

Running Head: END-OF-LIFE TREATMENT OPTIONS FOR DEMENTIA

STUDENT NURSES KNOWLEDGE OF END-OF-LIFE TREATMENT OPTIONS IN  
DEMENTIA PATIENTS

**Honors Thesis**

**Presented in Partial Fulfillment of the Requirements**

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**Abstract***Student Nurses Knowledge Of End-of-Life Treatment Options In Dementia Patients*

Dementia is a serious disease that affects 46.8 million elders globally with 9.9 million new cases each year. It is not often understood that dementia is considered a terminal illness, and it is thought that misconceptions about dementia may be a factor of poor quality of care for this vulnerable population at the end of their lives. Nurses are on the frontlines of caring for dementia patients, however nurses may lack knowledge of how to best care for dementia patients and their families.

A qualitative survey study will be conducted using a convenience sample of Salem State nursing students (N= 100). Specific study aims include: do nursing students know about dementia, advanced directives, and end of life care and treatment options specifically related to the dementia patient? Thematic coding methods will be used to analyze the data.

Results from this study will help identify knowledge needs of nursing students related to end-of-life treatment for dementia patients. Understanding knowledge needs of nurses can further inform future educational programs for nursing students in order to increase the quality of care for this population.

*Keywords:* dementia, student nurses, nursing school, curriculum, end-of-life treatment, advanced directives

**Table of Contents**

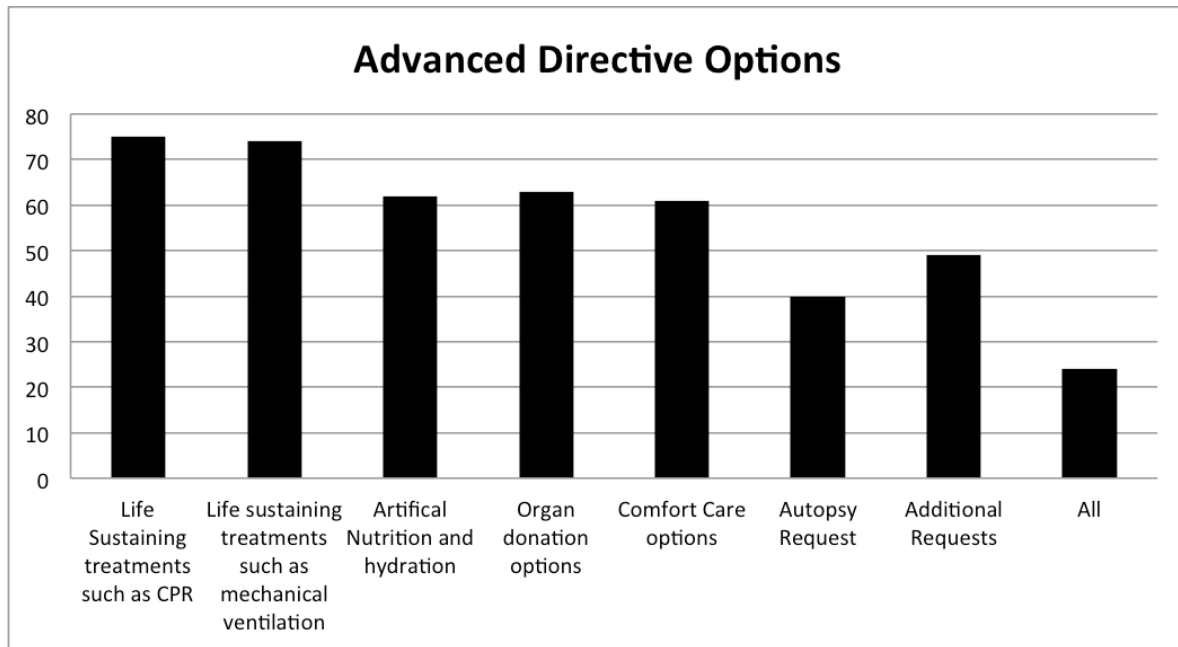
<b>I.</b>	<b>Introduction.....</b>	<b>1-2</b>
<b>II.</b>	<b>Literature Review.....</b>	<b>2-11</b>
	a. Dementia.....	2-6
	i. Definition.....	2
	ii. Diagnostic criteria.....	2-3
	iii. Types of Dementia.....	3-6
	iv. End-Stages.....	6
	b. Treatment options.....	6-10
	i. Palliative Care.....	7
	ii. Hospice.....	7-8
	iii. Artificial Nutrition.....	8
	c. Advanced Directives.....	8-10
	d. Student Nurses General Curriculum.....	10-11
<b>III.</b>	<b>Methods.....</b>	<b>11-12</b>
<b>IV.</b>	<b>Results.....</b>	<b>12-14</b>
	a. Discussion.....	14-15
<b>V.</b>	<b>Conclusion.....</b>	<b>15</b>
<b>VI.</b>	<b>References.....</b>	<b>16-17</b>

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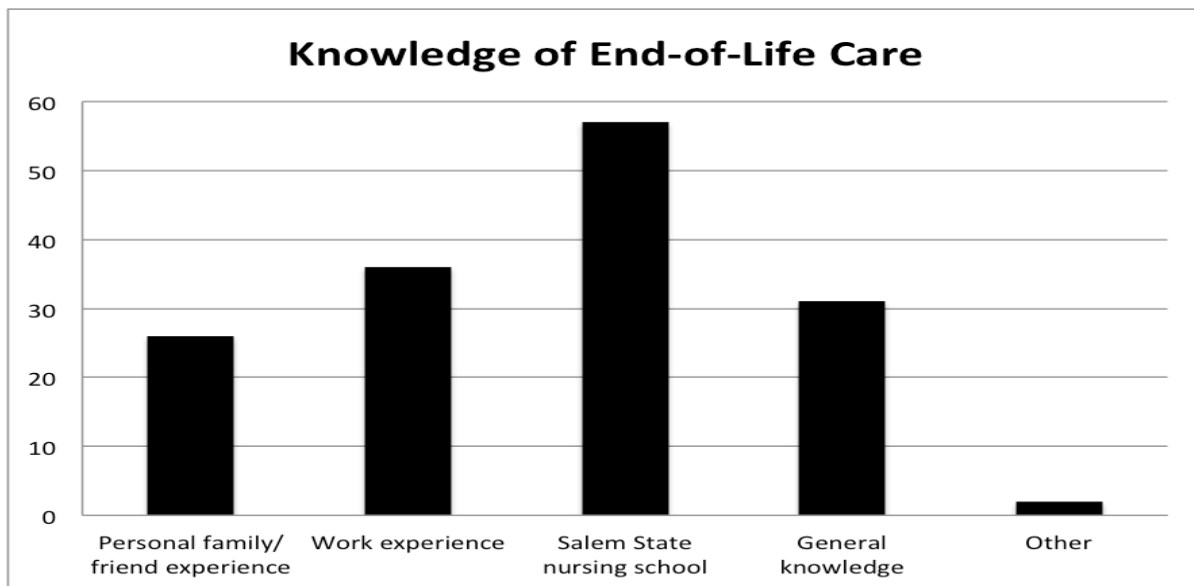
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Tables and Figures



**Figure 1**

Figure 1 shows the number of students that selected each option of the things that could be included in an advanced directive.



**Figure 2**

Figure 2 represents where the students state that they received their knowledge on end-of-life care.

## Introduction

End of life care is not something that your average student nurse learns about in their demanding course load. Dementia may be allotted one class day during a mental health rotation while end of life care gets a couple of minutes in a community health class. There is no focus on these topics while in school, but the number of people with dementia is growing constantly as people are living longer lives. With a larger population living well into their nineties or beyond, dementia is becoming more and more prevalent. The Diagnostic and Statistical Manual Fifth Edition (DSM-V) states that, “approximately 1%-2% at age 65 years and as high as 30% by age 85 years have dementia” (American Psychiatric Association [APA], 2013, p. 608). The Centers for Disease Control (CDC) (2011) suggests that by age eighty-five, between twenty-five to fifty percent of people will have Alzheimer’s disease specifically (CDC, 2011). Most nurses work with the elderly and will see this on a daily basis and they should be able to properly care for this population.

It is also important to know how to care for these people at the end of their lives because advanced stage dementia is considered a terminal illness (Kumar, 2013). This patient population is considered vulnerable and requires special care. They may not be able to communicate, ambulate, or feed themselves once they are in the end-stages of dementia. A nurse needs to be able to assess a patient’s body language, facial expressions, and reactions when they are unable to communicate (Kumar, 2013). These are all things that need to be included in a proper nursing education. Robinson (2004) found through her research that undergraduate nursing schools are not including an adequate amount of end-of-life care in their curricula. It would be beneficial for all undergraduate and graduate nursing schools to incorporate more end-of-life education in any way that they can (Robinson, 2004).

According to this research there is also a lack of knowledge about advanced care planning. Healthcare workers as well as family members find it difficult to discuss this with someone that has been diagnosed with dementia, especially when to initiate this conversation (Brooke & Kirk, 2014). Brooke and Kirk (2014) also found, “following advanced care planning discussions, that people with dementia reported a sense of relief and fewer worries for the future” (Brooke & Kirk, 2014).

## **Literature Review**

### **Definition**

The latest version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) classifies all types of dementia as neurocognitive disorders (APA, 2013, p. 591). To be considered a neurocognitive disorder it must be acquired, meaning that the disorder cannot have been present from birth. It represents a deterioration in the level of functioning that previously subsisted. Occasionally, the causal pathology and etiology can be determined, however this is not always the case with dementia. It is also very possible to be burdened with more than one type of neurocognitive disorder simultaneously. Even though the technical term is now neurocognitive disorder, the term dementia is still widely used and more commonly known. It is more acceptable to use with the elderly where there is a gradual decline. When younger people are affected in this way, the more customary term is neurocognitive disorder. The DSM-V gives the possibility of twelve different types of dementia (APA, 2013, p. 602).

### **Diagnostic Criteria**

In order for any kind of dementia to be diagnosed the person must meet certain diagnostic criteria. The evidence that must be obtained begins with a significant cognitive decline in at



least one cognitive domain. These include complex attention, executive functioning, learning and memory, language, perceptual-motor, or social cognition (APA, 2013). These symptoms need to be recognized by the person experiencing them, someone close to them with knowledge of the signs and symptoms. It is also preferred that this person notices a significant impairment in cognitive performance preferably documented by dependable medical testing. These declines must affect the person's independence in everyday life and they must not be explained by delirium or other mental disorders. To diagnose more specifically each subtype of dementia has its own criteria that needs to be met (APA, 2013).

## **Types**

### **Alzheimer's Disease**

Alzheimer's Disease (AD) is the most common form of dementia. It accounts for well over half of all dementia cases (APA, 2013, p. 612). AD has a subtle onset and progresses slowly and steadily in at least one cognitive domain. There is often a family history or genetic mutation that can be tested for. The greatest risk factor for AD is age. The older that a person gets, the more likely they are to develop AD (APA, 2013). Chung (2012) states that, "Alzheimer's disease affects a small percentage of those at age 65 years, with the incidence doubling every 5 years. By the age of 85 years, 1 in 3 are affected" (Chung, 2012, 1). The average lifespan from diagnosis to death is 10 years. It is possible to live longer if exceptional care is provided. Most death related to AD is not caused by the AD it is caused by aspiration (APA, 2013). Many people turn to percutaneous gastrostomy feeding tubes to prevent aspiration in the end stages of dementia, but literature shows that these tubes do not actually prevent aspiration, nor do they promote longevity or quality of life (Chung, 2012).

**Vascular Dementia**

Vascular dementia is the second most common form of neurocognitive disorder. This type of dementia is caused by some form of cerebrovascular disease, which causes the cognitive deficits (APA, 2013). Depending on the location and the severity of damage of the vessel or vessels that are affected, the decline of the persons cognitive functioning can vary and change. A person that has vascular dementia may see periods of stability and possibly even improvements. In the United States (U.S.), 20-30 percent of people that have a stroke are diagnosed with dementia within three months following the cerebrovascular accident (APA, 2013). This type of dementia occurs more frequently in men than in women and seems to be more prevalent in African Americans over other races (APA, 2013). This form of dementia is also seen more in people that have had an ongoing problem with hypertension. Long-time smokers are also at greater risk of developing vascular dementia (American College of Physicians, 2000).

**Lewy Bodies**

Dementia with Lewy Bodies (DLB) is also characterized by a progressive cognitive impairment. This is the third most common type of dementia with 20-35 percent of dementia cases being found due to Lewy Bodies (APA, 2013). It is also common for a person with DLB to experience complex visual hallucinations as well as hallucinations of other senses. There are often disruptions in rapid eye movement (REM) sleep behavior. Other symptoms that may be recognized are depression, delusions, and sudden onset of Parkinson-like symptoms (APA, 2013). With this type of dementia, there are microscopic blemishes that can be found in the brain. The microscopic blemishes are the Lewy Bodies. These are similar to what can be seen in the brain of someone with Parkinson's, which is why there may be similar symptoms (American College of Physicians, 2000). DLB can be difficult to diagnose due to the variable presentation

of symptoms. The major cognitive deficits must be observed at least one year before any of the motor symptoms. It has been found that men are affected slightly more than women. This is a gradual form of dementia that will progress to severe dementia and then death. The usual life span of someone with LBD from diagnosis to death is only 5 to 7 years (APA, 2013).

### **Frontotemporal**

This type of dementia also progresses gradually. With this form of dementia the typical characteristics are present as well as a language or behavioral change (APA, 2013). However, there may be fewer declines in memory and learning. This is a common cause of early onset dementia in people younger than 65. Unfortunately, this subtype of dementia has a survival period of about 3 to 4 years after diagnosis. The decline occurs much faster than AD (APA, 2013).

### **Prion Disease**

This is a very serious form of dementia and has the quickest progression from diagnosis to death, if it is even diagnosed. It is associated with Mad Cow Disease and is very rare. It is characterized by a low mood, withdrawal, and anxiety. It can become a major neurocognitive disorder within 6 months and it is accompanied by very severe symptoms. It is not uncommon to go undiagnosed until autopsy (APA, 2013).

### **Other Less Common Types of Dementia**

There are five other types of dementia that are less common and some are treatable. These include dementias due to traumatic brain injury, substance or medication induced, HIV infection, Parkinson's disease, and Huntington's disease. These are often found more in young people and are referred to as neurocognitive disorders as opposed to dementia (APA, 2013).

## **The End Stages**

Most dementias are terminal illnesses. The end-stages of dementia have specific characteristics, but cannot always be identified with absolute confidence that it is really the end for someone. It is possible for the end-stage of dementia to last up to two to three years (Birch & Stokoe, 2010). According to Birch and Stokoe (2010), things that can put someone into the end-stage category are the inability to walk without assistance, incontinence of urine and stool, no meaningful communication, needing assistance with dressing, a Bartel score of less than three, reduced ability to perform tasks of daily living, loss of ten percent body weight without any other explanation, urinary tract infections, pressure ulcers, recurrent fevers, aspiration pneumonia, decreased oral ingestion. The Bartel Index is a scale that measure's functioning (Birch & Stokoe, 2010).

## **Treatment Options**

There are several different treatment options for people that are in the end-stages of dementia. Everyone should be comfortable and pain free. Some people will choose to put their loved ones into hospice when they are near the end, and others choose to use aggressive treatments to attempt to elongate their family member's life. It very often becomes a choice for the caregiver to make instead of the person affected by dementia because they become incompetent of making decisions for themselves. This is why advanced directives are so important either before diagnosis or shortly after diagnosis and before there are major deficits that make someone with dementia incompetent to make decisions.

## **Palliative Care**

Palliative care is a growing area in healthcare. It is for people that have chronic illnesses that are looking for pain management and support. "Most often, palliative care is described as a

way to meet the physical, mental, and spiritual needs of chronically ill and dying patients” (Lynn, Lynch Schuster, & Kabcenell, 2000, p.134). However, all is not lost for someone that chooses palliative care. It is more beneficial for those that are near the end of life, but it is possible to receive treatments for the life-threatening illness as well as relief from pain and symptoms. This is the major difference between palliative care and hospice (Lynn et al., 2000). Other things that may be included in a palliative care consultation are preventing and relieving physical and emotional symptoms, assisting patients to make goals about treatment as well as other personal goals, assessing what the patient needs psychologically and spiritually, supporting the patient and their family, estimating and discussing prognosis, aiding with discharge plans, and providing any other resources that could help the patient (Lynn et al., 2000). Many hospitals are trying to integrate a palliative care program to better help their patients. “The goal of palliative care is the achievement of the best possible quality of life for patients and their families” (Poor & Poirrier, 2001, p. 129).

### **Hospice**

Hospice is patient-driven care that can be provided either in the patient’s home or in a home-like atmosphere (Poor & Poirrier, 2001). The goal is for the patient to feel comfortable as they approach the very end of their lives. Hospice hopes to promote a better quality of life rather than a longer life. Curative treatment is not a focus of hospice care. Healthcare workers teach family members about how to best care for their loved ones and involve the family in all decisions and care when necessary. Hospice is meant for people diagnosed with terminal illnesses that have a life expectancy of six months or less. This does not mean that they have to be bedridden for six months. Hobbies and other activities are encouraged as long as the patient is able (Poor & Poirrier, 2001).

**Artificial Nutrition**

It is not uncommon to see a person with advanced dementia receiving artificial nutrition. At the end-stages of dementia the person affected may forget or refuse to eat. They may not remember how to eat, and they will not be able to prepare their own food. As mentioned above, one of the greatest causes of death for someone with dementia is aspiration. Considering both of these things, percutaneous endoscopic gastrostomy tubes are placed to allow the person to receive adequate nutrition (Miller, 2012). However, studies show that there is no increase in survival found and there was also no improvement in nutritional status (Chung, 2012). Chung (2012) also states, “There is no evidence that tube insertion prevents aspiration pneumonia. In fact, the presence of a tube may be associated with increased risk of aspiration pneumonia, which results from larger gastric volumes and regurgitation” (Chung, 2012, 2). PEG tubes have not been shown to increase the patient’s quality of life. These tube feedings also lead to increased frequency of diarrhea and incontinence, which can cause skin breakdown (Chung, 2012).

**Advanced Directives (Advanced Care Planning)**

An advanced directive is something that every adult should have. Often there are no advanced directives in place when it comes time to making life altering or ending decisions and the choice is no longer the patient’s (Miller, 2012). Some things that can be included in an advanced directive are whether or not they would like to be resuscitated if their heart stops, if they would like to be on mechanical ventilation if they are not oxygenating properly, if they would like to receive artificial nutrition, or they can state that they would like to be made comfortable and no life-sustaining measures should be taken. Miller (2012) mentions other things that can be included such as “preferences about pain management, organ donation, place of death, and specific treatments he or she would want to receive” (Miller, 2012, p. 189)

When creating an advanced directive, you have the freedom to include exactly what you want at the end of your life. There can be specific stipulations that can be included. For example someone could say, “If I have been on a ventilator for three days and do not make any substantial progress according to the medical doctors, please take me off of the ventilator and make me comfortable.” For an advanced directive to be official it must be written, signed by the patient, individuals specified by law must witness them, and some states require them to be notarized (Poor & Poirrier, 2001). Health care workers can be protected from any civil, criminal, and disciplinary actions if they are following the wishes that are provided in the patient’s advanced directive (Poor & Poirrier, 2001).

The health care proxy as well as immediate family should be aware of the person’s wishes before they become incompetent or there is an emergency situation. The health care proxy and family should know how important it is for wishes to be respected so that code status is not reversed. If the person decides to sign a do not resuscitate order (DNR), this should be placed on the fridge if they are staying at home, just in case emergency services are called to their home. There is such a thing called the Five Wishes that is a type of advanced directive. It includes in it the person that you wish to make care decisions when you are unable, the kinds of medical treatment either wanted or unwanted, how comfortable you would like to be, how you want to be treated, and what you want your loved ones to know (Lynn et al., 2000). This type of advanced directive is allowed in 33 states as of when this book was published and it can include anything that you want including wishes for a funeral and how it will be carried out (Lynn et al., 2000).

### **Student Nurses General Curriculum**

Student nurses in the undergraduate programs across the U.S. take courses in everything that you would expect to see. There is medical-surgical nursing, pediatrics, women's health, mental health, advanced practice nursing, and community health for many nursing schools. Dementia falls under mental health and there may be one class that discusses the facts of dementia. It does not matter that most of the patients that a medical-surgical nurse sees could have a diagnosis of dementia. End-of life care could fall under any one of these nursing categories, unfortunately even pediatrics. However, in most nursing schools across the country end-of-life care education does not even consume one entire class period in the four or more years it takes to earn a baccalaureate degree. "Only 3% of nursing programs in the United States reported having a course dedicated to end-of-life issues in 2002" (Robinson, 2004). Many medical and nursing organizations are pushing for the inclusion of end-of-life care in the undergraduate-nursing curriculum because they are finding that there is such little knowledge among the people in the field. There is a push for textbooks to include more, more classroom discussion time, as well as actual practice with the dying patient (Robinson, 2004). "American Association of Colleges of Nursing has established suggestions for incorporating competencies within the existing curriculum" (Robinson, 2004). The literature does not suggest that an entire course is necessary, but it should most definitely be included more, possibly in the course of caring for the older adult, which is usually a medical-surgical focused course.

## **Methods/Goals**

### **Methods**

#### **Design**

This study consists of a literature review on dementia, advanced care planning, end-of-life treatment options, and the general curricula of a student nurse as well as a



qualitative survey study using a convenience sample of Salem State University (SSU) nursing students (N=80). A convenience sampling method was utilized where students were chosen from their classrooms and during other events that nursing students attended given accessibility of the population of interest. All grade levels within the undergraduate class were surveyed to achieve the most variety of nursing students at different levels of their nursing coursework. This was to attain the best sample population and to obtain the most accurate results.

### **Data Collection**

Surveys were distributed to a convenience sample at SSU throughout the school of nursing. The survey was developed to discover the areas of education that nursing students lack in relation to dementia and end-of-life care. There were a couple of personal questions that were included, primarily to understand what the person thinks about what they would want at the end of life. The aim included encouraging the subject to see the perspective of their patient and not just from the nurse's view. Thematic coding methods were used to analyze the qualitative data resulting from the surveys.

### **Aim**

The aim of this survey was to identify what nursing students at Salem State University know about dementia, advanced directives, and end-of-life care and treatment options specifically related to the dementia patient.

### **Goal**

The goal of this study was to be able to identify the knowledge needs of nursing students related to end-of-life treatment for dementia patients. Once the knowledge needs

are identified, the quality of care provided by nurses could greatly improve for the dying patient.

### **Ethical Considerations**

Before any research was conducted, a sample of the survey as well as the proposal for other aspects of the research project were approved by Salem State University's Institutional Review Board. There was minimal risk to any participants and minimal benefits. Written informed consent was obtained from all participants.

## **Research Results**

### **Results**

The results showed that of the eighty students that were surveyed only fifty-nine percent of them recognized dementia as a terminal illness. Students were asked if they would feel comfortable, as a nurse, putting their patient with dementia in restraints if it became necessary. Thirty percent said they would, forty-five percent said that they would not, and twenty-one percent said maybe they would feel comfortable. This was meant to be a thought-provoking question because many students are not exposed to this kind of situation while in school.

There was a select all that apply question on the survey about what could be included in an advanced directive. The elements that were included were life-sustaining treatments such as CPR, life-sustaining treatments such as mechanical ventilation, artificial nutrition and hydration, organ donation options, comfort care options, autopsy request, and additional requests. Ninety-four percent knew that the option of receiving CPR could be included and ninety-three percent knew that the option of choosing mechanical

ventilation could be included. Seventy-eight percent knew that choosing to receive or refuse artificial nutrition and hydration was something that could be in an advanced directive. Seventy-nine percent knew about organ donation, seventy-six percent for comfort care options, fifty percent for autopsy requests, and sixty-one percent knew that additional requests could be included. Only thirty-seven percent of the students that participated knew that all of the options could be included. See Figure 1.

The survey participants were asked about what they would include in the conversation with a family member of a dementia patient if they were nearing the end-of-life. The students responded as follows: seventy-six percent would discuss pain management, seventy-eight percent would talk about palliative care, sixty-four percent about hospice, forty percent would discuss further treatment for their illnesses, fifty-six percent would mention code status and advanced directives, and only twenty-eight percent would talk about artificial nutrition and hydration. Only fourteen percent of the participants would bring up all of those topics in their end-of-life discussion with the family of a dementia patient.

When the participants were asked about where they got their knowledge of end of life care they were given the options of personal experience, work experience, Salem State nursing school, general knowledge, and other. Thirty-three percent chose a personal experience, forty-five percent chose work experience, thirty-nine percent chose general knowledge, and seventy-one percent chose Salem State nursing school. See Figure 2.

## **Discussion**

End-of-life care is a very important topic for nurses to know about. It is especially important for people with terminal illnesses such as dementia, where they may get to the point that they can not communicate their own needs and wishes. These results show that student nurses lack in end-of-life care and knowledge about dementia.

Sixty-three percent of the students that participated in the study were considered seniors in the nursing school. As part of the Salem State nursing curriculum they would have already completed their mental health rotation when dementia is covered, and classes such as care of the older adult and community health when end-of-life care should have been discussed. Just over half of the students did not know that dementia was a terminal illness. This could be an issue when they are in the practice setting caring for someone that they do not realize is terminally ill. Also, it could potentially be an issue if they do not know how to proceed with the proper discussions and providing the necessary patient and family education to someone diagnosed with dementia early in their disease or towards the end of their disease.

Based on the results of the survey, seeing that there is a lack of knowledge regarding dementia and end-of-life care for these patients it is important to know where the participants felt that they learned about these topics. The majority at seventy-one percent said that they learned these things Salem State nursing program. Several people chose multiple options in this category. Even though students feel that they know about dementia and end-of-life care, they are still lacking important pieces that are necessary when caring for this population.

## **Conclusions**

Following the completion of 80 surveys by Salem State University undergraduate nursing students it has been found that there is a knowledge deficit in the topics of end-of-life care as well as dementia. The study was limited to only eighty students and could have yielded different results if they were done by class or if there were more students included. The questions that were included to be thought provoking about what the participants would want if they were diagnosed with dementia showed that the majority would not want life-sustaining treatments provided. It can be concluded that more teaching is necessary in the nursing school setting for future nurses to be prepared to take care of a very vulnerable population as well as their families. End-of-life care needs to be more thoroughly discussed so students will be able to properly educate their patients and families. Dementia will be more prominent in the future and it is essential to have nurses properly educated to manage their patients in the best possible way.

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