS will not reimburse hospitals if a patient develops a stage III or IV pressure ulcer under their care (HSS, 2008).

While most pressure ulcers are preventable, there are certain situations that a pressure ulcer will develop even with evidence-based interventions taken (Black et al., 2011). Another type of ulcer that can be misdiagnosed as a pressure ulcer is the Kennedy terminal ulcer (KTU) (Yastrub, 2010). The KTU has a different etiology than a pressure ulcer and appears at the end-of-life in some patients (Yastrub, 2010).

### Problem

There is minimal, yet growing, research available on the KTU and some providers and nurses are unaware of this type of ulcer. Therefore, generating research on this type of ulcer and providing education to providers and nurses about the indications of the KTU is paramount.

### Purpose

The goal of this project was to complete a retrospective chart review to gather data on pressure ulcer prevalence, characteristics of pressure ulcers, and the average length of life after a pressure ulcer development in hospice patients. Pressure ulcers that appeared on the sacrum/coccyx area were specifically reviewed to establish a baseline prevalence and incidence rate as well as average time from development of the KTU to death. In addition, multiple education sessions were completed to understand the current knowledge of the KTU and to inform providers and nurses of the disease process and implications.

## CHAPTER TWO

## REVIEW OF LITERATURE

A review of literature was completed to gain a better understanding of pressure ulcers, skin changes at life's end and the implications of skin failure for healthcare providers. CINAHL, COCHRENE, MEDLINE, PUBMED and ScienceDirect library databases were searched. There was no limit placed on year of publication. All articles were written in the English language. Thirty-six articles were evaluated. Search terms included: skin changes with aging, pressure ulcer, pressure ulcer cost, pressure ulcer risk factors, unavoidable pressure ulcer, skin failure, skin changes at life's end, Kennedy terminal ulcer, pressure ulcer knowledge, skin changes at life's end knowledge, and skin failure knowledge.

Skin

The largest organ in the human body is the skin (DiAgostino, 2009). The skin is susceptible to injury and provides several functions that aide in homeostasis and protection (Voegeli, 2012). The skin responds to external stimulus: temperature, pressure, touch and pain (McLafferty, Hendry, & Farley, 2012). It is supplied with nerve fibers that communicate with the brain to understand the different sensations (McLafferty et al., 2012). The skin also aids in thermoregulatory control (Voegeli, 2012). The skin provides a protective barrier to the internal organs from external forces and synthesizes vitamin D (Voegeli, 2012). Lastly, the skin plays a role in people's psychosocial

wellbeing. The skin is extremely visible therefore any skin breakdown or disease that manifests on the skin can be embarrassing for individuals (Cowdell & Garrett, 2014).

### Changes in Skin Associated with Aging

The geriatric population is at an increased risk for skin injury due to normal skin changes associated with aging. With aging, the lipid content in the epidermis decreases which causes drying of the skin and reduces the barrier function (Voegeli, 2012). The dermo-epidermal junction flattens; this increases the movement of layers of the skin which increases the risk of shearing, friction and pressure injury (Kottner, 2015). The dermis becomes thinner and has decreased elasticity, which also increases the risk of shearing and pressure damage to the skin (Chang, Wong, Endo, & Norman, 2013). The epidermis has a decrease in basal cells with age and a slower epidermal turnover which causes for delayed epithelialization and decreased ability for wound healing (Kottner, 2015; Voegeli, 2012).

Gunin, Kornilova, Vasilieva, and Petrov (2011) identified the different cells present in the skin throughout the lifespan. The elderly have less fibroblast cells in the dermis, which are important for the extracellular matrix (Gunin et al., 2011). One specific cell that decreases in numbers with age is the PCNA-positive fibroblast-like cell which helps with DNA synthesis and repair (Gunin et al., 2011). The other cellular change involved with aging is an increase in mast cells; this increase of mast cells causes inflammation and also leads to the release of toxic products that ultimately lead to cell damage (Gunin et al., 2011). The elderly have reduced fibroblast regeneration, less nerve

endings in the skin, and impaired vascular responses to cutaneous pressure (Chang et al., 2013). Having less nerve endings in the skin and coupled with impaired mobility, sensation and cognition increases the risk for elders to develop a pressure ulcer (DiAgostino, 2009; Chang et al., 2013).

### Facts and Figures of Pressure Ulcers

In the US, approximately 2.5 million patients per year are affected by a pressure ulcer and about 60,000 patients die as a direct result (HSS, 2014b). A retrospective study analyzed the average cost of stage IV pressure ulcers and found that the average hospital treatment was approximately \$129,248 for a hospital acquired pressure ulcer and \$124,327 for a community acquired pressure ulcer (Brem, et.al, 2010). Pressure ulcers are expensive and pressure ulcer treatment is estimated to grow to \$11 billion annually in the US and it is estimated that individual cost will be \$500-\$70,000 (NPUAP, 2015). Annually, there are approximately 17,000 lawsuits over pressure ulcers (HSS, 2014b).

### Pressure Ulcer Risk

Prevention of pressure ulcers has been a growing concern for healthcare facilities across the US. It is of utmost importance for facilities to prevent pressure ulcers for their residents and properly identifying high risk patients can be helpful with prevention (HSS, 2014b). A large study evaluated long-term care residents (19,981 participants) and compared the survival rates between residents with a pressure ulcer to those without and found 26% of residents with a pressure ulcer had died in a six month follow up compared

to 12.1% of residents who died without a pressure ulcer (Berlowitz, Brandeis, Anderson, Du, & Brand, 1997). Other variables significantly associated with death included: a diagnosis of a terminal illness, residents on oxygen and/or radiation therapy, dialysis, and/or residents that received blood transfusions (Berlowitz et al., 1997). Pressure ulcer prevalence in a nursing home setting ranges from 7.7% to 25.16% (Berlowitz et al., 1997; Kwong, Pang, Aboo, & Law, 2009). A prospective cohort study in a nursing home setting found patients with decreased mobility (bed or chair bound), lower ratio of nurses to residents in the facility, and a diagnosis of comorbidities (renal failure, cerebrovascular accident and pneumonia) to be associated with pressure ulcer development (Kwong et al., 2009).

A cross-sectional study of home care agencies found pressure ulcer prevalence to be 9.12% and the main risk factors identified include: history of a previous pressure ulcer, subjects with higher disease burden, incontinence, decreased mobility, recently discharge to home from a healthcare facility and subjects identified as high risk with the use of the Braden Scale (Ferrell, Josephson, Norvid, & Alcorn, 2000). The prevalence of pressure ulcers in a hospital setting was 1.8% and risk factors identified are: length of stay, frequency of surgeries, immobility, history of pressure ulcers, exposure to friction/shearing forces, and skin breakdown at pressure ulcer risk areas (Nonnemacher et al., 2008). In the ICU, the risk factors associated with pressure ulcer development include: decreased mobility, age, length of stay in an intensive care unit, history of cardiovascular disease, friction/shear and norepinephrine (Cox, 2011).



There are several factors that play into a person developing a pressure ulcer; the reoccurring risk factors include: history of a pressure ulcer, disease burden, decreased mobility, and moisture (Ferrell et al., 2000; Kwong et al., 2009; Nonnemacher et al., 2008; Brink, Smith, & Linkewich, 2006). A systematic review found decreased mobility, history of pressure ulcers, decreased perfusion (diabetes), hypoalbuminemia, moisture, malnutrition, and age to be risk factors associated with pressure ulcers (Coleman et al., 2013).

Furthermore, a small retrospective chart review identified patients that developed a pressure ulcer even with proper interventions (Levine, Humphrey, Lebovitis, & Fogel, 2009). The risk factors identified for unavoidable pressure ulcers included: hypoalbuminemia, respiratory failure (with intubation), anemia, hypoxia and hypotension (Levine et al., 2009). This study was a basic start of understanding which patients are at risk for developing an unavoidable pressure ulcer.

### Unavoidable Pressure Ulcers

The National Pressure Ulcer Advisory Panel held a consensus conference to determine if some pressure ulcers are unavoidable (Black et al., 2011). This panel defined an unavoidable pressure ulcer as a pressure ulcer that develops even with the provider evaluating the patient's condition and risk factors, the provider taking appropriate interventions that are consistent with family and patient goals, standards of practice and evaluating interventions and also making changes as appropriate (Black et al., 2011). The consensus was unanimous due to certain patient situations that pressure

cannot be relieved and/or perfusion cannot be improved (Black et al., 2011). The panel recognized two scenarios in which this could happen (Black et al., 2011). First, if a patient is hemodynamically unstable; perfusion to the organs (skin) is decreased and cannot deliver enough oxygen and nutrients (Black et al., 2011). Turning and repositioning may not happen as often as needed due to the instability of the patient's vital signs with frequent turning (Black et al., 2011). The second situation identified is the patient's right to refuse interventions, this can be in the case of comfort care (Black et al., 2011).

In 2014 The National Pressure Ulcer Advisory Panel held another interdisciplinary consensus conference to determine risk factors for unavoidable pressure ulcers (Edsberg, Langemo, Baharestani Posthauer, & Goldberg, 2014). The intrinsic factors that were found to be associated with unavoidable pressure ulcers include: hemodynamic instability that causes impaired tissue oxygenation (hypotension, use of vasopressors, hypoxemia, hypoventilation, and heart failure), low blood volume in the circulatory system (sepsis and hypoalbuminemia), edema, arterial and venous disease, and age (Edsberg et al., 2014).

### Pressure Ulcers in Hospice

The panel also addressed specific issues related to the end of life (Edsberg et al., 2014). A prevalence study at a hospice facility found 17.5% of patients developed a pressure ulcer (Tippett, 2005). From this sample, the primary risk factor for pressure ulcer development was cognitive-related disorders (dementia) and the most common

location for a pressure ulcer to develop was the sacrum (40%) (Tippett, 2005). In a palliative care setting, pressure ulcer prevalence was 10.5% and risk factors identified are: poor activities of daily living, inability to lie supine due to shortness of breath, catheter or ostomy care, and male gender (Brink et al., 2006). Additionally, the National Pressure Ulcer Advisory Panel discussed how skin failure is an unavoidable skin injury and patients with multiple organ dysfunction syndrome (MODS) are at a high risk for developing skin failure (Edsberg et al., 2014).

### Skin Failure

The skin, like other organs, is susceptible to failure. Skin failure is defined as, “an event in which the skin and underlying tissue die due to hypoperfusion that occurs concurrent with severe dysfunction or failure of other organ systems” (Langemo & Brown, 2006, p. 210). Skin failure can be acute, chronic, and occur at the end of life (Worley, 2007). With multisystem organ failure, the body shunts the blood away from the skin and towards the vital internal organs (Worley, 2007). The skin is unable to receive enough nutrients and oxygen due to a decrease in blood supply, this leads to waste build up and eventually tissue death (Langemo & Brown, 2006). The skin is more susceptible to injury: including friction, moisture, pressure and shearing forces (Lepak, 2012).

A retrospective chart review found that 19.6% of all pressure ulcers in a hospital setting were unavoidable and a manifestation of skin failure (Shanks, Kleinhalter, & Baker, 2009). Additionally, a prospective and descriptive study found the most common

factors associated with skin failure are: renal and respiratory failure, generalized edema, use of ventilator and sedatives, hypoalbuminemia, hypotension, and age greater than 50 years old (Curry et al., 2012).

It can be difficult for providers to differentiate between a pressure ulcer and skin failure (White-Chu & Langemo, 2012). However, it is important for providers to understand and differentiate between a pressure ulcer and skin failure because the family and patient may choose to focus on palliative care instead of aggressive treatment (Langemo & Brown, 2006).

#### Skin Changes at Life's End (SCALE)

SCALE is the term used to describe uncommon wounds that may appear at the end of life (Krasner & Stewart, 2015). Some examples are pressure ulcers, unavoidable pressure ulcers, ischemic wounds, mottling of the skin, Kennedy terminal ulcer and deep tissue injury (Sibbald et al., 2009). In 2009 a SCALE expert panel developed 10 consensus statements about skin changes associated with the end of life (Sibbald et al., 2009). The first statement discussed how the dying process affects the skin; the physiologic changes can be unavoidable and can be present as changes in skin color, integrity and/or turgor (Sibbald et al., 2009). Statement four discussed how SCALE are a result from compromised perfusion to the skin; decreased nutrition supply and decreased removal of waste from the skin (Sibbald et al., 2009). Additional statements discussed the importance of understanding the patient's wishes and end of life goals, using

interdisciplinary teamwork to discuss the plan of care, and educating the patient and family about SCALE (Sibbald et al., 2009).

Risk factors for developing a SCALE ulcer include: hypoperfusion, limited mobility, malnutrition, decrease in tissue perfusion, loss of skin integrity, and decrease immune function (Sibbald et al., 2009). SCALE ulcers occur due to unavoidable factors in some patients at the end of life (Krasner & Stewart, 2015). It is important to have open and honest communication between the healthcare team and patient/family to understand that SCALE are unavoidable and the patient is not being neglected, as this is a result of the dying process (Beldon, 2011).

#### Kennedy Terminal Ulcer (KTU)

The KTU was originally identified from a study started in 1983 (Kennedy, 1989). A team collected data from 1983 to 1988 on pressure ulcer prevalence in a long term care facility (Kennedy, 1989). There was an increase in pressure ulcer prevalence during this period of time (from 1.95%-3.36%); this increase was believed to be attributed to an increase in acuity of illness of patients (Kennedy, 1989). The team also gathered data on the average length of life of residents after a pressure ulcer was diagnosed; they found that 55.7% of residents died within six weeks of pressure ulcer development (Kennedy, 1989). Kennedy and team found a terminal pressure ulcer (KTU) and Kennedy defined the characteristics of this ulcer as: shaped similar to a pear, located on the coccyx or sacrum, is red, yellow or black in color, having a sudden onset and death is nearing

(Kennedy, 1989). From this original study the life expectancy was reported as two weeks to several months after development of the KTU (Kennedy, 1989).

In 1989 the Byron Health Center medical director, Dr. Stephen Glassley, named this specific terminal pressure ulcer as the Kennedy Terminal Lesion (Kennedy-Evans, 2009). Pressure ulcers usually develop from high pressure placed over one area of the skin (Yastrub, 2010). Whereas, a KTU is believed to develop from hypoperfusion and/or hypoxia to the skin due to the end of life disease process and usually develops over a few days with a rapid progression (Yastrub, 2010). This ulcer is a sign that the skin itself is starting to fail (Lepak, 2012).

There has been one study completed to understand the prevalence of the KTU in a hospice setting and to identify how long patients live after diagnosis of the KTU (Brennan & Trombley, 2010). A small study was completed in a 10-bed palliative care unit and approximately 5% of their patients developed a KTU (Brennan & Trombley, 2010). The length of time between development and death ranged from two hours to six days (Brennan & Trombley, 2010). More research needs to be completed on the KTU.

#### Nurses/Providers Knowledge on Pressure Ulcers

It is important for nurses and providers to be able to identify people at risk of developing a pressure ulcer to take evidence-based prevention measures and also to ensure early diagnosis and proper treatment (Joseph & Davies Clifton, 2013). A cross-sectional survey was completed and found the average score of the Pressure Ulcer Knowledge Assessment Instrument of nursing students was 51.1% (Simonetti,

Comparcini, Flacco, Giovanni, & Cicolini, 2015). Another cross-sectional survey found the average score of the Pressure Ulcer Knowledge Assessment Tool to be 29.3% in nurses and 28.7% in nursing assistants in a nursing home setting (Demarré et al., 2012). Nurses certified in wound care scored 89% on The Pieper Pressure Ulcer Knowledge Tool compared to 76.5% that were not certified (Zulkowski, Ayellow, & Wexler, 2007).

Physician scores on The Pieper Pressure Ulcer Knowledge Tool were 69% (Levine, Ayello, & Zulkowski, 2012). Provider and nurses knowledge is alarmingly low about pressure ulcers (Joseph & Davies Clifton, 2013; Simonetti et al., 2015; Demarré et al., 2012; Zulkowski et al., 2007; Levine et al., 2012). Full prevention measures in nine nursing homes in Belgium showed that only 6.9% of residents at risk had full prevention measures taken (Demarré et al., 2012). No literature was found on skin failure knowledge, SCALE knowledge, or KTU knowledge. Therefore, providers and nurses need to be educated on pressure ulcers, skin failure, SCALE and the KTU.

### Summary

There is growing literature to support that not all pressure ulcers are avoidable (Black et al., 2011; Edsberg et al., 2014; & Levine et al., 2009). Skin failure and SCALE are specific conditions of skin breakdown that are considered to be unavoidable (Langemo & Brown, 2006; Sibbald et al., 2009). The KTU is an ulcer that appears at the end of life in some patients; it has a sudden onset with rapid progression, is shaped similar to a pear, butterfly or horseshoe, and usually located on the coccyx or sacrum (Kennedy, 1989; Yastrub, 2010). There is minimal, but growing, literature available on

the KTU. Providers and nurses have scored low on knowledge exams of pressure ulcers (Joseph & Davies Clifton, 2013; Simonetti et al., 2015; Demarré et al., 2012, Zulkowski et al., 2007; & Levine et al., 2012). There is no literature available on knowledge of SCALE, KTU and skin failure. Therefore, further research is needed to have a better understanding of the KTU. Also, providers and nurses need to be educated on this topic.



## CHAPTER THREE

## THEORETICAL UNDERPINNING

Cognitive Load Theory (CLT) is the framework that guided the educational lecture for this project. CLT focuses on reducing unnecessary information to maximize learning in participants (van Merriënboer & Sweller, 2010). This theory first assumes that the participant's cognitive system has a restricted working memory and cannot handle more than five to nine information elements (van Merriënboer & Sweller, 2010). Information during this process is almost all lost after approximately 20 seconds unless it is rehearsed by the participant (van Merriënboer & Sweller, 2010). However, there are no identifiable limitations when working memory is presented information with long-term memory (van Merriënboer & Sweller, 2010). van Merriënboer and Sweller (2010) stated, "long-term memory alters the characteristics of working-memory. Long-term memory holds cognitive schemas that vary in their degree of complexity and automation" (p. 86). Sweller (1988) described a schema as an identified structure that allows participants to problem solve by recognizing a problem and understanding it belongs in a specific group of problems. The participants can know a solution to the problem from a similar situation or schema (Sweller, 1988).

This concept describes how experts are able to solve problems faster than novices. Sweller (1988) stated, "Novices, not possessing appropriate schemas, are not able to recognize and memorize problem configurations and are forced to use general problem-solving strategies such as means-ends analysis when faced with a problem" (p. 259).

When presenting new information a participant can become overloaded with information and this will actually decrease their learning. Sweller (1988) discussed, “We know that human short-term memory is severely limited and any problem that requires a large number of items to be stored in short-term memory may contribute to an excessive cognitive load” (p. 265). CLT helps prevent overwhelming the participants to enhance learning and memory. For the educational lecture developed for healthcare professionals, CLT was used to develop the lecture to prevent overwhelming the participants and to maximize new information retention.

## CHAPTER FOUR

## METHODS

The purpose of this study was to collect data on pressure ulcer prevalence, pressure ulcer characteristics, and length of life after pressure ulcer development in hospice patients. Sacral/coccyx pressure ulcers were specifically reviewed to determine a baseline prevalence and incidence rate of the KTU and the average length of life after ulcer onset. The second portion of the study was to educate providers and nurses on the KTU disease process, implications and also to understand their current knowledge.

Ethical Considerations

The institutional review board of Montana State University indicated an exempt status for this study. The retrospective chart review was exempt because no patient identifying information was collected. The education session was also exempt because there was no identifying information and the pre and posttest was optional to complete for participants. The pretest was handed out prior to the educational session with a number on the test. After the lecture was completed a posttest was handed out and the participants wrote the number that was on the pretest, therefore there was no way for the educator to identify who completed which test.

## Sample and Setting

### Patient Information

The retrospective chart review was completed at a local hospice center that utilizes electronic charting. The hospice facility provides both home hospice services and inpatient hospice services. Using the electronic database, data were collected from the nursing assessment. Data were collected on date of admission, inpatient or home hospice, ulcer present on admission, date of ulcer onset, location and description of ulcer, date of death, and time between ulcer onset and death. Data were collected from January of 2014 through June of 2015, over an 18-month period. Patients met criteria if they were admitted to either home or inpatient hospice and died within the timeframe of the charts being reviewed. Three hundred and sixty-three patients met criteria and were used for this study. Patients that did not die within this timeframe did not meet criteria; 63 patients did not meet criteria. If a pressure ulcer developed in an inappropriate area it was considered to be an outlier.

### Educational Session

The first education session was completed at a wound conference in Wyoming in June of 2015. Two education sessions were completed at the hospice facility in January of 2016. The lecture was optional and the pre and posttest was also optional for the participants. The wound conference had 22 participants attend the lecture. At the hospice facility, the first lecture had 12 participants and the second lecture had 5 participants. All pre and posttests were completed at all the lectures.

### Intervention

For the educational intervention the cognitive load theory (CLT) was identified as an effective tool to design the outline and presentation of the lecture. This theory assumes that the participant's cognitive system has a restricted working memory and is influenced by the intrinsic load, extraneous load and germane load (van Merriënboer & Sweller, 2010). The intrinsic load is the central nature of learning tasks, the method which the information is presented is the extraneous load and lastly the actual learning is the germane load (van Merriënboer & Sweller, 2010). The intrinsic, extraneous and germane cognitive loads are additive and this stresses the importance of cognitive load being influenced with the educational design of material (Pass, Tuoriene, Tabbers, & Gerven, 2010). This further stresses the importance of the intrinsic, extraneous and germane cognitive load needing to stay within working memory limits during the lecture to prevent overwhelming the participants (Pass et al., 2010).

Participants can become overwhelmed with the intrinsic and extraneous load and thus the germane load will be decreased. Germane cognitive load is essential for the building and storage of schemata into the participant's long term memory; this is especially important while learning new material as it requires more elements (Kirschner, 2002). It is important to focus on decreasing the extraneous load because the intrinsic load cannot be altered by lecture design interventions (van Merriënboer & Sweller, 2010). However, the intrinsic load can be managed and aid in optimizing the germane load (van Merriënboer & Sweller, 2010). This is essential for this education session as it is introducing new information to nurses and providers about the Kennedy terminal ulcer.

This theory helps reduce the extraneous load, manage the intrinsic load while optimizing the germane (learning) load.

Multiple tools were utilized to help decrease the extraneous load during the lecture. First, the modality principle involves replacing written explanatory text with spoken text with the use of visual information (van Merriënboer & Sweller, 2010). Mayer and Moreno (1998) completed a study to compare auditory narration to visual narration with pictorial information. The results revealed that students learn better with pictorial information accompanied by verbal information rather than visual narration (Mayer & Moreno, 1998). It is believed that students are overwhelmed with both the pictorial information and written information and cannot process both simultaneously (van Merriënboer & Sweller, 2010). The participant's attention is split between the picture and words; they will look back and forth between the written text and the picture and will not focus completely on one (Mayer & Moreno, 2003). However, with the auditory narration the student can focus on the picture and process the words simultaneously (van Merriënboer & Sweller, 2010). Therefore, verbal narration was used with the presentation of pictorial information in replacement of written text.

An additional tool to decrease extraneous load is the temporal contiguity effect. Participants better understand information when animation and narration are presented at the same time rather than consecutively (Mayer & Moreno, 2003). Mayer, Moreno, Boire, and Vagge (1999) completed two experimental studies that evaluated how presenting information concurrently with visual and narration information was different from presenting information segregated with the narration first and then the animation.

The participants scored significantly better when the information was presented congruently compared to segregated (Mayer et al., 1999). When the information was presented both visually and narratively it maximized the cognitive load and enhanced the learning experience (Mayer & Moreno, 2003). For the educational design for this lecture visual information was presented simultaneously with the narration material.

An additional component to help decrease the extraneous cognitive load is signaling. Signaling helps guide the process involved in forming processes and helps identify the appropriate schema, making conclusions, depict decisions and construct arrangements that assist in retrieval (Mautone & Mayer, 2001). The process of signaling is to guide the participants learning process while not adding new information to the lecture (Mayer & Moreno, 2003). Three randomized control studies were completed and showed that signaling increased the learners understanding of the presented material (Mautone & Mayer, 2001). In experiment 1, the signaled group had 3 headings, a 69-words summary that was presented after the introduction, 16 connecting words, and 14 words that were bolded, highlighted or in italic print (Mautone & Mayer, 2001). Signaling works to decrease the extraneous cognitive load by allowing the reader to know what information is crucial throughout the entire lecture (Mayer & Moreno, 2003). For this lecture, an outline of the lecture was provided in the beginning, there were main headings for each topic and there were 6 words that were bolded throughout the entire lecture: failure/fail, unrelieved pressure, age, hypoperfusion, Kennedy terminal ulcer and communication.

Another strategy for having a productive education session is managing the intrinsic load. For complex material it is recommended to start with simple material and gradually introduce more complex tasks (van Merriënboer & Sweller, 2010). This concept helped design the flow of the presentation. The lecture started with material the participants were familiar with, pressure ulcers. Then the lecture progressed to new material for the participants, skin changes at life's end and the Kennedy terminal ulcer. Lastly, there was a case study for the participants to apply their new knowledge.

In summary, the design of the education session was intended to decrease the extraneous load, manage the intrinsic load while optimizing the germane cognitive load for the learners. This was accomplished with the use of signaling; including utilization of main headings, a summary of pertinent information, and key words. Verbal narration was provided with pictorial information during the lecture to reduce split attention. The temporal contiguity effect was also utilized by having visual and auditory material presented simultaneously. The intrinsic load was managed by having the educational design start simple and then progress into more complex material. By using the CLT, the learners experience was enhanced by promoting the use of schemas in long-term memory in conjunction with working memory.

### Data Analysis

#### Retrospective Chart Review

To determine pressure ulcer prevalence in hospice patients, the number of patients that had a pressure ulcer upon death was divided by the total number of patients in



hospice. The characteristics of the pressure ulcers involved the staging of pressure ulcers and location. Descriptive statistics, including mean, standard deviation, and median, were utilized for average length of life after pressure ulcer development.

### Educational Session

The Wilcoxon Signed Ranks test was used to compare matched pre education session scores to post education session scores. To determine a statistically significant difference between the pretest and posttest answers a two-tailed p value of less than 0.05 was used. Statistical analysis was performed using SPSS software.

## CHAPTER FIVE

## RESULTS

The purpose of this study was to complete a retrospective chart review to gain an understanding of pressure ulcer prevalence and characteristics in a hospice setting. Sacral and coccyx ulcers were specifically reviewed to evaluate the average length of life after Kennedy terminal ulcer (KTU) onset and the prevalence rate of this specific ulcer in the hospice setting. The second portion of this study involved completing multiple educational sessions to evaluate nurses and providers understanding of the KTU and further educate them on the importance and significance of the disease process.

Pressure Ulcer Prevalence

A total of 363 patients qualified and were reviewed for the retrospective chart review. Of these charts 101 (27.8%) patients had or developed a pressure ulcer prior to death. Out of the 101 patients that had an ulcer, 23 patients had multiple ulcers. The total ulcer count was a 127, with 4 outliers. The 4 outliers include pressure ulcers that developed on the toes and thumbs of patients. These were considered to be outliers because of the low probability that they were true pressure ulcers. See figure 1 for a flowchart description of the chart review.

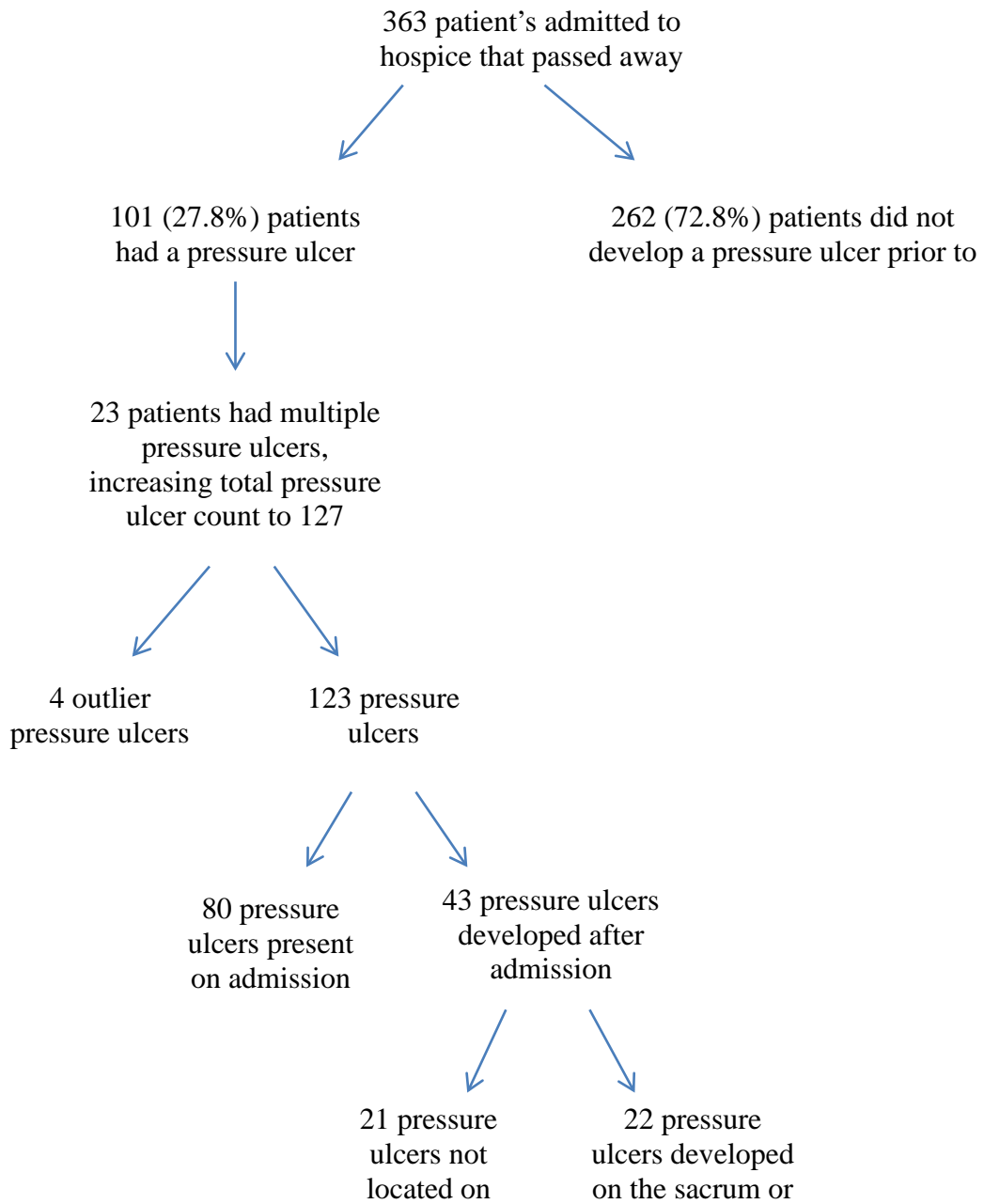


Figure 1. Retrospective Chart

### Pressure Ulcer Characteristics

Pressure ulcer staging was the main description of pressure ulcers provided in the charting system at the hospice home. The majority of pressure ulcers were classified as a stage 2 (53). There were 0 stage 4 pressure ulcers identified. The rest of the pressure ulcers were classified as stage 1 (36), stage 3 (7), and unstageable (27), see table 1. The majority of ulcers were identified in the home hospice patients 67.5% compared to 32.5% of inpatient hospice.

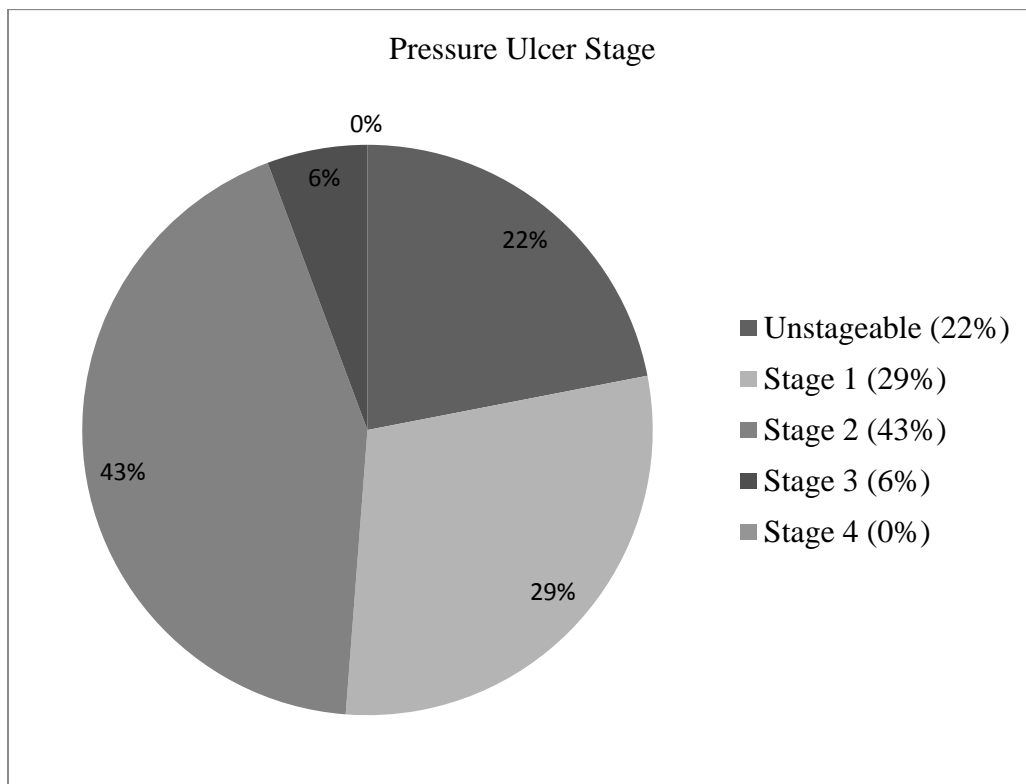


Table 1. Pressure Ulcer Stage

Locations for pressure ulcers included: coccyx (56), buttock (22), heel (20), spine (4), hip (4), ankle (4), sacrum (3), ear (2), shoulder (2), low back (2), arm (1), breast (1), foot (1), and rib (1), see table 2.

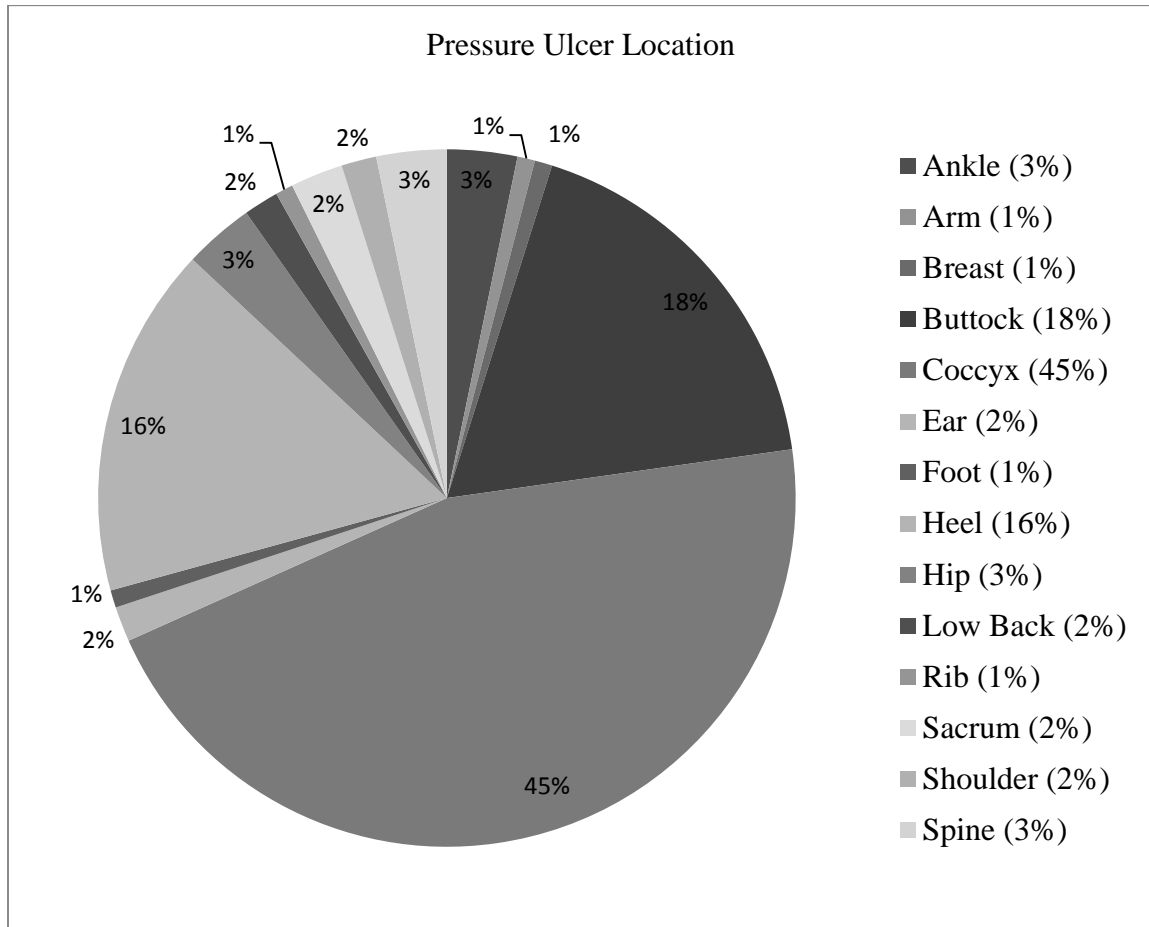


Table 2. Pressure Ulcer Location

Sacral/Coccyx Ulcers

Eighty of the pressure ulcers were present on admission and therefore were unable to determine average length of life after ulcer formation. This resulted in loss of 22% of the data because the date of onset is unknown. Forty-three ulcers were not present on

admission. Of these forty-three ulcers, twenty-two were located on coccyx or sacrum. The average length of life after ulcer onset in this location was 17.7 days, the standard deviation was 21.9 days, median was 9.5 days, minimum was 1 day and maximum was 79 days, see table 3. The prevalence rate of the Kennedy terminal ulcer was 6.1% in a hospice setting. Sixteen of the ulcers were identified in home hospice patients and 6 ulcers in inpatient hospice patients. The average length of life in home hospice patients was 20.1 days and a median of 11.5 days. Whereas, in inpatient hospice the average length of life was 11.3 days and the median was 9.5 days.

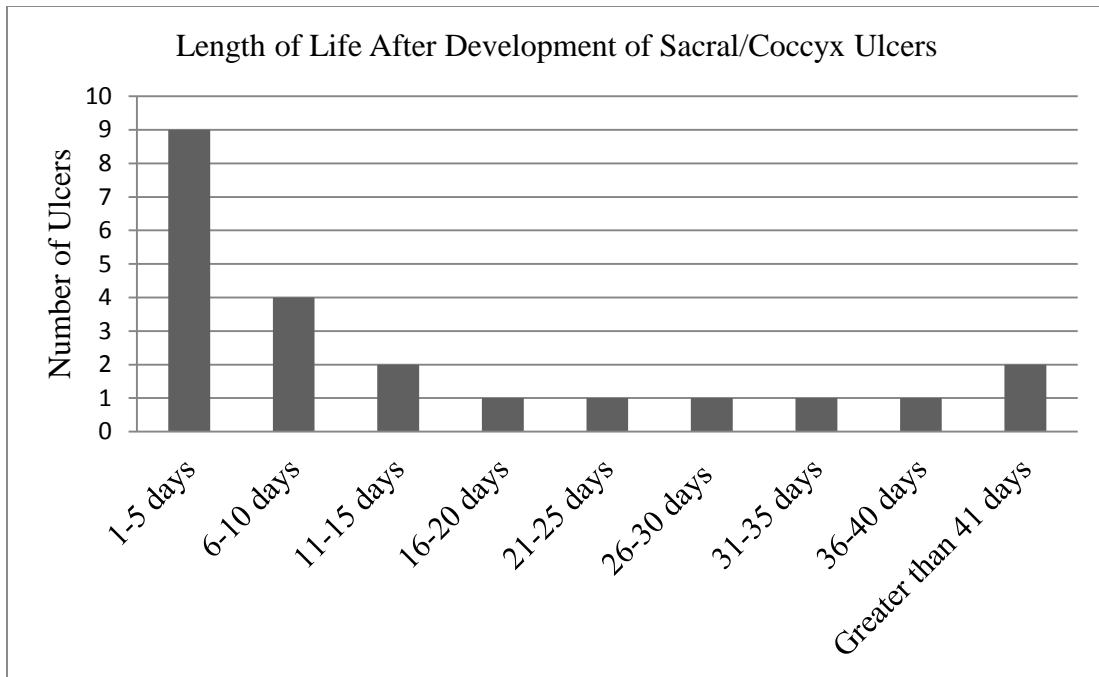


Table 3. Length of Life After Development of Sacral/Coccyx Ulcers

Education Session

There were a total of 39 participants. The majority of the participants age was between 40 and 49 years old (28.2%), followed by 50 to 59 years old (25.6%), 30 to 39 years old (20.5%), 20 to 29 years old (17.9%) and greater than 60 years old (7.7%). The majority of participants were registered nurses (35.9%), licensed practical nurses (15.4%), certified nursing assistants (12.8%), and wound certified nurses (10.3%). Other professions that attended the lectures include: master's prepared nurses (7.7%), nurse practitioners (5.1%), certified other than wound nurses (5.1%), and other (7.7%). See figure 2 for the number of year's worked and current working location for the participants.

Years Worked

	Frequency	Percent	Valid Percent
Valid 0-5	9	23.1	23.1
6-10	14	35.9	35.9
11-15	4	10.3	10.3
16-20	4	10.3	10.3
>20	8	20.5	20.5
Total	39	100.0	100.0

Current Working Location

	Frequency	Percent	Valid Percent
Valid Hospital	7	17.9	17.9
Outpatient Clinic	5	12.8	12.8
Long Term Care	7	17.9	17.9
Wound Clinic	2	5.1	5.1
Hospice	16	41.0	41.0
Other	2	5.1	5.1
Total	39	100.0	100.0

Figure 2. Years Worked and Current Working Location of Education Participants

There was a slight difference between the wound conference participants (31.8%) compared to the hospice facility participants (47.1%) that have not previously heard of the KTU. Of the 39 participants, 15 (38.5%) have previously not heard of the KTU. There were 7 pre and posttest questions that evaluated the participant's knowledge on pressure ulcers, unavoidable pressure ulcers, skin failure, and KTU, see appendix A for test questions. See table 4 for the percentages correct of the pre and posttest of each question.

Question Number	Pretest score	Posttest score
1	100%	100%
2	92.3%	94.5%
3	100%	97.4%
4	61.5%	94.9%
5	100%	92.3%
6	87.2%	100%
7	59.0%	97.4%

Table 4. Pretest/Posttest Score Results

A Wilcoxon Signed Rank Test determined a statistically significant difference between pretest and posttest answers for questions 4 ( $p=0.000$ ), 6 ( $p=0.025$ ), and 7 ( $p=0.000$ ). The Wilcoxon Sign Rank Test indicated these were positive results with improvement from pre to post testing. Therefore, it is assumed that the education session produced a significant positive result for question 4 which addressed unavoidable pressure ulcers, question 6 which evaluated the pathology of the KTU, and question 7 concerning the usual presentation of the KTU. See table 5 for the Wilcoxon Signed Rank Test evaluation of each question.



## Wilcoxon Signed Rank Test

Test Question	Z	Asymptotic Significance (2-tailed)
Post 1-Pre 1	0.000a	1.000
Post 2-Pre 2	-0.577b	0.564
Post 3-Pre 3	-1.000c	0.317
Post 4-Pre 4	-3.606b	0.000
Post 5-Pre5	-1.732c	0.083
Post 6-Pre 6	-2.236b	0.025
Post 7-Pre 7	-3.873b	0.000

- a. The sum of negative ranks equals the sum of positive ranks.
- b. Based on negative ranks.
- c. Based on positive ranks.

Table 5. Wilcoxon Signed Rank Test

## CHAPTER SIX

## DISCUSSION

Pressure Ulcers in a Hospice Setting

The prevalence of pressure ulcers in a hospice setting found in this study was 27.8%. This percentage was higher than what was found in a study completed on urban-suburban hospice patients, which found a 17.5% prevalence rate of pressure ulcers (Tippett, 2005). The higher prevalence rate could be related to patients living longer and living with complex comorbidities, as there is over a 10 year gap in-between studies. The most common locations for a pressure ulcer to form were the coccyx area, buttock and heels. These areas are under high stress and are more prone to skin breakdown and pressure ulcer development. The majority of pressure ulcers were stage II and unstageable, with no findings of stage IV pressure ulcers.

Kennedy Terminal Ulcer

Unfortunately, during the time of data collection there was not enough detail in the charting to evaluate the difference between a pressure ulcer and a Kennedy terminal ulcer (KTU). Therefore, the sacral/coccyx ulcers that developed after a patient was admitted to hospice were used as a proxy for the KTU to determine the average length of life after ulcer development. The mean length of life after ulcer onset was 17.7 days and the median was 9.5 days. Patients that were admitted to inpatient hospice had a shorter length of life (11.3 days) compared to patients admitted to home hospice (20.1 days).

Patients admitted to inpatient hospice are usually more ill with an acute complication that requires more aggressive nursing care. Therefore, it is expected that inpatient hospice patients would have a shorter length of life compared to home hospice patients. These findings are similar to the original study completed on the KTU (Kennedy, 1989).

Kennedy (1989) determined the life expectancy to be two weeks to several months after development of the KTU. It is important to note that half of the patients did pass away within 10 days of ulcer onset. There was also two patients identified that lived longer than 60 days after ulcer onset. This could be related to these patients having chronic skin failure compared to an acute skin failure. With the sacral/coccyx ulcers in terminal ill patients being used as a proxy for the KTU the prevalence rate was 6.1%. Brennan and Trombley (2010) found a similar prevalence rate of 5% of the KTU in a palliative care setting.

#### Education Session

Three educational sessions for nurses and providers were completed for this study, one at a wound conference and two at the hospice home. It is critical to note that 38.5% of participants had not previously heard of the KTU. Skin changes at life's end and skin failure are critical to identify as they are considered to be unavoidable skin injuries. It is worrisome that 31.8% of the wound participants and 47.1% of hospice participants were not aware of the KTU as they are in settings that would identify this type of ulcer more regularly. The comments in the posttest found several participants

encouraged and grateful to understand the disease process and help provide comfort to the family about skin changes at life's end and that they are unavoidable.

To evaluate the education session, a pretest and posttest was administered to all participants. Questions 1, 2 and 3 addressed pressure ulcer facts, location and risk factors. The pretest scores were all above 90%. This finding of high pretest scores on pressure ulcer knowledge helps support the strategies used with the cognitive load theory. The cognitive load theory suggests starting with familiar and simple information at the beginning of the lecture and then moving to more complex ideas. There was a slight decrease in question 3 from 100% to 97.4%. One participant missed this question in the posttest and this can most likely be attributed to survey fatigue, as the participant answered with the correct response and circled an additional answer.

Question 4 addressed unavoidable pressure ulcers. Using the Wilcoxon Signed Rank test there was a statistically significant difference between the pre and posttest answers. This supports a positive response in answers from the pretest to the posttest. In the past there has been a notion that all pressure ulcers are preventable. While the majority of pressure ulcers are preventable, there is growing literature to address that there are some situations that pressure ulcers cannot be prevented. This is a new concept for nurses and providers to understand.

Question 5 addressed skin failure and there was a negative response for this question in the pretest and posttest. In the pretest the participants scored an average of 100% and in the posttest the participants scored an average of 92.3%. Therefore, 3 participants answered incorrectly during the posttest. During the lecture, skin failure was

identified to be acute, chronic and/or at the end of life. However, the majority of the lecture focused on end of life situations of skin failure and this could have confused the participants with this question.

Lastly, questions 6 and 7 addressed the participant's knowledge on the KTU. The Wilcoxon Signed Rank test found a positive statistically significant difference between the pretest and posttest scores that addressed the KTU usual presentation and pathology. Therefore, the educational session using the cognitive load theory helped improve knowledge on the KTU. This is also a developing concept for nurses and providers to understand. Without being educated on a topic, a provider or nurse cannot have the knowledge to take appropriate interventions or properly educate the family about the patient's wounds.

### Limitations

There are several limitations that need to be addressed with this study. The first is there are limitations with using a retrospective chart review. Specifically, incomplete charting and variance in the quality of charting caused difficulty interpreting the data. The incomplete charting posed a large limitation for this specific study. The reviewer was not able to determine if the wound was a pressure ulcer or KTU with the charting provided. Therefore, pressure ulcers that developed in the sacral/coccyx area in terminally ill patients after admission to hospice were used as a proxy. The incomplete charting and not being able to determine what type of ulcer the patient had further strengthens the need for education of nurses.

An additional limitation with the data collection involved not knowing the ulcer onset date if the patient developed the ulcer prior to admission of the hospice facility. Eighty ulcers (22%) could not be used in the data for the average length of life because the ulcer formed prior to the patient being admitted to the hospice facility and no onset dates were available. Lastly, this study only utilized one hospice facility for data collection. Therefore, having multiple hospice facilities would have strengthened this study.

The pretest and posttest evaluation of the educational session also had limits. It would have been beneficial to have an additional posttest about 6 months after the presentation to evaluate if the nurses and providers were seeing the KTU in practice and if they retained the information from the retrospective chart review.

#### Future Recommendations

There is still a large gap in the literature about the KTU. Further studies need to be completed on the prevalence and average length of life after ulcer onset. It would be beneficial to complete additional studies involving educating the staff prior to implementing the study and performing a prospective chart review. This would greatly strengthen the study and allow for more real time data collection while addressing some of the limitations with a retrospective chart review. It would be beneficial to complete a prospective chart review and measure the progression of ulcers determined to be a KTU and compare this to the progression of pressure ulcers. Also, nurses and providers need to be educated on the importance of skin changes at life's end and skin failure. As this

information is growing in the literature however there is still a gap in provider knowledge.

## CHAPTER SEVEN

## CONCLUSION

There is growing evidence in the literature to support that some pressure ulcers are unavoidable due to advanced disease process and the end-of-life process. The main risk factors for patients to develop an unavoidable pressure ulcer include: hypoalbuminemia, respiratory failure with intubation, anemia, hypoxemia, sedation and hypotension (Levine et al., 2009). One situation in which an unavoidable pressure ulcer may develop is when a patient chooses comfort care at the end of life. At the end of life, turning and repositioning can cause nausea and pain. This may conflict with patient's end of life goals. Providers need to respect patients and families treatment options. It is still extremely important for facilities to implement evidence-based interventions with patients to prevent pressure ulcer formation, but in some situations the patient's individualized goals need to be a priority.

There is no official guideline in the literature to diagnose a Kennedy terminal ulcer (KTU). Part of the diagnosing process is to rule out a pressure ulcer. The KTU will present usually over the sacrum, is a butterfly/pear shape, is purple, red, blue or black, has a rapid onset, and has irregular borders (Yastrub, 2010). Whereas, a pressure ulcer presents as a red shape similar to the bony prominence causing the pressure, has regular borders and has a slow progression (Yastrub, 2010). When a KTU is properly diagnosed it is of utmost importance to educate the patient and family on multisystem organ failure, end-of-life disease process and that the skin is failing due to hypoperfusion. The patient



and family also should be educated on the connection of the patient's rapidly deteriorating health and its effect on the circulatory system. The visual changes in the skin can help explain this process to the family (Lepak, 2012; Sibbald et al., 2010). Even with the preventative measures at the end of life a KTU or skin changes at life's end may develop and are considered to be unavoidable.

Treatment goals that may be presented to the family depend on the patient's overall condition. It is important that the patient and family have the right to choose their treatments after being educated about the patient's current health status (Langemo & Brown, 2006). When considering treatment goals/options it is important to look at the entire picture and then inform the patient/family of the patient's condition and support their decisions. At this point, the patient goals may focus on the quality of life rather than promoting wound healing. From this study the average length of life was 17.7 days after ulcer formation. The provider needs to be understanding and thorough with the patient and family during this process. There is still a gap in the literature about skin changes at life's end and further studies need to be completed to help understand this process further.

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APPENDIX A

PRETEST AND POSTEST QUESTIONNAIRE

1. Which statement(s) are true about pressure ulcers:
  - a. Occur at bony sites
  - b. Caused by unrelieved pressure
  - c. Localized areas of tissue damage
  - d. All of the above
  
2. Which of the following sites are at highest risk to pressure ulcer development?
  - a. Soft tissue areas
  - b. Abdominal areas
  - c. Sacrum and heels
  - d. Hands
  
3. Which of the following patients is at highest risk for pressure ulcer development?
  - a. A generally healthy 27 year old male
  - b. A 70 year old male with a new diagnosis of a stroke and is immobile
  - c. A 34 year old female with a broken leg
  - d. A physically active 88 year old female in a nursing home
  
4. All pressure ulcers are preventable. **True** **False**
  
5. Skin failure can be acute, chronic and/or at the end-of-life. **True** **False**
  
6. What is the main cause of the Kennedy terminal ulcer?
  - a. Hypoperfusion to the skin
  - b. Unrelieved pressure
  - c. Exposure to feces and urine
  
7. What is the usual wound description of the Kennedy terminal ulcer?
  - a. Round and images the boney prominence underneath the skin
  - b. Butterfly or pear shaped, irregular borders, and usually located on the sacrum
  - c. Excoriation with slough, usually located in the perianal area
  - d. Red or purple irregular patches, usually located on fingers, toes, ears or nose