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Improving Family Involvement Through Dementia Education Using a Video Sharing Service

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IMPROVING FAMILY INVOLVEMENT THROUGH DEMENTIA EDUCATION USING A VIDEO SHARING SERVICE

A Project Submitted to the Graduate School in Partial Fulfillment of the Requirements
for the Degree of Doctor of Nursing Practice

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IMPROVING FAMILY INVOVLEMENT THROUGH DEMENTIA EDUCATION USING A VIDEO SHARING SERVICE

An Abstract of the Scholarly Project by
Marissa Bernabe

Dementia is a growing issue among healthcare organizations within the United States (U.S.) with approximately 5.7 million individuals diagnosed. These numbers of affected individuals are expected to increase and reach approximately 152 million by 2050 globally. Dementia is a progressive disease of cognitive loss. Establishing goals or items the patient can perform can have a positive impact on patient care by allowing for a collaborative approach and initiating the family as necessary participants in the care of the dementia patient. Video sharing services such as YouTube have made learning easily accessible for a multitude of varied reasons.

A descriptive quality improvement project was undertaken to determine what type of dementia education is provided to families and patients, determine if family involvement for the patient diagnosed with dementia has the potential to continue in the long-term care setting by providing education via video sharing through YouTube technology, and determine if education via YouTube were available would the LTC support its use for patients and families. A survey consisting of fifteen questions using Google Forms was disbursed to fifteen different long-term care facilities in the counties of Labette and Montgomery in Kansas and Washington and Nowata in Oklahoma. A population size of 34 participants were utilized for the project. After the fourth week of survey availability, the data was collected and analyzed using Excel and Minitab.

The results were able to demonstrate that fifty percent of the survey respondents indicated that dementia education would improve family involvement. Seventy-five percent indicated support for the delivery of dementia education. Lastly, over fifty percent of participants believe that the family’s participation could increase throughout the progression of dementia if education was provided.

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Introduction

Dementia is a disease process that “encompasses a wide range of neuropsychiatric and medical conditions: producing significant loss of cognitive functioning” (Rakesh et al., 2017, p. 1). This significant loss of cognitive impairment involves language, executive function, attention, perceptual-motor function, social cognition, learning, and memory from a previous level of functioning (Dunphy et al., 2019). Many individuals have been affected by dementia, especially within the older populations. According to the *Healthy People 2020 report*, 15% of individuals over 70 are affected by dementia, and that number increases to 40% at about 90 years of age (Ames et al., 2020). Dementia not only affects individuals singularly but also has negative effects on the population globally. Worldwide around 50 million people live with dementia, and this number is projected to increase to 152 million by 2050, rising particularly in low income and middle income countries (LMIC) where around two-thirds of people with dementia live. Dementia affects individuals, their families, and the economy, with global costs estimated at about one trillion dollars annually in the United States (Ames et al., 2020).

It is necessary to ensure measures are taken to adapt to the large number of individuals diagnosed with dementia, especially considering the caregivers. The cognitive loss that individuals experience affects those that surround them, such as their family members and care providers. The changes associated with dementia result in a deficit that requires others to intervene to ensure the welfare of the individual. These deficits create opportunities for family members to be involved in patient care in order to reduce the negative impact of a dementia diagnosis. Dementia is a progressive disease of cognitive loss. Establishing goals or items the patient can perform can have a positive impact on patient care by allowing for a collaborative approach and initiating the family as necessary participants in the care of the dementia patient. Prior to and early in the disease process, patients are capable of performing self-care, but as the disease progresses, the dementia patient may forget that they can perform a task creating an apparent self-care deficit that can be mitigated if family members are able to work with the patient to maintain and promote the patient’s self-care agency and prevent a self-care deficit.

When self-care deficits do begin to occur, a family is a critical part in the involvement of patient care. Most of the care for the dementia patient is provided by family. When transition is made to a long-term care (LTC) center or nursing home, the nursing system tends to provide the care for the self-care deficits identified. These deficits can include dressing, feeding, or ambulating which requires adaptations be made to allow the patient to perform at their highest level. The identification of deficits occurs during care plan meeting initiation, history and physical, and lastly during quarterly care plan meetings. In the LTC setting, the family members that wish to participate in the patient's care would be part of the nursing care system. By including the family in the nursing system, family can gain confidence in their ability to care for the patient, and their skills to care for the patient can be enhanced on, improving the relationship of the family and patient.

If the family is to be included as part of the nursing care team, dementia education should be provided to the family members involved in patient care. When given education about the diagnosis, progression, treatment, and interventions for dementia, family members can often become competent care providers. The information received by the caregiver during the education can increase their ability as a caregiver and give them confidence. After receiving dementia education, the family can more readily assist LTC staff in the identification of self-care deficits and intervene as necessary. Providing education will encourage the family to be involved in the patient's care, allowing the family to remain a constant in the patient's life. Family visits and interaction should not decrease as dementia progresses but instead should be sustained as time passes and the disease progresses. Decreases in dementia behaviors in patients are achieved when family remains involved in the patients care, as well as an increase in the psychosocial well-being of the family and patient (Graske et al., 2015; Sorenson & Conwell, 2011). Lack of education for caregivers and possibly family members has increased possible negative outcomes for the patient with increases in mortality, falls, and other care areas such as nutrition and hydration (Livingston et al., 2019).

Description of the Clinical Problem/Issue

Dementia is becoming an increasing issue in the United States (U.S). Approximately 5.7 million individuals in the U.S. have a diagnosis of dementia (American-Speech-Language-Hearing Association, 2020). Gaugler et al. (2014) found that approximately two thirds of the US population with dementia are living in nursing homes or LTC centers. As a result, admissions to nursing homes or LTC can be expected to increase in proportion to the increases in population expected to occur in the future.

Dementia is a very complicated disease process with different changes occurring during the progression of the disease. There is no functional exact number of months or years an individual has after a diagnosis of dementia; progression of the disease process is patient specific. Knowing there is no definitive process to determine the stages and progression of dementia can be a frustrating barrier to patient care.

Education for family members about dementia and its progression is a major component of improving the care of patients diagnosed with dementia. If families were provided education about the aspects and different components of dementia, as well as its progression, and interventions that can be provided, there could be a potential for improvement in the quality of life in a dementia patient. Availability of dementia education programs can be limited, especially in rural areas of the U.S. This lack of education and availability of education could have the potential to negatively affect a patient's outcomes and lead to a decrease in family involvement. To prevent decreased family involvement with the progression of dementia, it is important for the healthcare provider to ensure education is available. Providing education to patients, as well as families, about dementia and its challenges has the potential to prevent the decrease of family involvement as the progression continues. Many LTC facilities may not have education programs that support dementia education for the family and patients or may not have adequate resources to ensure this step-in care is provided. It is important to determine what modes of technology can be utilized to deliver dementia education to ensure the overall well-being of family and patients in the progression of dementia. Research regarding the need for dementia education is paramount especially when considering the patients possible admission to a LTC facility. LTC facilities care for a large portion of individuals diagnosed with dementia and are at an advantage to deliver education to patients and families to improve the family's ability to remain involved in the patient' s care.

Significance

An important aspect of care for the patient and family, dementia education can be provided in a variety of sources such as journals, articles, online, or through health care professionals. Although these resources are available, it is necessary to ensure patients and families have access to them, especially in rural communities, where "the impact of dementia and the availability of support for people with dementia and their caregiver is a particular issue" (Bauer et al., 2019, p. 22). These issues may include inability to transport to libraries, lack of knowledge of the location of the resources, or lack of access to a healthcare professional. The LTC center plays an important role in ensuring some type of dementia education is provided to the patient and family. Rural areas may have less access to the resources that urban locations do and in order to further research of the delivery of dementia education, it's important to look at what types of education are available.

Caregivers of the dementia patient are at a disadvantage if they are not adequately prepared to care for the patient. Knowledge is a necessary component of patient care, and if the caregivers are not adequately educated about dementia, it will negatively impact both the patient and the caregiver. "Levels of psychological distress and stress are significantly higher, and levels of self- efficacy, subjective wellbeing, and physical health significantly lower, in dementia caregivers than in other caregivers; these differences are even larger when compared with no caregivers" (Brodaty & Donkin, 2009, p. 219).

Education about dementia, its progression, and possible interventions has the potential to decrease these negative effects of patient care.

As the disease progresses, the increased demands on caregivers and family members' inability to effectively care for the dementia patient may require the discussion of admission to a LTC facility. Although this conversation can be difficult, it may be necessary for some patients diagnosed with dementia, especially when progressing to the moderate to severe stages. In 2014, approximately 47.8 percent of the dementia population were living in LTC centers or nursing homes (Centers for Disease Control, 2014). These numbers are expected to increase to 12.7 million by 2050 (Rubin, 2022). "Approximately one-third of seniors younger than 80 who've been diagnosed with dementia living in LTC homes" with 42% accounting for those over 80 years of age (CIHI, 2022, p 1). LTC providers have an advantage of providing education about dementia, its progression, and interventions that can be provided by family members or previous caregivers to ensure their involvement with patient care continues and can be beneficial for the relationship of all individuals involved with providing care to the patient.

Specific Aims/Purpose

Family involvement is an important aspect of patient care, especially after admission to a LTC facility. Family visitation is encouraged to continue in the LTC facility and should continue after the admission to a LTC facility. Benefits of continued family involvement for the dementia patient are the reduction of infection risk, increased activity participation, and improved quality of life (Cohen et al., 2014). The benefits of education to the family member are more related to their well-being. Improvements have been identified as improved psychological stability, decrease in fatigue, and nurturing the relationship (Cohen et al., 2014). In order to encourage family involvement, education can be provided as an intervention. Although families believe assisting with activities of daily living are the responsibility of the staff in the LTC facility, there are many things they can do to remain an active part in the patients care (Cohen et al., 2014). Research about the need for dementia education for the patient and family has the potential to influence the involvement of family consistency during the different stages of dementia. LTC facilities can play an integral part in providing this education and ensuring families stay involved in the patient's care. By providing education about dementia, it's progression, and interventions; improvement in the relationship between family and the patient can continue to be an effective part of the patient's care. It is important to determine the type of dementia education that is being provided, as well as the delivery method, and the availability of dementia education to improve the dementia patient's life.

The specific aim of this Doctor of Nursing Practice (DNP) scholarly project is to: 1) determine what type of dementia education is provided to families and patients; 2) determine if family involvement for the patient diagnosed with dementia has the potential to continue in the LTC setting by providing education via video sharing through the use of YouTube technology; and 3) determine if education via YouTube were available would the LTC support its use for patients and families.

Although dementia education programs are available on the internet, it is important to remember that some elderly individuals do not have access or the technological knowledge to find those programs. In order to improve family involvement, the patient and family should undergo some type of dementia education, even if sought through their own means to improve their understanding of dementia, progression, and expectations for the disease process. The LTC setting is greatly affected by the dementia population and the organization caring for the patients should be involved in the education of the patient and family. Providing an in-depth dementia program that provides education about the diagnosis, progression, treatment, and interventions has the potential to positively affect the outcome of the dementia patient and using a video sharing service can provide accessibility. The education received can allow the family to remain constant in the patient's care.

Availability of dementia education programs are limited, and many individuals are unaware that these programs exist, but the internet, particularly YouTube, makes it easy to share materials. The continuance of family involvement can be encouraged through providing dementia education via YouTube to families and patients diagnosed with dementia in the LTC setting. Gaining knowledge regarding the current dementia education being provided to patients and families in the LTC settings and the technology used to provide this education can allow for the development of an in-depth educational program over dementia. The educational program could be used to educate families and patients about the disease process, its progression, possible treatments, and interventions. By encouraging the involvement of the families in the patient's care, outcomes can be improved for both the patients and the families. The educational program could be provided on admission to the LTC facility or as requested by the family or patient as the disease progresses.

Theoretical Framework

There are many different options for a theoretical framework for dementia education. The one chosen for this DNP scholarly project is Dorothy E. Orems, “Self-Care Deficit Nursing Theory.” In this theory, Orem describes the different components of self-care, nursing agency, and self-care deficit. Self-care refers to tasks the patient can perform independently. The achievement of self-care needs are addressed in the nursing system which determines how the needs are met by both the nurse and patient. Self-care deficit indicates the tasks patients are unable to perform and will require assistance to complete (Alligood, 2018).

The Self-Care Deficit Theory has five major assumptions:

1. Self-reliance and responsibility of care belong to the patient and family. Continuous input is required to maintain or possess the actions required for the actions of human beings.
2. No individuals are the same and require the ability to act for themselves when making decisions or identifying their needs.
3. Limitations in health are experienced through hardships through the inability to care for self or others.
4. Knowledge is required to identify needs and make self-care needs known with the assistance of others.
5. Responsibilities of care and relationships are provided through others who attempt to provide care that may be required for a patient. (Alligood, 2018).

There are four related theories that compose Orem’s self-care deficit nursing theory. The first theory is self-care and gives reasoning for the patient's ability to care for themselves, as well as how they had cared for themselves before their diagnosis of dementia (Alligood, 2018). Self-care requisites are the items the patient is able to care for themselves and their reasoning for the way they perform these acts. The way a family member cares for an individual who depends on them encompasses the related theory of dependent care (Alligood, 2018). Dependent care is especially important when caring for the patient diagnosed with dementia because they heavily rely on others to care for them as the disease progresses. The third related theory is self-care deficit which encompasses the reason an individual cannot care for themselves and can be supported through nursing (Alligood, 2018). Self-care deficits are common among the population affected by dementia, especially as the disease progresses and requires more dependent care. Nursing systems are the fourth related theory that describes the interaction between the nurse and their relationship with the patient through intervening when needed (Alligood, 2018). The nursing system is a major component of patient care for those diagnosed with dementia. The dementia patient relies heavily on the nursing system and if the nursing system is unable to interact or create a relationship with the patient through realizing their needs and encouraging their independence the patient may have a negative outcome.

Project Hypotheses and Research Questions

1. Fifty percent of the administrators, medical directors, directors of nursing, and care plan coordinators, who work in long-term care facilities and are involved with educating patients and families about dementia, will report providing dementia education to family will improve family involvement.
2. Seventy-five percent of the long-term care staff will indicate support for delivering dementia education.

3. Administrators, medical directors, directors of nursing, and care plan coordinators will indicate the use of YouTube videos as a valuable conduit for delivery of dementia education.
4. Do administrators, medical directors, directors of nursing, and care plan coordinator believe providing dementia education will increase family's participation throughout the progression of the disease process in long-term care facilities at least fifty percent of the time?

Definition of Key Terms or Variables

The following terms are defined as follows for the purpose of this research study.

Activities of daily living (ADLS)- Functions that are required daily such as dressing, meal consumption, bathing, toileting, and ambulation, or wheelchair locomotion. These tasks can be performed independently or with assistance from caregivers, nurses, healthcare providers, or family (Pioneer Network, n.d).

Alzheimer's Disease- A disease that causes intellectual deterioration with the first symptom being memory impairment. Thought and speech are also affected, and the individual loses the ability to care for themselves (Pioneer Network, n.d). Death is the result of this deteriorating disease process.

Caregivers- refers to the family member who is providing the majority of the patient's care. It can be a spouse, family member, or other individual that cares for the patient. These individuals assist the dementia patient with completing ADLs and maintaining quality of life (Pioneer Network, n.d).

Dementia – a significant decline in cognition from a previous level of functioning in at least one of the cognitive domains of language, executive function, attention, perceptual-motor function, social cognition, learning, and memory (Ames, 2020).

Educational Program- Uses audiovisual media and other forms of technology to disperse and share information about a particular topic (Alligood, 2018). Education is an important concept in nursing and patient care, especially when a disease process is expected to progress. Information received on a patient's condition should be dispersed to families through many different sources, such as technology, and should be updated often to ensure the most current information is provided.

Health Care Practitioner- Individuals that provide medical, nursing, and healthcare services. Primary care providers, Directors of Nursing, Certified Nursing Assistants, and Administrators are included within this definition. Responsibilities of the patient’s well-being fall on the health care practitioners within the LTC center (Pioneer Network, n.d).

Long-Term Care (LTC)- Assists individuals with activities of daily living that have health problems that inhibit their ability to care for themselves (Pioneer Network, n.d).

Long-Term Care Services- Medical and non-medical services that are utilized to care for individuals with chronic illnesses which decreases the patient’s ability to care for themselves (Pioneer Network, n.d). Employees of an LTC center assist individuals with their ADLs to improve their quality of life.

Nurse Practitioner (NP)- Nurses with advanced degrees and education that allows them to diagnose and treat patients while collaborating with other members of the healthcare team. Theses advanced practice nurses can specialize in areas such as geriatrics or adult family practice (Pioneer Network, n.d).

Nursing Care System – refers to the LTC staff, physician, and any healthcare provider that addresses the needs of the patient or assists the patient to overcome their self-care deficit. This system allows those providing care to represent their patient and meet the self-care demands of the patient (Alligood, 2018). This system encourages the patient to meet their self-care goals, as well as encourages the functioning and development of the patient.

Patient – Refers to the dementia patient or the patient experiencing cognitive loss. Many patients with dementia require assistance with ADLs related to their loss of cognitive function (Pioneer Network, n.d). The patient is an individual that consists of different components represented by their culture, beliefs, and development throughout the lifespan. Their needs will change throughout their progression, but the patient should still be addressed as an individual.

Self-Care- Activities the patient can perform independently. These activities involve health, development, and well-being to continue to progress functionally (Alligood, 2018).

Self-Care Deficit- Items the patient is unable to perform without the assistance of the nursing agency (Alligood, 2018). These deficits occur because the patient is unable to meet the therapeutic demand. The nursing system must intervene to contribute to the patient's well-being and meet the patient therapeutic self-care demand (Alligood, 2018).

YouTube- Internet website that allows users to share, view, or post videos for public or private use (Dictionary.com, 2021). Easily accessible resource to reach a wider audience.

Logic Model of DNP Project

<table>
<tr><td colspan="4">Purpose: To assess dementia education availability in rural areas in Southeast Kansas and Northeast Oklahoma. To attempt to determine if familial involvement can be sustained throughout the progression of dementia by providing education via a video sharing service.</td></tr>
<tr>
<td>Input:
• Time
• DNP Student
• Irene Ransom Bradley School of Nursing
• LTC centers in Southeast Kansas and Northeast Oklahoma.
Constraints:
• Motivation of the LTC facility to participate
• Uncertainty of progression
• Cognitive loss
• Involvement of other healthcare providers
• Frequency of medication changes
• Attention span of family members and patients</td>
<td>Activities:
• Develop a survey to assess current availability of dementia education
• Distribute the survey among clinics in Southeast Kansas and Northeast Oklahoma
• Gather the surveys and analyze the data
• Determine if there is support for a dementia education program in the Northeast Oklahoma and Southeast Kansas area.</td>
<td>Output:
• LTC facilities in Southeast Kansas and Northeast Oklahoma.
• Director of Nursing, Care Plan Coordinator, and Medical Directors.</td>
<td>Effects:
• Improve family involvement
• Improve patient outcomes
• Improve communication between staff, patients, and families
• Improve knowledge of dementia
• Improve knowledge of the availability of programs for rural areas.
• Further research into dementia and the importance of education.</td>
</tr>
<tr><td colspan="4">Contexts or Conditions: Lack of education, setting of LTC, other caregivers' involvement, such as hospice provider or psychiatry involvement</td></tr>
</table>

Summary

Dementia is a degenerative disease process that affects all aspects of a patient's life. The patient's ability to remember important items, such as how to care for oneself, is affected immensely. Most patients and family are unprepared for the changes that are associated with the disease process which makes it important for the healthcare professional to ensure the proper education is provided to these individuals. Education is an important component of dementia care, and families, as well as patients should receive education to ensure the family remains a constant throughout the disease process. Approximately 47 percent of individuals living in LTC have a diagnosis of dementia and require extensive patient care and assistance for their well-being (Centers for Disease Control, 2014). This places the LTC at an advantage to ensure the patient and family remain involved throughout the patient's lifespan with dementia. There are many different ways that dementia education can be delivered, such as video sharing services, but these modes of delivery aren’t used as often as face-to-face delivery.

Family involvement is also an important part of care for the dementia patient. It’s important to ensure their involvement within the care of the patient and prepare them for the changes that will occur as the disease progresses. If adequately prepared for the changes that will occur, the family may remain present throughout the disease process, instead of decreasing visits as the disease worsens. Healthcare providers and physicians are responsible for encouraging “accessible interactions and situations that promote health and well-being" (Paterick et al., 2017, p. 112). Accessibility to dementia education could be eased with the use of a video sharing service, such as YouTube, to deliver the education whenever and where it is convenient for the patient and family members. If provided in the LTC center, the patient, family, and care center can collaborate to ensure the patient’s needs and wants are met, as well as improve the relationship between family, patient, and the healthcare providers.

Chapter II

Review of Literature

Dementia is a growing issue among the U.S. population and is expected to increase in the future. Dementia and Alzheimer's dementia are diseases with a progression of stages that begin mildly and progress into more severe diseases requiring family involvement. In many instances, family members become the sole caregivers for the patient diagnosed with dementia. Loyalty or love could influence a family member's decision to care for the patient without regard to the significant negative effects they might experience, such as resentment, hostility, and frustration (Jojokgbola et al., 2018). Due to the severity of dementia, family caregivers may look to other sources to find relief from the stresses of caring for a loved one diagnosed with dementia as well as their inability to effectively care for the patient.

Long term care (LTC) admission may be a necessary component of care towards the second or third stage of dementia (Alzheimer's Association, 2020). An important component that is often missed when caring for the dementia patient is education for family members about dementia. Typically, education should be given early in the diagnosis, but it can be provided at any stage of dementia. The variability in available education offers an opportunity for the LTC provider to provide education to the family and patients diagnosed with dementia. Lack of education about dementia can result in decreased family visitation because of the trauma witnessing the disease process can cause for family members. Reduced family visitation may result in negative patient outcomes and impair the relationship between the family member and patient which can continue to affect the patient long after admission to an LTC (Pahlavanzadeh et al., 2010). Advances in technology have provided a unique opportunity for individuals to gain education about various topics. This can improve the ability of the patient and family to understand their diagnosis, interventions, and treatment.

The purpose of this literature review is to determine the differences between types of dementia and gauge the level of family involvement with dementia patients. Another area that was sought for clarification by the literature review was the success, utilization, and accessibility of technology in providing education and different ways dementia programs have been implemented in the past. The databases Cumulative Index to Nursing and Allied Health Literature (CINAHL), ProQuest, PubMed, and Summons were searched with the following key terms used individually and in various combinations: dementia, education, involvement, YouTube, video sharing services, family, and LTC, with the operators of OR and AND. To increase availability of the literature, the years of search to included 2007 though 2020.

Prevalence of Dementia

When discussing dementia, it's important to understand the prevalence of dementia. Although it has been stated previously, the incidence of dementia is expected to increase, "ethnic and racial diversity of older Americans will increase dramatically resulting in an ethnogeriatric imperative for health care providers” (Mehta & Yeo, 2017, p 72). Mehta and Yeo (2017) searched 1215 studies to identify the incidence and prevalence of dementia in the U.S. based on racial and ethnic differences. African Americans were identified as the largest group for the prevalence and incidence of dementia, in comparison of American Indians, Alaska Natives, Japanese Americans, Korean Americans, Mexican Americans, Puerto Ricans, Cuban American, and Pacific Islanders (Mehta & Yeo, 2017).

According to the CDC, African Americans still account for the highest prevalence of Alzheimer's disease followed by Hispanics, then non-Hispanic Whites, American Indian and Alaska Natives, and Asian and pacific Islanders (2018). Although African Americans account for the largest group in the U.S. currently, Hispanics are expected to be the largest group by 2060 with 3.2 million being diagnosed with dementia in comparison to 2.2 million African Americans (CDC, 2018).

Differences in Dementia

The literature covers material specific to the different types of dementia and allows for differentiation between the different types that can occur. The different types of dementia pose a significant challenge to the family member or caregiver, especially if they are unaware of what stage the patient is in or if the family doesn’t know which type of dementia their loved one has. Dementia can have many different descriptions and involves many different stages. As a whole, “dementia refers to a clinical syndrome characterized by a progressive cognitive decline that interferes with the ability to function independently” (Chang, Duong, & Patel, 2017, p 118). The cognitive decline that occurs with dementia is insidious and presents in different ways that include “memory loss, communication and language impairments, agnosia (inability to recognize objects), apraxia (inability to perform previously learned tasks) and impaired executive function (reasoning, judgement, and planning)” (Chang, Duong, & Patel, 2017, p 118).

Patients that have mild amounts of deficits or impairment, but do not meet the criteria for a diagnosis of dementia are referred to as having a mild cognitive impairment. Mild cognitive impairment has similarities with dementia, but the patient can complete the tasks of daily life or the patient's independence and these individuals may have a possibility of returning to normal cognition status (Chang, Duong, & Patel, 2017). Although the patient may have a chance of returning normal cognitive status, there are some instances where mild cognitive impairment advances which can result in the patient receiving the classification of dementia.

There are several subtypes that fall under the umbrella of dementia that have different characteristics which assist with a proper diagnosis. The subtypes of dementia include Alzheimer’s disease (AD), Vascular dementia (VS), Lewy body dementia (LBD), and Frontotemporal dementia (FD) (Chang, Duong, & Patel, 2017). Alzheimer's disease is the most severe form of dementia and is the most common neurodegenerative disease. During Alzheimer's disease, neurofibrillary tangles and beta amyloid plaques that cause degenerations in the brain and reduces the brain's ability to effectively transmit choline acetyltransferase and cholinergic neurons (Chang, Duong, & Patel, 2017). AD is slow growing with the first signs being short term memory loss. There are non-cognitive and cognitive symptoms with AD with the non-cognitive involving depression, verbal aggression, and many behavioral changes such as wandering and hallucinations (Chang, Duong, & Patel, 2017).

Vascular dementia, also known as multi-infarct dementia, has many neuropsychiatric features including depression, apathy, hallucinations, and delusions much like AD (O'Brien & Thomas, 2015). Vascular dementia results from decreased oxygenation or blood flow to the brain, usually from a stroke which may result in the patient having "confusion, disorientation, difficulty with speaking, understanding speech and vision loss" (O'Brien & Thomas, 2015, p 120). These symptoms can be very distressing to both the family members and patient and can also include impairments in memory and language (O'Brien & Thomas, 2015). A diagnosis of young-onset dementia is given when symptoms emerge before the age of 65 and these individuals are able to function as normal members of society with limited impairments until the late stages (Rabanal, et al., 2018). Lastly, if a patient were to be diagnosed with AD and vascular dementia it is known as mixed dementia (O'Brien & Thomas, 2015).

Frontotemporal dementia can be masked by other psychiatric disorders and can be underdiagnosed (Bang et al., 2015). Picks disease is also used as term to describe disorders that involve the frontal and temporal lobes or frontotemporal dementia (O'Brien & Thomas, 2015). Three variants account for the umbrella of frontotemporal dementia: behavioral-variant, non-fluent variant primary progressive aphasia, and semantic-variant primary progressive aphasia. The behavioral variant can cause more distress to the family because of its symptoms which can range from careless remarks and inappropriate behaviors to reduced interests in activities they once liked to perform, and loss of sympathy or apathy (Bang et al., 2015). Non-fluent variant primary progressive aphasia and semantic-variant primary progressive aphasia cause language deficits. Language production, word comprehension, anomia, and word difficulties account for these types of dementia which can make communication with the family member difficult (Bang et al., 2015).

Lewy body dementia (LBD) progresses from approximately 80 percent of Parkinson's patients and can have an onset before age 65 (Walker et al., 2015). Lewy body dementia can be difficult to diagnose because of its close relationship to Alzheimer's disease and Parkinson's. In LBD, abnormal deposits of alpha synuclein proteins are found inside the neurons and can results in excessive sleepiness or periods of decreased attention, as well as staring off into space (O'Brien & Thomas, 2015). Visuospatial impairments, hallucinations, fluctuating cognition, and olfactory dysfunction are among the clinical manifestations that affect the patient diagnosed (Walker et al., 2015).

Seven Stages of Dementia

Dementia has seven stages that individuals progress through. Stages one through three are recognized as "pre-dementia", stages two through four are the "dementia" stages, and stages five through seven are the stages where a patient and family may notice the most changes and more need for assistance with ADL's (Reisberg, 2008, p 1). The progression of dementia should be looked at like a continuum in slow loss of cognitive functions and functional abilities (Cipriani et al., 2020).

Stage I

Stage I of dementia progression may be very difficult to notice. The individual with a dementia diagnosis may complete their ADL's as they normally would. The individual can be free of any signs or symptoms of dementia which makes it a difficult task for the primary care provider to acknowledge (Reisberg, 2008). This stage of dementia may begin 10 to 15 years prior to symptoms of dementia and can be known as the “pre-clinical Alzheimer's disease” because of the lack of subjective and objective symptoms (Penn Med, 2020).

Stage II

Stage II of dementia progression is when the patient may notice slight changes in their memory or make comments of their forgetfulness (Penn Med, 2020). Forgetfulness may be the first sign of the progression of dementia. It is especially important that families take their loved one's concerns into account because they may be alerting them to cognitive changes that may support a dementia diagnosis. Individuals with dementia decline at a faster rate than those of the non-dementia population and this stage may last up to 15 years (Reisberg, 2008).

Stage III

In Stage III of dementia, the patient may experience mild cognitive impairment which may inhibit the individual's ability to function normally. The individual's job or occupational setting can be affected, and the individual may become more repetitive with speech (Penn Med, 2020). The individual may notice issues with remembering recent items, organization, and new challenges in a social setting (Reisberg, 2008). It’s important that the individual seek medical attention and determine if there are any health issues that can be corrected.

Stage IV

Stage IV can also be known as “moderate cognitive decline” and a diagnosis of Alzheimer’s can be made (Reisberg, 2008). Stage IV involves damage to the brain that can include memory, language, organization, and calculations (Penn Med. 2020). Long term memory is preserved in this stage and many individuals can recall important dates in their life such as their wedding date or date of children's births. Social interactions may have some decline in this stage related to the stress social occasions may place on the individuals (Penn Med, 2020). Although there are many cognitive changes in this stage, the individual with dementia may continue to live independently in the community (Reisberg, 2008). Denial is a component in this stage of dementia because the patient doesn't want to acknowledge their cognitive loss. The individual may decrease social gatherings or make excuses for not participating in activities (Reisberg, 2008). This stage of dementia can last for two years or longer depending on the progression of the patient.

Stage V

Moderately severe cognitive decline or Stage V of dementia occurs when the patient has sufficient deficits to impair their ADLs (Reisberg, 2008). In this stage, the individual will not be able to function intendedly or recall some of the same information they may have been able to previously. This stage lasts for approximately 1.5 years and the individual will have incipient abilities to perform ADL's (Reisberg, 2008). Emotional changes occur frequently during this stage of dementia which includes hallucinations, delusions, and paranoia (Penn Med, 2020).

Stage VI

Stage VI, also known as severe cognitive decline, occurs when the individual is unable to complete ADLs independently. The patient may require assistance with every step of their ADL's which can last approximately 2.5 years (Reisberg, 2008). Short-term and long-term memory are affected which impairs an individual ability to live independently. Communication is also affected during this stage of dementia.

Communication is not effective as it once was and becomes a challenge to the person. Specific behaviors may worsen such as delusions, hallucinations, or paranoia, and can cause communication to be laborious (Penn Med, 2020). Although there are interventions that can make behaviors manageable, communication will likely not improve.

Stage VII

In the last stage of dementia, the patient will be at the end stage of their disease process. Stage VII is known as Alzheimer’s disease or end stage cognitive loss. The individual will have physical, mental, and emotional deficits that will require extensive assistance to accommodate (Reisberg, 2008). In this stage, dementia lasts approximately 6 years and is the end result of the disease process. Contractures can be a common occurrence with this stage of dementia. Contractures are “irreversible deformities which prevent the completion of active or passive range of motion in joints” (Reisberg, 2008, p 1). Patients in this stage may appear infantile because of their inability to adequately care for themself. Admission to an LTC center may be a necessity because of the increased need for assistance with ADLs. The patient may require around the clock care that families may not be able to adequately provide. Infections can become a risk, especially since the patient has difficulty communicating the way they feel to those caring for them.

Family Involvement

Families are posed with a unique set of challenges when having to place their loved one with dementia into a care facility. Family members may experience feelings ranging from guilt to loss, though most family members want to actively remain involved (Graske et al., 2015). Family involvement is an integral part of the dementia patient's quality of life while living in LTC setting. Graske et al., (2015) investigated the impact of quality of life of dementia residents that received family visits in comparison to those that do not in a shared housing arrangement. Outcomes of family visits include a reduced number of negative behaviors and a higher quality of life (72.1%) in comparison to those that did not receive visits from family members (55.9%) (Graske et al., 2015). Family members are an indispensable support team for the patient diagnosed with dementia.

Family members may be the first to notice the slight changes in memory that occur during the beginning stages of dementia. This would be beneficial for the healthcare provider to establish a baseline for cognitive function earlier (Anderson et al., 2017). Family members play an integral role in the everyday care of the individual diagnosed with dementia which makes them a necessary component of patient care (Anderson et al., 2017). When the patient’s disease process has advanced, the family can provide a multitude of information about the patient's past health history. Family can also give insight into the patient's preferences to help advocate for the dementia patient when advancement of the disease has occurred. After advancement of dementia, the family will be burdened with making decisions on their loved one's behalf (Carter et al., 2017).

Need for Education

Many of the sources addressed the need for more education about dementia diagnosis and care because of the negative outcomes that caregivers can experience as the disease progresses in the patient. High levels of stress, depression, and anxiety symptoms occur more often in dementia caregivers in comparison to non-dementia caregivers (Sorenson & Conwell, 2011). Sadness, discouragement, aloneness, anger, and hope can be experienced by the family of a dementia patient (Grabher, 2018). Negative patient outcomes can result if there is a lack of dementia education for caregivers and can include increased mortality rates, falls, malnutrition, dehydration, and increased hospital stays, as well as emotional distress for the patient (Livingston et al., 2019). Privacy, sleep deprivation, and the *lone soldier* syndrome or feeling the full burden of being the full time caregiver can occur when the family is responsible for caring for a loved one without support (Grabher, 2018).

Caregivers can include spouses, other family members, friends, as well as health care workers. Interventions are needed to reduce the burden experienced by caregivers, as well as to provide information that will allow family caregivers to be well informed about the responsibilities and demands of caring for the dementia patient in order to improve their ability as a caregiver (Andren & Elmstahl, 2008). Delivery of education can be problematic or ineffective because many patients look to the primary care provider (PCP) to deliver the necessary education but find the information provided by PCP's to be very limited and insufficiently address components of the disease process, treatment, and needs of the patient (Peterson et al, 2016).

Education should be attempted to ensure the patient and the family member understand the expectations for progression of dementia. "The value of knowing, especially in the early stages of the disease is that the patient and family can plan for the future" (Grabher, 2018), p. 3). Family education can decrease the burden of dementia especially in the advanced stages of the disease and can adequately make decisions, as well as assist in the care of the patient (Carter et al., 2017). Dementia education has the ability to allow the patients family to avoid becoming the "second victims of dementia" (Pahlavanzadeh et al., 2010). In order to be an effective team member to the dementia patients care, education needs to be provided to ensure everyone involved in the patients' care understands when treatment is no longer needed for the patient (Carter et al., 2017). There is an influx of need for family caregivers related to the increase in incidence of dementia. Education allows the family caregivers to gain the skills and knowledge needed to care for their loved one with dementia (Gaughler, 2015).

Barriers

Barriers to education for caregivers are identified as lack of acknowledgement of symptoms on the part of the patient, lack of knowledge about how to look for information, feelings of being overwhelmed, avoidance, the PCP being too busy to provide the needed education, or inadequate knowledge on the part of the PCP about the diagnosis or the disease (Peterson et al., 2016). Heim et al. (2019) sought to determine the attitudes of general practitioners about dementia and their ability to assess and provide education about dementia: of those providers, 50% cited a lack of time, 14.4% indicated inadequate knowledge about the assessment techniques, and 8.3% believe testing should be performed by a specialist. Although primary care providers have first contact with patients, it’s important for resources to be available for them to become more self-aware of their attitudes towards the disease process.

Werner et al., (2017) identified three critical needs faced by family caregivers for adequate dementia education: timely access to information, access to information tailored to the patient’s needs, and information that is usable for behaviors that are associated with dementia. If education adequate to address the needs of both the patient and the family caregiver were provided, improved identification of signs and symptoms of dementia, decreased role strain, decreased caregiver’s anxiety, and decreased depression could result (Cohen et al., 2018). Delivery of education through the use of portable online delivery platforms can decrease the barrier of accessibility and eliminate the possible needs for scheduled appointments (Gaugler et al., 2015).

Another barrier to consider with delivery of dementia education is the family members motivation to learn the information. To encourage the family members motivation to learn, it’s important to understand their feelings regarding the disease process. If they have a negative attitude towards the information, they may be less likely to participate. Educators should consider the family members and patients different ways of learning to promote the delivery of information. Advancements in technology have led educators to seek different ways to teach, rather than using traditional methods, to ensure the information is retained and can reach a mass of individuals (Romanelli, 2009).

Family members' ability to use the internet and technology is another potential barrier when delivering education electronically. The COVID 19 pandemic brought even more challenges for family members and patients with disease processes such as dementia. Many individuals had to resort to using technology to communicate with their healthcare provider through many different modes of technology (Alexander et al., 2021). Individuals have had to adapt their lifestyles around COVID 19, which improved many individuals' abilities to use technology appropriately.

Technology Used to Deliver Dementia Education

Technology has improved the availability of dementia education. Caregiver outcomes have improved with the availability of multimedia interventions, and caregiver confidence and knowledge have also increased (Cohen et al., 2018). Advances in technology have allowed a variety of educational materials to be dispersed to people of various age groups. These modes of technology have been to deliver education about dementia and interventions to improve the ability of the caregiver to involve the patient in their care. Peterson et al. (2016) revealed the internet, touchscreens, and computer or mobile applications were modes of education delivery that caregivers would be motivated to use when learning about dementia. Touchscreen capabilities have allowed for ease with searching information or utilizing technology. Camic and Tyack (2017) sought to determine the use of touchscreen technology to deliver dementia education. The interventions utilized for the research study were interactive computer based cognitive training which stimulated ADLs and daily decision making and, supported conversation by allowing the viewing of videos or listening to music (Camic & Tyack., 2017). Touchscreen utilization was found to be effective in the earlier stages of dementia because touchscreens require minimal training to use and provide ease of access (Camic & Tyack, 2017). Many devices utilize touchscreen applications for interaction, especially if utilizing a mobile device. Although this study addressed the touchscreen method of learning, many devices utilized by patients and families to view services like YouTube are touchscreen. This study supported the need for further interventions, such as education, utilizing touch screen methods for family members and patients diagnosed with dementia.

Telehealth

Telehealth has been utilized in the delivery of dementia education and by caregivers to reach the rural populations affected by dementia. Doyle et al. (2016) sought to determine if technology such as telehealth services could improve the supervision and clinical governance of staff in remote areas that were unable to access psychiatric services, especially concerning a dementia diagnosis. Telehealth use was able to accomplish satisfaction with the education provided, increased knowledge, confidence, competence, and self-esteem, as well as improved availability of education from health care providers in more rural areas or those that are less accessible to health care providers (Doyle et al., 2016).

The COVID 19 pandemic brought new concerns to our world on a global scale. Many health care providers had to find alternative means to have appointments and continue to provide continuity of care while the pandemic placed restrictions. A key factor in the social distancing issues COVID 19 placed on patients, with the avoidance of person-to-person contact, was their ability to reach their healthcare provider. Telehealth allowed those with a COVID-19 diagnosis and those without a diagnosis to continue to see their healthcare provider without having the risk for infection reaching others that may be more clinically unstable (Smith et al., 2020). Telehealth has provided new modes of healthcare delivery to allow healthcare providers and patients relief during restriction's placed by the CDC.

Facebook

Social media resources and in-person education using Facebook has been shown to be an effective delivery method of dementia education over the disease, treatment, and progression of Alzheimer’s disease (AD). Shih et al. (2014) addressed the issue of utilizing social media to deliver education through Facebook, as well as in person education, and found that there was an increase in knowledge following the delivery of in-person educational services, as well as increased knowledge and awareness of AD.

Facebook is a popular social networking service (SNS) that has allowed people to remain in constant with each other on a daily basis (Prescott et al., 2013). Although

Facebook can be seen as potentially dangerous related to the unreputable information that can be provided, it can still allow for the spread of a multitude of information to users. This is valuable when attempting to provide education to individuals. If Facebook has the capability to provide information, even though it is unprofessional, it has the accessibility that an education program would seek to find. Hassan (2014) used “Facebook for Educator” which outlined policies about using Facebook for teaching and learning, as well as safety and privacy in the digital world. Hassan was able to provide support for use of Facebook as a mode for technological delivery for teaching and learning.

Many social media platforms are being used for different purposes than was originally intended. Facebook has allowed users to “share materials (e.g., video clips, sound files, photographs, Word files, presentation, spreadsheets, database files and websites); follow daily news, people or groups; participate in discussion platforms to support collaborative learning; and support questioning, critical and problem-solving" (Kaleliglu, 2016, p 84). These changes, along with the restrictions placed by COVID-19, have allowed for information to reach individuals that would otherwise not have been proactive about finding information. Kaleliglu determined that users were supportive of the use of Facebook to deliver education and materials for learning (2016).

Internet Delivery Programs

Another mode of education delivery identified was online delivery. The internet program “Mastery over Dementia” addresses self-help interventions for the caregiver of the dementia patient to reduce the risk for depression and anxiety that are associated with caring for the dementia patient (Blom et al, 2015). Techniques utilized for the program were management of behavioral symptoms, demonstration of coping strategies, explanation of social support, and psychoeducation with participation of the caregiver (Blom et al., 2015). Internet interventions for family members were found to be effective for both dementia patients and caregivers, and are both accessible and affordable (Blom et al., 2015). Livingston et al. (2019), sought to determine the family's motivation for participating in the Time for Dementia (TFD) educational program. Motivators for family participation were to gain increased knowledge of dementia, a recommendation on the part of a health professional, and a feeling of being involved with the dementia patient (Livingston et al., 2019).

Gitlin and Hodson (2016) sought to determine the challenges faced by the caregivers of the elderly and the advantages of providing online education regarding dementia. Although the researchers focused on the eldercare workforce a multitude of different caregivers could utilize this mode of education. Online learning provides the opportunity to learn utilizing a variety of tools such as simulations, courses, and videos. Online environments have the potential to become a powerful mechanism for transferring knowledge and possibly enhancing skills (Gitlin & Hodson, 2016).

CARES Dementia Care for Families (CARES) is another program that utilizes online delivery of dementia education for family members. Interventions chosen for CARES are psychoeducational interventions which are “structured programs that provide information about the disease, resources and services, and about how to expand skills to effectively respond to symptoms of the disease (e.g., cognitive impairment, behavioral symptoms, and care-related needs)” (Barclay et al., 2015, p 1). Education was delivered by professionals who assisted with information from a respectable resource. The benefits from delivery of CARES showed reductions in stress, improvement in coping skills of family caregivers, improvement of communication and caregiver skills, and helped decrease barriers such as transportation (Barclay et al., 2015).

Internet based programs allow COVID-19 precautions to be followed by minimizing face-to-face interactions which increases cost effectiveness related to accessibility (Boni et al., 2007). This delivery allows the provider to maintain safety during the pandemic as well as protect infection control measures to prevent the spread of COVID-19. More individuals participated in the interventions when they were provided via internet-based programs than those that did not have the availability (Boni et al., 2007). This is helpful when trying to implement education-based programs via the internet.

YouTube as an Education Tool

Video has become a mainstream form of education throughout COVID-19 pandemic. Educators had to find alternative means to provide education without face-to-face contact. Technology has increased and enhanced the student's ability to learn, especially while restrictions have been placed on classrooms. Students and educators have to find alternative ways to teach and learn through many different modes of technology.

YouTube is the world's largest video sharing service and is available to a multitude of individuals from various age groups. In 2007, YouTube grew from being a personal video sharing service to becoming a large entity that supplied information to over 70 million individuals (Skiba, 2007). Auxier and Anderson (2021) found that 81 percent of Americans utilized YouTube which is an increase from 73 percent in 2019. Maynard (2021) reported that over two billion users utilize YouTube to view over a billion hours of videos daily. It can be utilized to create a learning community and can allow the viewer to revisit the video as often as needed. The literature suggests that an online learning tool such as YouTube offers a form of active learning that allows information to be remembered and reinforced in a variety of environments. Learning can be maximized by using resources such as YouTube. According to Brame, (2016) YouTube can improve and enhance the student's ability to remain engaged in the material.

Although the use of technology in learning has become a mainstream tool to utilize, it is important to understand the type of content and how it will be used to ensure the information reaches the targeted audience. Students had a positive perception for using YouTube for education purposes and ease with accessibility (Beckman, 2014). YouTube was able to provide a new, interactive, stimulating resource for students to utilize to further their knowledge, especially while restrictions were placed with regards to COVID-19. “YouTube videos create a novel way of conveying educational content through real-life situations and observations, as well as connecting students with external experts” (Beckman, 2014, p 33). “There are largely untapped opportunities for academics to contribute to the richness, diversity and trustworthiness of video content available to casual learners, and to effectively mobilize their knowledge at scale” (Maynard, 2021, p 3). Although the study discussed students use of YouTube, it can be expected that YouTube may have the same effect on dementia education for family members.

YouTube has become the second largest search engine behind Google and is the most widely used platform for education purposes or learning new skills (Maynard, 2021). Many of the increases in users could be attributed to the COVID-19 pandemic where many individuals had to find different means for education. Learning environments have been nurtured and become successful through video views and subscriptions on YouTube, which is encouraging if attempting to provide dementia education to families. Over 2 billion users utilize YouTube to watch billions of hours of videos per day, even though users may be looking for entertainment, some are looking to gain new knowledge or familiarize themselves with information from health sources. “YouTube continues to provide academics with a unique yet still deeply under-utilized platform for directly making their knowledge, expertise and insights accessible to casual learners” (Maynard, 2021, p 7).

Benefits

Benefits from utilizing YouTube for education included a combination of visual, auditory, and animation components that enhanced the individual's quality of learning (Logan, 2012). A multigenerational group of individuals, including Baby Boomers, Generation Xers, and Millennials can be reached through the use of the video sharing service because it allows for convenience with viewing and, increases the accessibility of the information (Logan, 2012).

Burbridge and Stoneham (2014) supported the delivery of education through YouTube as long as the source is providing accurate information. Undoubtedly, YouTube can be utilized for educational means if information is provided from a supported, educational, and reputable source. Education provided via YouTube has the opportunity to improve information delivery to the public and improve patient outcomes (Lopez-Journet et al., 2017). YouTube is an efficient way to exchange information, provide video-based instructions, and provide clinical information to a multitude of populations over different disease processes (Jamal & Kumar, 2016).

Student engagement is another benefit of provided education via YouTube. Time is the first consideration with ensuring student engagement occurs in the program. Videos should be kept short to ensure students remain engaged (Brame, 2016). Although the research focused on students, family members can be used interchangeable with students because both groups are attempting to learn. Interactive features were also seen as a benefit for delivery of education via YouTube. Interactive features allow students to control the progression of the video as well as the capability to review material already discussed. YouTube has the ability to allow the user to remain interactive for better comprehension of the material provided (Brame, 2016). Ease of use is another benefit of using YouTube to deliver education to family members. Over 10 to 20 hours of material are posted to YouTube each minute, which makes its contribution massive especially if used for education purposes (Beckman, 2014).

Summary

Education is an important component of care for the dementia patient and those caring for the patient. Family members are an integral part in the care of the dementia patient, and they should receive adequate education to prepare them for the challenges that dementia may present to the patient and the family. Many family members are unaware of the constraints that a family member with dementia can place on them and providing dementia education could prepare them for the changes that will occur throughout the disease process.

Technology was heavily regarded in the literature as an effective mode for delivery of education. Dementia education has been provided using many different technology platforms. Education has been provided via YouTube for various health profession areas, though few resources are available for dementia, especially resources directed towards the family member. A vast number of individuals utilize YouTube, making it a promising medium for the delivery of education.

Although technology has been delivered through multiple different platforms, YouTube is the best option or delivery of videos for educational purposes. Facebook, Twitter, and many other social media platforms have proved to be valuable in reaching millions of individuals, it's important that the education provided be from knowledgeable, reputable sources. The source of information is the most important component of education to ensure the population reached is receiving accurate information. Benefits from using internet delivered programs such as YouTube include cost effectiveness, accessibility, and reproducibility. Other benefits that can be potential for delivering education via YouTube are student engagement and availability of interactional learning. Offering family members the same benefits of education as students have could allow the family to remain knowledgeable and active in the dementia patients' care when progression may make care difficult. Negative outcomes can occur if education over the disease process, progression, and treatment have not been provided or if families do not understand their role in the patients' care.

Another component to consider, especially with restrictions, is the pandemic of COVID-19. Social distancing has become a new way of life for socialization and refraining from hand-to-hand contact (CDC, 2021). Internet delivery programs, telehealth, and video sharing services have allowed educators the opportunity to continue to make education plans with the assistance of these technological services.

Most of the literature indicates that this education is expected to be provided by the PCP, but the provider may not be adequately prepared or comfortable with delivery of the education. As the disease progresses, the family may need to consider admission to the LTC facility because of the increased needs of the patient. Admission to the LTC facility provides the opportunity for education to be provided once more to prevent negative consequences after admission. Delivery of dementia education will remain an important component of patient care, and re-education should be encouraged to ensure the information is retained. YouTube has the ability to allow for delivery of education and also has the capability to replay information if the family member or patient desires.

Chapter III

Methodology

The research on dementia education has shown there is a need for more accessibility and implementation of education with patients and families in the LTC setting. Many patients that are diagnosed with dementia on admission to LTC facilities and their families can be impacted in a negative way if dementia education has not been provided. Research is limited to the use of technology to disperse information within the LTC setting. YouTube is an accessible resource for the delivery of education and the literature supports the use of this platform for education in many different areas of healthcare. The LTC environment provides an opportunity for distribution of dementia education. A video sharing service can increase the accessibility of information in this context. A review of the literature was unable to find research that addresses the use of a dementia education program in the LTC setting. However, it is known that education for dementia patients and their family members is an important component of patient care. According to Heim et al., (2019), healthcare providers often fail to provide dementia education or do not feel comfortable enough to provide information regarding the disease process and its progression. Education on expectations for patients with dementia would contribute to continued family involvement after admission to the LTC facility.

A descriptive quality improvement project was undertaken to provide information for the development of a dementia educational program to serve as a tool for providers to use with families upon patient admission to the LTC facility.

This quality improvement project is based on the following hypotheses and research question:

1. Fifty percent of the administrators, medical directors, directors of nursing, and care plan coordinators who work in LTC facilities will agree that providing dementia education to family members would improve family involvement in the LTC setting.
2. Seventy-five percent of the long-term care staff will indicate support for delivering dementia education.
3. Administrators, medical directors, directors of nursing, and care plan coordinators will see YouTube videos as a valuable conduit for delivery of dementia education.
4. Do administrators, medical directors, directors of nursing, and care plan coordinator believe providing dementia education will increase family's participation throughout the progression of the disease process in long-term care facilities at least fifty percent of the time?

Project Design

This project sought to determine what providers are currently doing to provide dementia education to patients and families, if providing dementia education in the LTC setting using YouTube would be beneficial, and the probability that healthcare providers would utilize this method of education to improve family involvement within the LTC setting. A survey was created using Google Forms and distributed electronically to LTC agencies in the Northeast Oklahoma counties of Nowata and Washington and Southeast Kansas counties of Montgomery and Labette.

The participating agencies were limited to those that provide only LTC services. Prior to distribution, the LTC agencies were contacted to explain the purpose of the survey and to obtain informed consent. Participation was voluntary and confidentiality was protected by the anonymous submission of the survey. The data obtained via the surveys was compiled and statistically analyzed.

Sample

The four counties where the LTC agencies were located were within a close geographic location to the researcher conducting the study. The sample population was limited by the number of LTC agencies within the identified area and those willing to participate. A total of 13 facilities agreed to participate, with 34 individuals receiving the survey. A sample size of fifteen medical directors, administrators, directors of nursing, and care plan coordinators of the facilities participated in the survey. Respondents were limited to individuals involved with LTC patients diagnosed with dementia. Inclusion criteria for this project required that participants be employed by the LTC agency, have licensure in the state where the LTC agency is located, care for dementia patients, and be involved and communicating with the family of the dementia patient.

Protection of Human Subjects

Approval was obtained from the Irene Ransom Bradley School of Nursing's Protection of Human Subjects Committee and the Pittsburg State University Institutional Review Committee (IRB) before data was collected from the participants. After receiving approval, the participants were contacted, and permission was requested to utilize electronic mail to send the survey link for completion of the survey. An informational e-mail was provided to the participants with instructions for completion of the survey and affirmation of confidentiality and anonymity. Electronic mail addresses were compiled and kept anonymous, then destroyed through shredding after completion of the project. Participants were given anonymity when taking the surveys. The Google Forms software that was used to collect the data was set to provide anonymous responses. The academic scholar and project committee members were the only individuals with access to the anonymous surveys used to obtain data.

Ethical Considerations

Anonymity of the project was an ethical concern. Although information was kept anonymous, it is unknown if within the LTC agencies issues with confidentiality could occur. COVID19 precautions were another ethical concern to ensure the safety of the participants. No face-to-face contact was made with the participants and the precautions being followed by each LTC facility were respected in completion of the project.

Instrumentation

The survey (Appendix B) consisted of fifteen questions that pertain to the families of dementia patients, dementia patients, education, technology, and caregivers of dementia patients. The survey was delivered electronically to the LTC facilities. The survey questions were both multiple choices and Likert scale questions to allow the participant multiple options for answering. These question types were chosen to improve data collection. The survey tool was reviewed by committee members to determine appropriateness prior to distribution to the participants. Google Forms was utilized to distribute the survey and gather the data. The data was kept anonymous throughout the project. After completion of the project, the data was kept in a secure location in the School of Nursing.

Procedure

Facilities were contacted by placing telephone calls prior to the dispersal of the surveys to obtain contact information and included electronic mail addresses. The surveys were dispersed via electronic mail for completion, allowing participants time to review the survey and complete it at their earliest discretion. A reminder phone call to the facilities was made in the third week and then again in the final fourth week. The time frame for completion was no later than four weeks from the distribution. If any participants wished to discontinue participating in the project at any time, they were instructed they could do so without repercussions and not complete the survey to ensure anonymity. After the fourth week, data collection and analysis of the survey responses occurred using Google Forms, Excel, and Minitab.

Assumptions

It was assumed the participants would answer the survey questions to the best of their ability. Licensure of the participants was another area that could be assumed. Individuals working in LTC centers were required to be licensed in order to provide care to patients. Another assumption was that those within the LTC settings would want to promote the use of dementia education. Those completing this survey were assumed to be licensed professionals caring for the LTC population. Lastly, it was assumed the survey would be applicable to both urban and rural areas LTC centers.

Limitations

Limitations for this project include the LTC facilities regulations, COVID 19 restrictions, time limitations, small sample size, and limited geographic areas included in the study. Regulations of the facility may impair the academic scholar's ability to conduct the project appropriately. Many facilities have regulations that must be followed which could prohibit participation in the project. Another limitation that could affect this project is time limitations. Time limitations can occur because many LTC settings have large populations to care for which potentially limits the participants' time to take part in the project. The size of the sample was limited by the number of participants who met the including criteria in the designated facilities. The project being conducted in a rural area may also cause limitations on the size of the sample population.

Summary

A descriptive quality improvement project was used to identify current dementia education provided in LTC facilities and included knowledge of technology use in providing dementia education for families and patients. A survey was administered via Google Forms using different types of survey questions to collect data from nursing care staff at LTC facilities in Northeastern Oklahoma and Southeast Kansas. IRB approval was obtained from all appropriate committees and from participating LTC facilities. Participants were contacted prior to distribution of the survey via a letter sent by electronic mail that describes the process for obtaining data and informed the participants of their right to refuse to participate at any time. Surveys were delivered, and participants had four weeks to complete the survey. A telephone call reminding participants of the survey was performed in the third and fourth week to encourage every individual to participate. Survey data was collected while maintaining confidentiality.

Chapter IV

Findings

This descriptive quality improvement project was undertaken to determine if a dementia education program through YouTube could be a tool for providers to utilize for families and patients upon admission to a LTC facility. This quality improvement project sought to test the following research hypotheses and question:

1. Fifty percent of the administrators, medical directors, directors of nursing, and care plan coordinators, who work in long-term care facilities, will report providing dementia education to family will improve family involvement.
2. Seventy-five percent of the long-term care staff will show support for delivering dementia education.
3. Administrators, medical directors, directors of nursing, and care plan coordinators will agree that the use of YouTube videos to be a valuable conduit for delivery of dementia education.
4. Do administrators, medical directors, directors of nursing, and care plan coordinator believe providing dementia education will increase family's participation throughout the progression of the disease process in long-term care facilities at least fifty percent of the time?

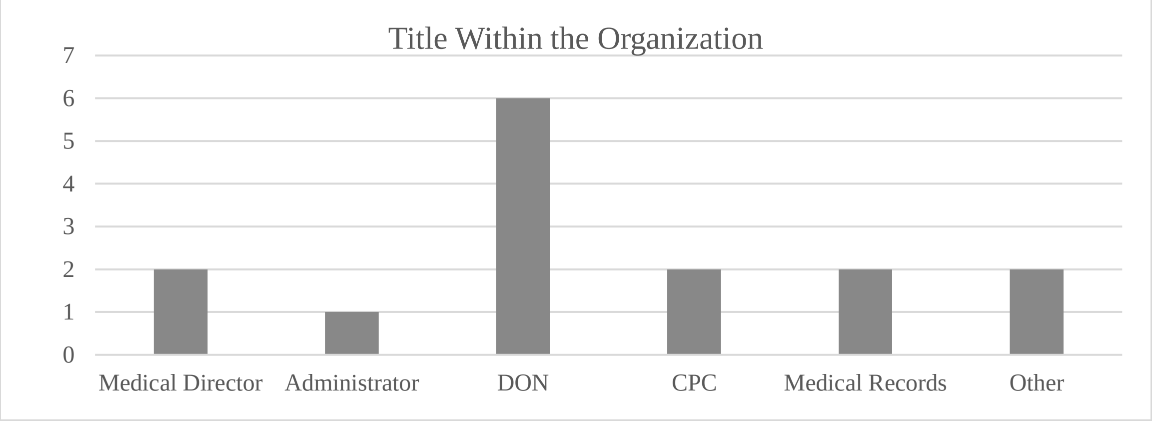
The data collected for this project was from medical directors, providers, and staff that provide care planning procedures or education within the LTC facilities in the counties of Washington and Nowata in Oklahoma and Montgomery and Labette counties in Kansas. A survey was utilized to gather data for a total of 14 facilities in the designated counties. The survey consisted of fifteen questions (See Appendix B). The introduction and instructions for survey procedure and completion can be found in Appendix A. Electronic addresses were collected in the first week and reminder telephone calls were placed in the third and fourth weeks. Five facilities that were considered for participation did not return telephone calls to allow for collection of contact information or electronic mail addresses. The survey was sent to 34 individuals with only 15 actually participating in the survey with some facilities representing more than one person. All individuals that were invited to complete the survey were involved with care planning and educating patients and families within the organization.

Title within the Organization

According to the survey results, two medical directors, one administrator, two care plan coordinators (CPC), six DON's, two medical records, one social service director, and one licensed practical nurse completed the survey (Figure 4.1). All other potential participants chose not to participate or did not complete the survey.

Figure 4.1

Title Within the Organization

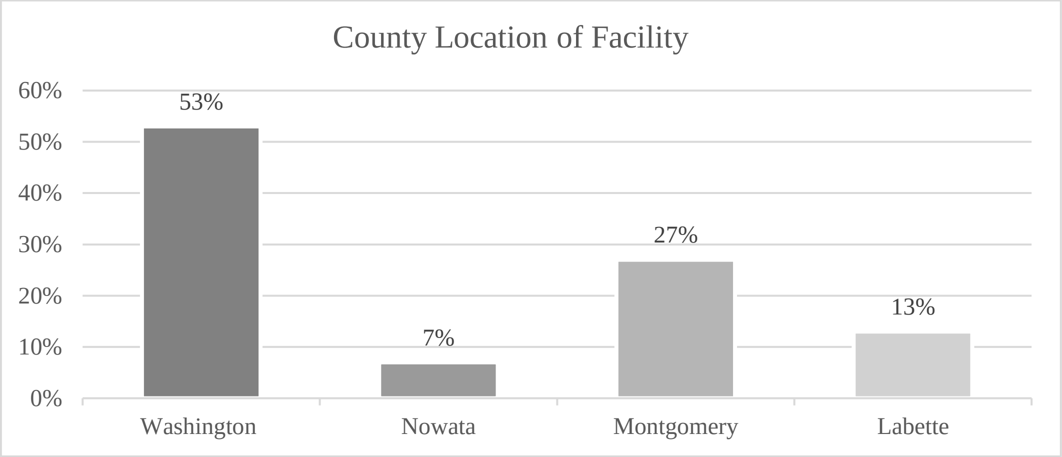


County of Facility Location

This project utilized LTC facilities in the counties of Washington and Nowata in Oklahoma and Montgomery and Labette counties in Kansas. Washington County accounted for the largest area for data collection with 53% of the data collection followed by Montgomery County accounting for 27%. Labette County accounted for 13% of the data, and the lowest participation for survey completion was Nowata at 7% where only one LTC agency resided (Figure 4.2).

Figure 4.2

County Location of Facility

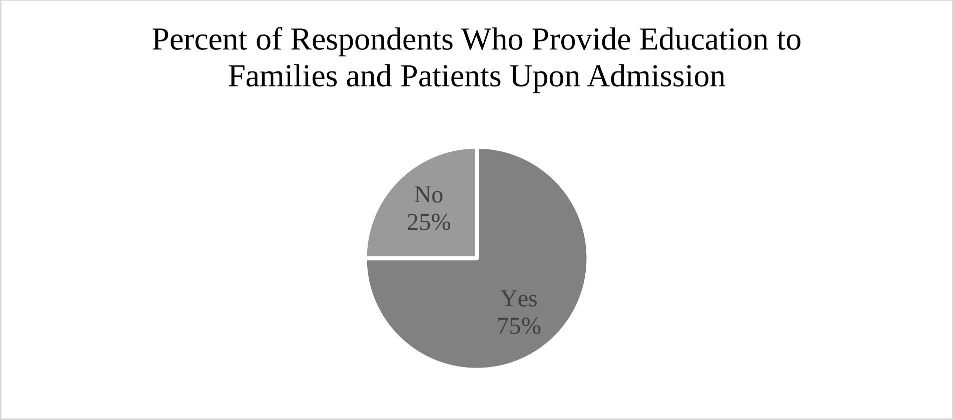


Current Dementia Education and Patient/Family Request for Information

For this project and to answer the research questions, it was important to know which facilities currently provided education about dementia and its progression on admission to the agency. A large number of participants indicated they already provided some type of education within their facility. Seventy-five percent of participants provided dementia education to patients and families about dementia and its progression upon admission to the LTC facility (Figure 4.3).

Figure 4.3

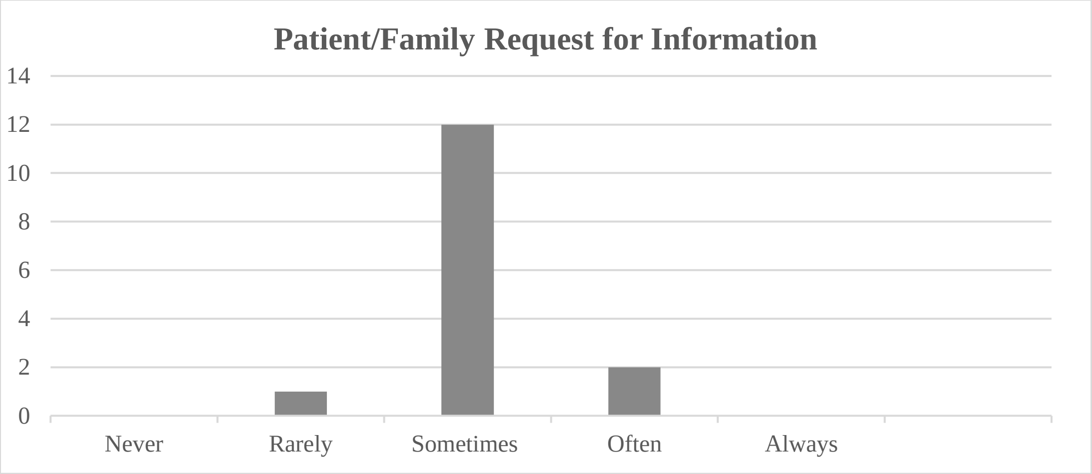
Percent of Respondents Who Provide Education to Families and Patients Upon Admission



Families and dementia patients requesting dementia education was also an area that the researcher sought to find because it would support the importance of education, as well as provide support for the delivery of dementia education. According to the survey results, twelve participants selected “sometimes,” two participants selected “often,” and one participant selected “rarely.” The other choices of “never” and “always” had no responses from participants. The median response was “sometimes” but the results could indicate that education isn’t provided very often related to the responses (Figure 4.4).

Figure 4.4

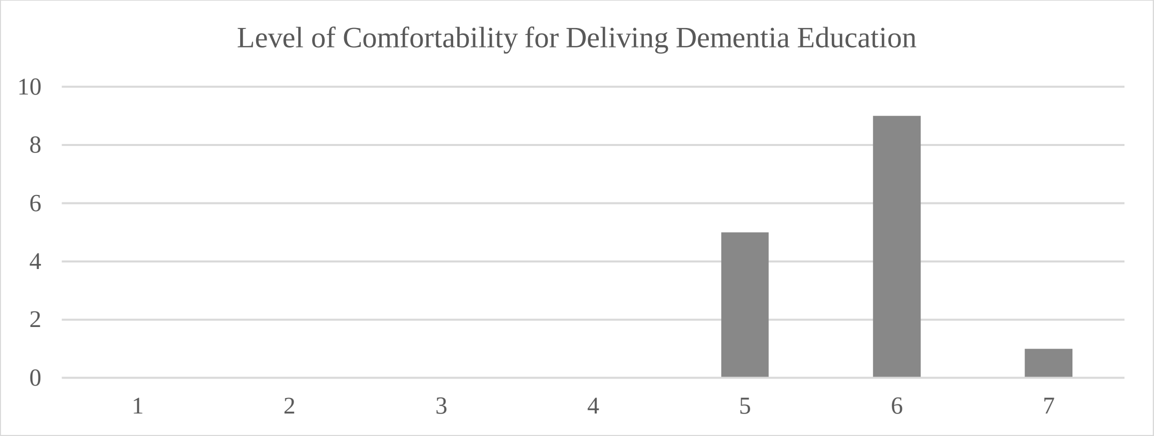
Patient/Family Request for Information



Although availability and delivery of dementia education was important to assess for this quality improvement project, it was also crucial to assess the participants' level of comfort with delivering dementia education. Survey participants were asked to report their level of comfort with providing dementia education to patients and families on a scale from one to seven, with seven representing the highest level of comfort and one rating the lowest. All participants reported a comfort level of five or above, indicating a high or relatively high level of comfort.

Figure 4.5

Level of Comfort for Delivering Dementia Education

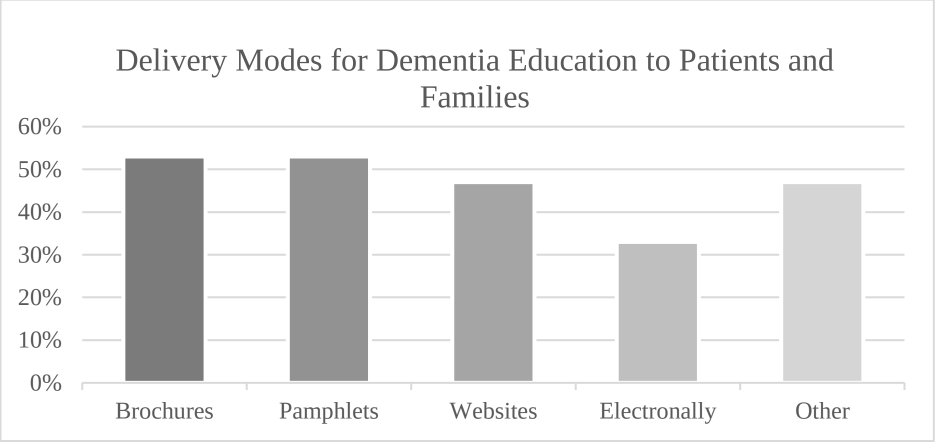


Delivery Modes of Education and Accessibility

The survey also asked respondents about modes of delivery used for dementia education in their facility. A *select all that apply* method of collection was utilized to determine which modes of delivery were most used to deliver dementia education among pamphlets, websites, electronically, brochures, or other methods. The survey demonstrated that 53 percent of respondents chose brochures, as well as pamphlets. Websites and Other methods of delivery followed closely behind at 47 percent, and 33 percent of respondents said they used electronic delivery.

Figure 4.6

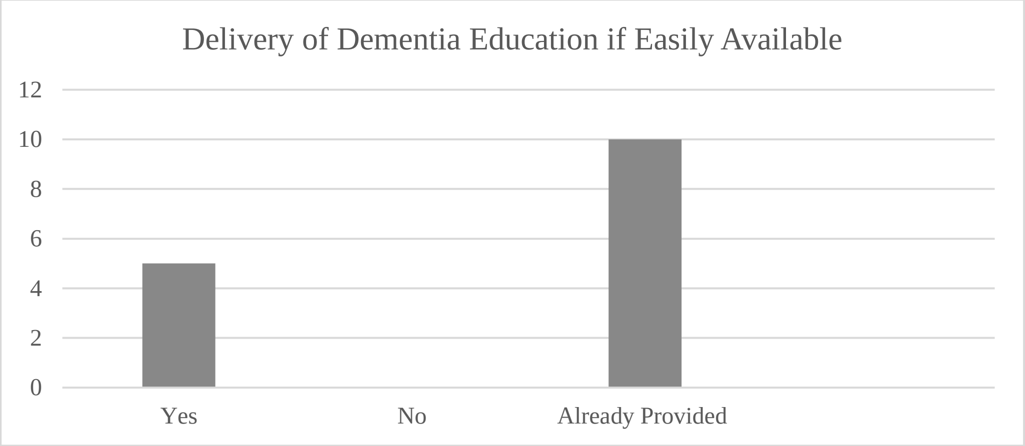
Delivery Modes for Dementia Education to Patients and Families



The survey addressed availability of dementia education by attempting to determine if participants would utilize dementia education if it were easily available. Sixty-seven percent or 10 participants indicated that they would, while 33 percent or five participants indicated their facility “already” provided dementia education. None of the participants said that they would not provide dementia education if it were easily available.

Figure 4.7

Delivery of Dementia Education if Easily Available



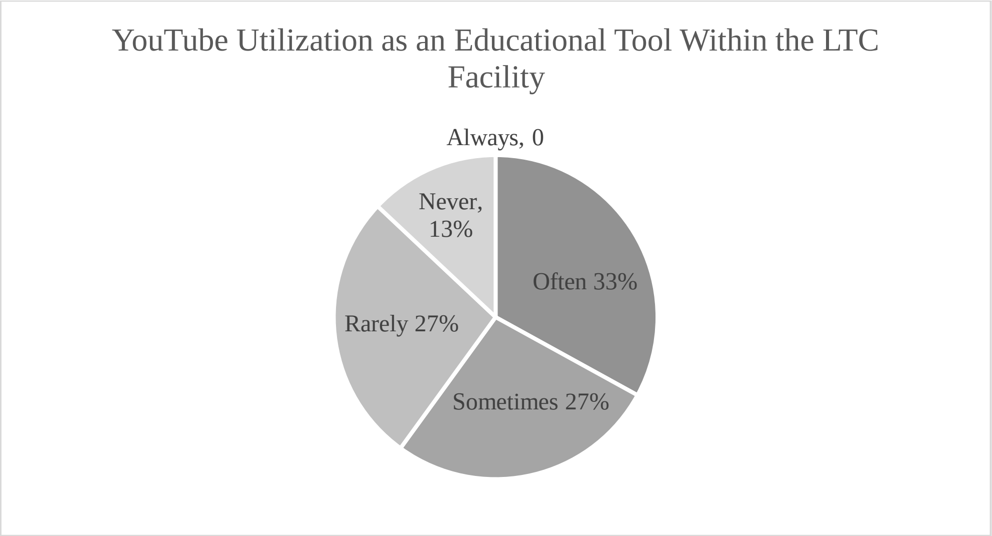
These results demonstrate that all participants either already provide dementia education or would be willing to do so if it were readily available.

YouTube Utilization and Patient/Family Use of Technology

Use of technology to improve knowledge within the facility may help support the potential use of YouTube as a delivery mode for dementia education. Among participants in this quality improvement project, 33 percent reported that they often used YouTube for education purposes in their facility, while 27 percent reported sometimes using YouTube for education purposes in their facility. 27 percent said they rarely used YouTube for education purposes in their facility and 13 percent said they never used YouTube for education purposes in their facility. Although more research would be needed to determine if YouTube would be a valuable conduit for delivery of dementia education within the LTC setting, some support could be drawn from the fact that two respondents reported that they never used YouTube for educational purposes in their facility.

Figure 4.8

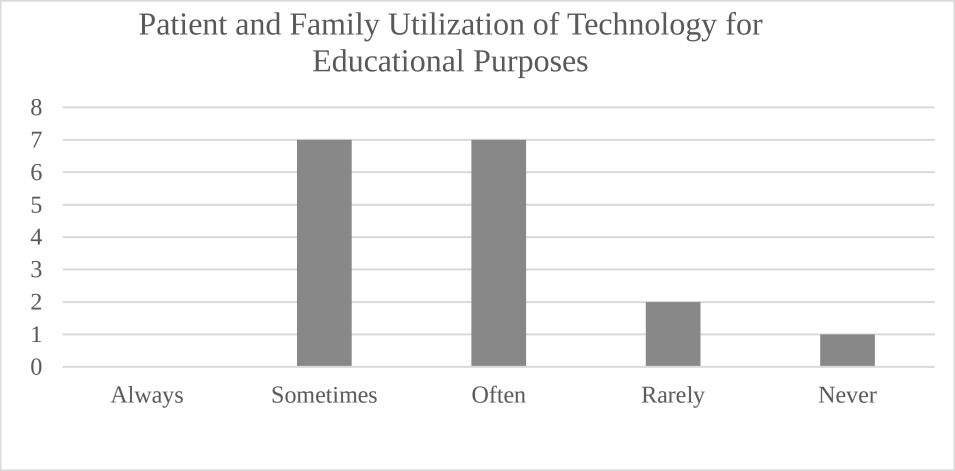
YouTube Utilization as an Educational Tool Within the LTC Facility



In order to determine if YouTube could be a valuable conduit for the delivery of dementia education within the LTC setting, it was also necessary to assess the patient and family use of technology. Participants were asked about the observation of families and patients within the LTC setting using technology for education purposes. The largest portion responses were “sometimes,” accounting for 47 percent or seven participants. The second largest group was those who’s response~~s~~ was “often” which represented 33 percent or five participants responses. Two participants chose “rarely” and accounted for 13 percent of the survey responses. Seven percent or one participant made the selection of “never.” None of the participants made the choice for “always” (Figure 4.9).

Figure 4.9

Patient and Family Utilize of Technology for Educational Purposes

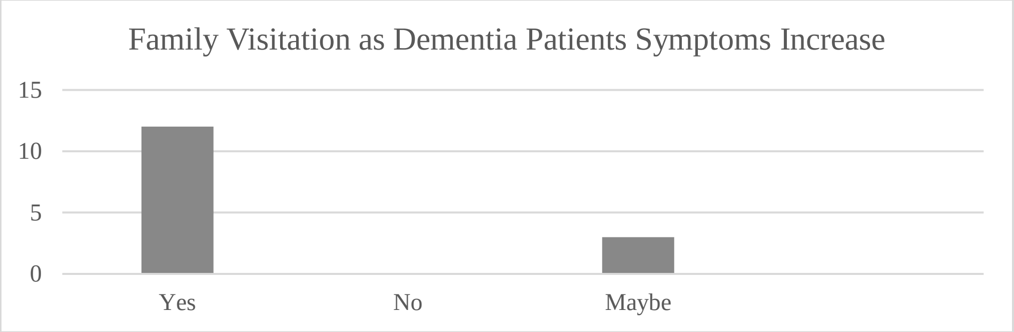


Effects of Dementia Progression and Possible Benefits with Dementia Education Delivery

Researchers sought to determine if visits by family members tended to decrease as the patient’s dementia symptoms increased. To determine if there were decreases in visitation, participants responded to a survey question. Twelve participants chose “yes” as their response regarding family members visits decreased as dementia symptoms increased. Three participants gave the response of “maybe” while no participants made the selection of “no.”

Figure 4.10

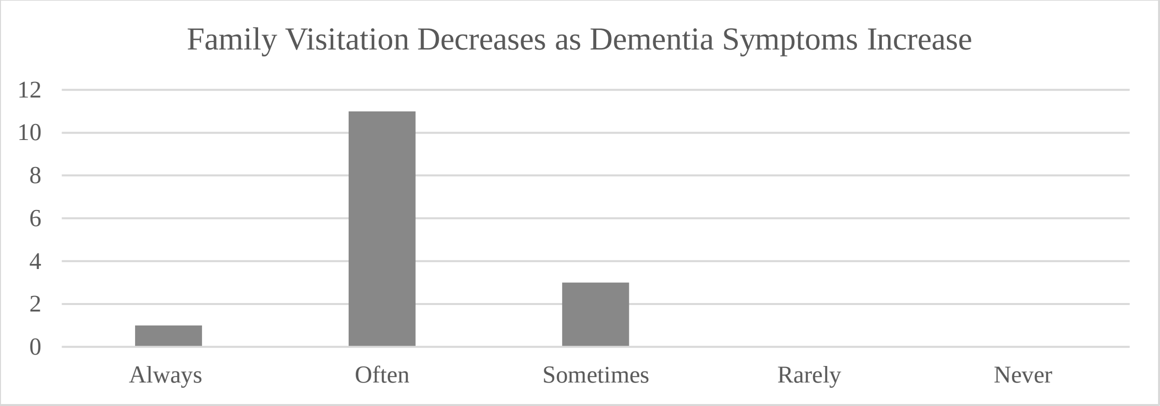
Family Visitation as Dementia Patients Symptoms Increase



Participants indicated that family visitation decreased as the patient's dementia symptoms increased so it was important for the researcher to ascertain how often these decreases in visitation occurred. Participations were asked how often they see family members decreasing visits as dementia symptoms increased. The largest portion chose "often" which accounted for eleven participants. The second largest group of three participants responded "sometimes." The last group of one participant chose "always." No participants made the selection of "rarely" or "never." Figure 4.11 demonstrates choices made by participants.

Figure 4.11

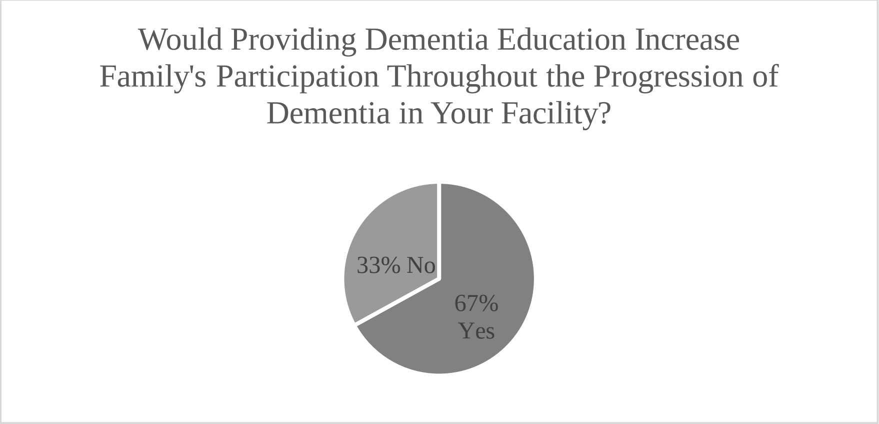
Family Visitation Decreases as Dementia Symptoms Increase



Participants were also asked if providing dementia education would increase family's participation throughout the progression of dementia in their LTC facility. Ten participants responded "yes" which accounted for 67 percent of responses. Thirty-three percent or five participants responded with "no." Figure 4.12 demonstrates these results. The results from this survey question supported research question one that 50 percent of participants believe providing dementia education would increase family's involvement throughout dementia progression. The P-value was 0.197. There was no evidence to reject the null hypothesis at 0.05 level of significance since the p-value was greater than 0.05. Research question four: Do administrators, medical directors, directors of nursing, and care plan coordinator believe providing dementia education will increase family's participation throughout the progression of the disease process in long-term care facilities at least fifty percent of the time? can also be addressed using the same survey question. The p-value was 0.041 which indicated that the null hypothesis would be rejected because more than 50 percent of participants believed that providing dementia education could increase family's participation in the LTC facility.

Figure 4.12

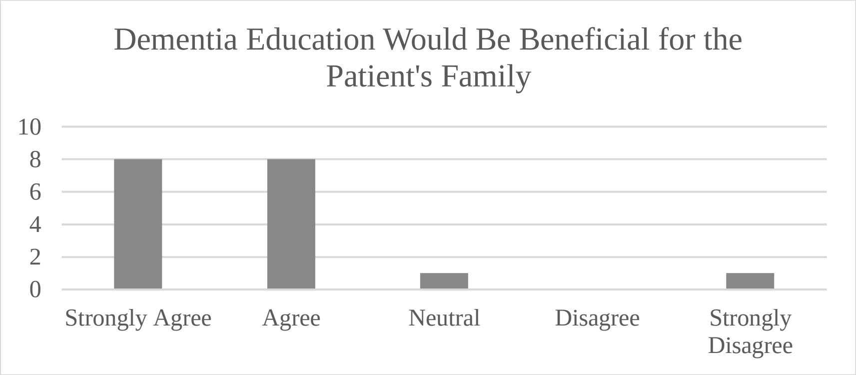
Would Providing Dementia Education Increase Family's Participation Throughout the Progression of Dementia in Your Facility?



Overall, many of the participants indicated they felt that dementia education may have the possibility of increasing family involvement as dementia symptoms increase. The same could be implied regarding if dementia education would be beneficial for the patient's family. The majority of participants chose strongly agree which accounted for eight responses. Five participants made the choice for "agree" and one participant chose "neutral" for their answer leaving one participant with the response of "strongly disagree." Figure 4.13 demonstrates the participants' responses. The survey responses indicated that 75 percent of the LTC staff support using YouTube for the delivery of dementia education. However, there was not enough evidence to reject the null hypothesis that 75 percent of LTC staff believe dementia education would be beneficial for the patient's family with a p-value of 0.298.

Figure 4.13

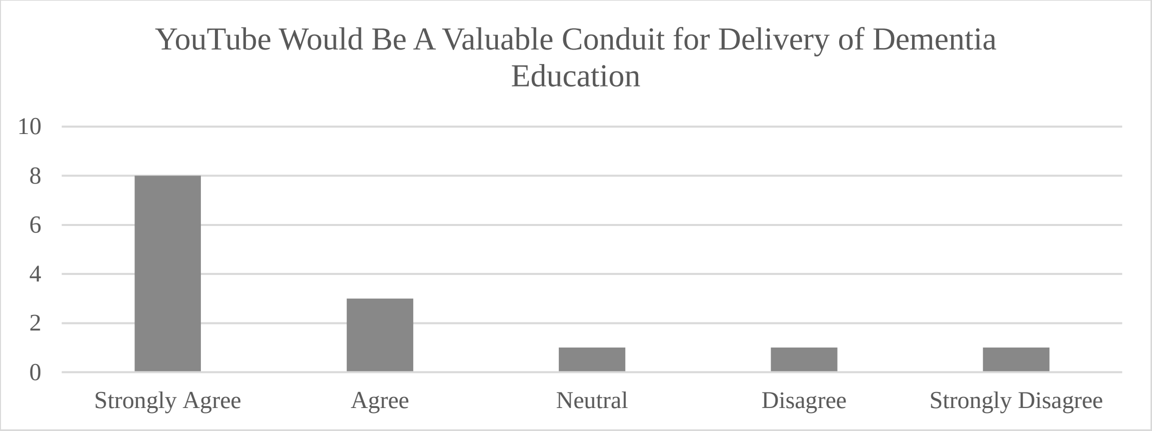
Dementia Education Would Be Beneficial for the Patient’s Family YouTube as a Valuable Conduit for Education



The review of literature found that YouTube is the most widely utilized platform for education purposes and learning (Maynard, 2021). Most of the participants indicated that they have used YouTube for educational purposes but the researcher wanted to seek knowledge if it would be a valuable conduit for education. The participants were asked if they believed YouTube would be a valuable conduit for the delivery of dementia education. Nine participants “strongly agreed” that YouTube would be a valuable conduit for dementia education. Three participants chose “agree,” one participant chose “neutral”, one participant chose “disagree,” leaving one participant with the choice of “strongly disagree.” Figure 4.14 demonstrates these results. Overall, twelve out of fourteen participants or 85.7 percent agreed that YouTube would be a valuable conduit for delivery of dementia education.

Figure 4.14

YouTube as a Valuable Conduit for Delivery of Dementia Education



Technology has increased in use, especially after the effects that COVID 19 placed on healthcare. YouTube technology doesn't use the traditional routes of teaching and allows for easier accessibility as well as retention because the video can be seen multiple times (Romanelli, 2009). YouTube also allows for different learning types to be engaged through active learning and can be provided through a pace that is comfortable to the viewer (Brame, 2016). Literature have both supported the use of YouTube as a valuable learning tool for accessibility as well as retention. If utilized to reach the LTC population, this could have the capability to improve the dementia patients families involvement because they will be able to know what can be expected as the disease process progresses.

Race Results Regarding the Prevalence of Dementia

The literature demonstrated the highest prevalence of dementia in the U.S. was in the African American population followed by Hispanics, non-whites, American Indians, Alaska Natives, and Pacific Islanders (Mehta & Yeo, 2017). The researcher wanted to determine what race had the highest prevalence of dementia in the population cared for by the project participants. All 15 participants chose Caucasian.

Research Hypothesis and Questions Summary

This descriptive quality improvement project was able to support the use of dementia education in the LTC setting and possibility of improving family involvement through its delivery. The findings support Hypothesis 1 and 2: fifty percent of LTC staff do believe that providing dementia education to families will improve family involvement and seventy-five percent of LTC staff supported the delivery of dementia education. YouTube was seen as a valuable conduit for dementia education according to almost 86% of participants. Research question four demonstrated to be true as the number of participants was more than what had originally been hypothesized. Over fifty percent of participants believe that providing dementia education will increase family's participation throughout the progression of the disease process.

The results received from the survey demonstrated that a large number of participants supported the use of dementia education within the LTC setting. Although most of the delivery modes for the dementia education were pamphlets or brochures, more accessible routes of delivery may be beneficial for the dementia patient, family, and LTC staff. YouTube was proven to be a valuable conduit by the participants. This platform can improve the ability to reach a multitude of individuals especially those within the LTC setting because the dementia education could be easily accessible. Most of the participants believe that family involvement can increase as the dementia patient progresses through the stages of dementia if they are provided dementia education. This research supports the development of a dementia education program via YouTube for utilization within the LTC setting to increase family involvement.

Chapter V

Significance and Conclusion

The purpose of this quality improvement project was to: 1) determine what platforms are used to deliver dementia education to families and patients within the LTC facility; 2) determine if providing dementia education to family members has the potential to promote continued family involvement with patients diagnosed with dementia; and 3) to determine if the LTC staff would support the use of dementia education through YouTube if available for patients and families. The data for this quality improvement project was collected from LTC facilities in Washington and Nowata County in Oklahoma and Washington, as well as Labette County in Kansas. Thirty-four employees of LTC facilities were invited to complete the survey; fifteen participants, fifteen completed and returned the survey. This quality improvement project found that 50 percent of the respondents believe that dementia education would improve family involvement for the dementia patient; seventy five percent of participants indicated support for the delivery of dementia education; and over 50 percent participants believed that family's participation would increase throughout the progression of the dementia.

Theoretical Framework

Dorothy Orem's Self-Care Deficit Theory was the framework chosen for this quality project. This theoretical framework was utilized mainly because dementia is characterized by increasing self-care deficits, with the result that dementia patients having increasing needs that must be met by family members or LTC staff, including dressing, bathing, toileting, or eating. The progression of the disease is slow and insidious which allows the family to be a major part in their care (Chang, Duong, & Patel, 2017).

Assumptions this theory reveals are that self-reliance and responsibility belong to the patient and family; all individuals are different and require the ability to make decisions for themselves; knowledge is required to identify the patients' needs and make these needs known to those caring for the patient; and the responsibilities for care and relationships must be assumed by others, not by the patient. Social decline begins in stage IV of dementia which hinders the ability of the patient to make choices or speak for themselves appropriately (Reisberg, 2018). The progression of dementia may be difficult for the family to understand, and in many instances the family may stop visiting because they may feel that their family member doesn't remember them. This project offers anecdotal evidence that family involvement does decrease as dementia progresses and that providing dementia education to the patient and family might have the ability to improve family visitation.

Family members can play an important role in the observation of decreases in cognition or changes that occur with the dementia patients which is essential information for the providers and LTC staff, especially if the patient arrives in the middle or later stages of the disease process (Anderson et al., 2017). Education can help provide knowledge about dementia and its progression, which may ameliorate the self-care deficits a patient may experience by allowing the family and LTC staff to acknowledge the patients' preferences and care for them in the way they would care for themselves if they were able. Assisting to provide relief from the self-care deficits the patient may be experiencing can allow the family to feel like a valuable participant in the patients care.

The project participants indicated that they had observed a decrease in family visitation as the patient's dementia symptoms increase and they thought providing dementia education could contribute to preserving family involvement. Dementia education may encourage the family members to remain a constant part of the dementia patient's life, help improve symptom identification, decrease role strain, and decrease anxiety and depression for the caregiver (Cohen et al, 2018). By providing dementia education, LTC facilities may improve family members' ability to remain a constant participant in the patient's life. Family is an enormous part of the dementia patient's environment. The family can be responsible for the patients care and ensuring their well-being. After admission to the LTC facility, the family can continue to be involved with the patient's care throughout the progression of dementia. Study results indicated that education may have the capability to increase families' visitation.

Implications for Healthcare

LTC facilities would benefit from ensuring that families and patients have education available regarding dementia and its progression. Admission to the LTC facility would be an opportune moment for dementia education to occur to increase the knowledge base of the patient and family to allow them to remain an active part in the patients care. It would allow the individuals adequate time to ask questions and clarify the information delivered. Many patients look to their PCP to deliver dementia education, but the information may be vague or insufficient to address the needs of the patient (Peterson et al., 2016). Providers indicated that their ability to deliver dementia education is limited by time, access to the information that the patient requires, and the availability of the dementia education by allowing staff, patient's, and families to view the material together (Werner et al., 2017). LTC facilities could provide in a timely manner dementia education that could be influenced by the particular needs of the patient relative to their type of dementia.

Currently, brochures and pamphlets were the most used method chosen by the participants of the study as the main delivery mode for dementia education. The LTC facility has a responsibility to ensure the family and patient knows where to intervene at any stage of the dementia process. If the patient or family doesn't understand dementia progression or future needs of the patients, then they won't be adequate at caring for their loved one. However, if dementia education were available and adequately provided, it might prepare family members with the knowledge needed to make evidenced based choices, as well as identify the patient's preferences to assist LTC staff with caring for the patient. Brochures and pamphlets were the most used method chosen by the participants of the survey as the main delivery mode for dementia education.

As the study results demonstrated, LTC staff believe dementia education is beneficial for the patient and family. Delivery of patient education has the capability to prevent the family from becoming a "second victim of dementia" (Pahlavanzadeh et al., 2010, p 103). Improved knowledge may allow the family to feel secure in the decisions they make for their loved one if they understand the needs of the patient. The survey results found the staff within the LTC facility noticed family visitation often decreases as dementia symptoms increase. The decreases in family visitation could result in negative patient outcomes and impair the family’s relationship with the dementia patient (Pahlavanzadeh et al., 2010). The study’s results also indicated the LTC staff believe providing dementia education has the potential to increase family visitation as dementia progresses which could have positive effects on the patient and family relationship.

It may also be beneficial to determine if the workload of the LTC could decrease if the family remained involved in the dementia patients care after receiving dementia education. Family members might feel competent to provide some assistance with the dementia patients ADLs to improve their ability as a caregiver and nurture their relationship with their loved one. Decreasing the workload on the LTC staff could improve the relationship between family and LTC staff by encouraging the family to become more involved and making the family more aware of what tasks they can perform.

Recommendations for Future Research

Although the review of literature for this project indicated a need for more options for delivering dementia education, the facilities represented ins the survey primarily utilized pamphlets and brochures to provide dementia education. This is in spite of the fact that YouTube technology was used as an educational resource for the LTC staff and respondents demonstrated support for the use of YouTube as a valuable conduit for educational content. A study with a larger population is needed to further determine if there is an advantage to using YouTube for the delivery of dementia education in the LTC setting. The information provided in this project may provide motivation for examining the quantity, quality, and scope of dementia education materials that YouTube provides to determine if availability was a limiting factor or if it was just the staff attitudes and beliefs about YouTube.

Additional research utilizing different types of care organizations would be relevant to understanding current practice in providing education to dementia patients and families. Other areas of healthcare delivery such as acute care facilities, primary care centers, or skilled nursing facilities should be assessed for the availability and delivery of dementia education. This quality improvement project only focused on the LTC facilities within four counties. If different types of facilities were included in future research, it could provide a more in-depth look at the need for dementia education through a greater variety of organizations and allow for assessments of other populations.

Although study participants reported that the majority of their dementia patients are Caucasian, evaluation of existing dementia education materials in terms of their appropriateness for racially-diverse and gender non-conforming audiences is also needed in order to ensure that all patients have access to the best possible care. A higher number of participants could cause some distinguishable data from these results because the number of participants weren’t very large, if more participated in the survey, these numbers may have had some variability.

Limitations

The researcher’s time constraints and ability to recruit a large subject pool was greatly affected by project deadlines. Small sample time proved to be a limitation because over 34 LTC employees were invited to participate and only fifteen chose to respond to the survey. The geographic area was also a limitation as there only four counties utilized to gather data. If the geographic area would include a larger number of counties, there may be more diversity in the respondents and their dementia patients populations.

The researcher had a limited amount of time of one month to recruit participants, collect data, and analyze results. This limitation had a negative effect of the population size as well as having strong support for a dementia education program via YouTube to decrease the risk for decrease family involvement for the dementia patient in the LTC setting. If time had not been a limitation, more participants and additional counties could have been included in the research to improve the survey results.

Summary

Dementia is a progressive, slow, and insidious disease process. Patients and families experience dementia at different stages within the progression. LTC facilities may need to educate patients and families in order to adequately provide care to the dementia patient. In order for family members to be prepared to make competent, knowledgeable decisions education is needed. Education that provides information on the diagnosis, progression, and interventions for the dementia patient helps decrease negative outcomes that could affect the patient such as increases in falls, mortality, and decreased nutrition and hydration (Livingston et al., 2019). When family members are not adequately educated, they may experience high stress levels, depression, and anxiety (Cornwell & Sorenson, 2011). Many benefits can result if patients and families are provided education such as improved psychological stability, decreased fatigue, and a healthier relationship (Cohen et al., 2014). Education is a needed intervention for dementia patients and their families and YouTube was seen in the literature and by the participants in this project as a valuable resource for the delivery of dementia education. Overall, this project was able to support the use of dementia education via YouTube within the LTC facility for patients and families.

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APPENDIX

Appendix A

To Whom It May Concern,

My name is Marissa Bernabe and I am a student with Pittsburg State University in the Doctor of Nursing Practice program. My doctoral project involves dementia education in long-term care. In order to learn more about present dementia education in long-term care facilities I need your assistance. I am seeking to determine if family involvement can improve for dementia patients by providing dementia education using a video sharing services such as YouTube in rural areas. Participation is voluntary and you may stop participating at any time without consequences. All data collected will be kept confidential and you may receive aggregated data, or your own data if requested after completion. I believe your participation in this project will increase current knowledge and promote further research over dementia education and family involvement, as well as provide the opportunity for the development of a dementia education program that can be shared with patients and their family members. I would sincerely appreciate your time committed to assisting me in the completion of the project and look forward to learning about the needs for dementia education in our area. If you would like a copy of the results of the project, please contact Marissa Bernabe using the contact information provided in this letter.

Thank you,

Marissa Bernabe RN, BSN

Contact Information:

Phone: (918) 440-7155

Email: mlevans@gus.pittstate.edu

Instructions

The following information will help guide you through the completion of the “Dementia Education Survey” to determine if YouTube would be a useful tool to allow long-term care centers to disburse dementia education to patients and families. The purpose of the survey is to attempt to determine if family involvement can improve for the dementia patient by providing education using a video sharing service such as YouTube for rural areas.

Steps for completion of survey are as follows:

1. Participants will be contacted by a telephone call and permission requested to obtain contact information, including electronic mail addresses.
2. The survey will be dispersed via electronic mail for completion using Google Forms.
3. Please complete the survey at your earliest discretion.
4. A telephone call will be placed three weeks after the survey has been disbursed and once again in the fourth week.
5. Discontinuation of participation can occur at any time during the survey process without any penalty.
6. To ensure you anonymity, electronic mail addresses will be compiled and the data will be kept in the School of Nursing in a locked secure location for 3 years and then destroyed.

7. Subjects will only receive aggregated data or their own data if requested after completion.
8. The academic scholar and project committee members will be the only individuals with access to the anonymous surveys used to obtain data.

If you have any questions regarding the instructions for completion of the survey, please contact Marissa Bernabe. I have included my contact information to ensure I am able to address any concerns.

Thank you,

Marissa Bernabe RN, BSN

Contact Information:

Phone: (918) 440-7155

Email: mlevans@gus.pittstate.edu

Appendix B

Dementia Education Survey

1. What is your title within the organization?
   - a. Medical Director
   - b. Administrator
   - c. Director of Nursing
   - d. Care Plan Coordinator
   - e. Other _____________
2. What county is your facility located?
   - a. Washington
   - b. Nowata
   - c. Montgomery
   - d. Labette
3. Do you provide education to families and patients about dementia and its progression upon admission?
   - a. Yes
   - b. No
4. How often do families or patients request information or education about dementia and its progression?

Never Rarely Sometimes Often Always

5. On a scale from 1-7 with 1 being the least comfortable, how would you rate your comfortability with providing dementia education to families and patients?

1 2 3 4 5 6 7

6. Dementia education would be beneficial for the patient's family?

Strongly Disagree Disagree Neutral Agree Strongly Agree

7. How often do you use YouTube technology for educational purposes in your facility?

Never Rarely Sometimes Often Always

8. How often have you observed families and/or patients utilizing technology such as cellular phones, computers, or other devices for educational purposes?

Never Rarely Sometimes Often Always

9. How often do you see family members decreasing visits as dementia symptoms increase?

Never Rarely Sometimes Often Always

10. Do family members visits decrease as their love one's dementia symptoms increase?

   a. Yes
   b. No
   c. Maybe

11. Would providing dementia education increase family's participation throughout the progression of the disease process in your facility?

    a. Yes
    b. No

12. Would your facility provide dementia education to patients and families if it were easily available?

    a. Yes
    b. No
    c. Already provide

13. How is education currently provided to families and patients in your facility? Select all that apply.

    a. Brochures
    b. Pamphlets
    c. Websites
    d. Electronically
    e. Other

14. What is the group with the highest incidence of dementia within your organization?

    a. White
    b. Hispanic or Latino
    c. Black or African American
    d. American Indian or Alaska Native
    e. Asian

f. Native Hawaiian or Other Pacific Islander

g. Other

15. YouTube would be a valuable conduit for the delivery of dementia education?

Strongly Disagree Disagree Neutral Agree Strongly Agree