Implementation of a Dementia-Specific Advance Care Planning Tool at a Program for All-Inclusive Care for the Elderly (PACE)

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Abstract

There are 55 million cases of dementia worldwide and the cost of care for these individuals is estimated to rise to $2 trillion by 2030. Dementia-specific Advance Care Planning (ACP) can help to reduce the burdens of providing care to those diagnosed with dementia. Does the implementation of a dementia-specific ACP tool help increase knowledge and decision-maker confidence, as well as decrease inappropriate healthcare utilization rates? New enrollees at a PACE site, diagnosed with a cognitive deficit and their surrogate decision-maker (SDM) were recruited. A dementia-specific ACP tool was used to facilitate discussion. Knowledge of dementia and care options was assessed for both members of the dyad. The SDM's confidence regarding their role was assessed. Healthcare utilization rates for study participants were obtained. There were eleven dyads that completed the ACP session and pre/post-implementation assessments and ten participants with cognitive deficits and nine SDM completed follow up. Non-parametric analytics were utilized to analyze the data. Chart review was performed and a healthcare utilization rate was obtained pre/post. Participants with cognitive deficits showed no statistical significance of learning. SDMs showed statistically significant improvement in knowledge and confidence across the study. The utilization rate decreased by two visits. Individuals diagnosed with cognitive deficits do not understand the terminality of their diagnosis and lose the ability to communicate their desired wishes. SDMs do not know what kind of care their loved one would want. Dementia-specific ACP should be implemented with all individuals with cognitive deficits as soon as possible after diagnosis.

Keywords: dementia, advance care planning or advance directive, quality of life, and dementia-specific

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Dementia is an umbrella term for a group of symptoms including deterioration in memory, cognitive function, speech, processing abilities, and problem solving (Alzheimer's Association, 2022). There are many types of dementia including the most common, Alzheimer's Disease (Alzheimer's Association, 2022). More than 55 million people worldwide have been diagnosed with some form of dementia and this number is expected to continue to grow exponentially with the increasing age of the population (World Health Organization [WHO], 2021). Some estimates expect the worldwide prevalence of dementia to reach 78 million cases by 2030 (WHO, 2021). While dementia mostly affects older adults, 9% of documented cases are early onset, defined as diagnosis before 65 years (WHO, 2021). There is no cure and the treatments that are currently available in practice simply work to delay the progression of the disease. As cases of dementia are expected to rise, there is an increased need for a healthcare intervention that promotes health, improves quality of life, decreases suffering, and engages the individual with dementia in active planning for future care.

Background & Significance of the Problem

Dementia is a chronic and progressive disease. One of the most important interventions for individuals with dementia is to understand care preferences while cognition remains intact. Advance Care Planning (ACP) is an intervention that seeks to understand and record an individual's wishes regarding their medical care in the event that they lose their ability to communicate their decisions personally. ACP has been in use in the United States since the 1960s working to ensure that patients receive the care they desire in every situation (Bosisio et al., 2021). In individuals with dementia, the ACP identifies the appointed surrogate decision-maker who assumes the role of spokesperson for the individual with dementia.

ACP initiation occurs in a variety of settings. Often, primary care providers in the ambulatory setting offer limited information about ACP. In many instances hospitalized patients and their families may be offered ACP information, perhaps for the very first time. ACP is especially important to implement in individuals with dementia due to the loss of cognitive function that limits informed decision-making. Current ACP practices, however, are limited when it comes to addressing specific needs and concerns regarding dementia (Fried et al., 2021; Ma et al., 2021, Sellars et al., 2018). Many standard ACP tools do not discuss life-prolonging interventions, such as enteral tube feedings, hemodialysis and ventilators, which are common in individuals diagnosed with dementia. It is therefore necessary for healthcare providers to reflect and identify current ACP practice in order to create a more consistent ACP process for all patients including individuals with dementia. A few dementia-specific ACP tools have been created and implemented in the past though the research on this topic is very limited and only from the past few years (Bosisio et al., 2021; Dartmouth College, 2019; Gaster 2017). Based on scope of practice, this suggests that Advanced Practice Registered Nurses (APRNs), specifically Clinical Nurse Specialists (CNS), can be key players in the implementation of ACP with their patients. CNSs have the expertise, education, and experience to work with vulnerable populations such as those diagnosed with dementia. CNSs play a large role in transitional care including identification of dementia-specific ACP tools and process analyses to work towards consistent implementation (National Association of Clinical Nurse Specialists [NACNS], 2017). An understanding of the progression of dementia and the care options available to individuals with dementia allows CNSs to educate and inform. It also allows CNSs to identify inconsistencies in ACP implementation and work towards a more consistent, sustainable ACP process.

As the population ages and the rate of individuals diagnosed with dementia are expected to significantly rise, the need for increased healthcare interventions, such as hospitalization rates and memory care, can be expected to rise. The population of individuals diagnosed with dementia and other cognitive deficits are on the rise secondary to the aging baby boomer population (Alzheimer’s Association, 2023). Healthcare utilization rates are highest among older adults and those with chronic diseases including dementia (Kim et al., 2021). Preventing unnecessary healthcare utilization is a priority of many organizations including older adult care centers such as PACE (Program for All-Inclusive Care for the Elderly). The population that PACE serves has a large population of participant diagnosed with dementia, many of which do not have ACP completed or limited ACP documentation. While a current process exists utilizing social workers as ACP initiators, stakeholders view this project as an alternative approach to tool implementation and education for participants with dementia. This project worked to assess and create a process improvement in order to individualize the ACP process for participants who have a dementia diagnosis.

As the population ages and the prevalence of dementia rises, the global estimated cost of caring for individuals with dementia(s) is expected to rise to $2 trillion in 2030 and by 2050, an estimated $9 trillion (Counts et al., 2022). The lifetime costs of care for an individual with dementia is $184,500 more than their counterparts without dementia due costs of formal and informal caregiving (Jutkowitz et al., 2017; Michigan Dementia Coalition, 2019). Michigan Medicare beneficiaries over 65 years old who have dementia pay over $11,000 out-of-pocket for healthcare annually (Michigan Dementia Coalition, 2019). Interestingly, research conducted by the National Institute for Health (NIH), in the United Kingdom (UK), found that individuals with ACP have lower rates of healthcare costs (Bauer et al., 2020). Individuals who had ACP in place had a Quality-Adjusted Life Year (QALY) savings of £18,966 which is equivalent to $23,064 in today’s dollar (Bauer et al., 2020). There is increased potential for cost-savings depending on the types of life-sustaining treatments that would be avoided based on the individual’s diagnosis and ACP preferences (Bauer et al., 2020). The cost of cardiopulmonary resuscitation followed by a stay in the intensive care unit costs upwards of $16,441 (Bauer et al., 2020). According to Duncan et al., the average inpatient Medicare cost per day within 1-3 days of a patient's death is $5983 (2019). An average ED visit is $2032 according to a study by United Healthcare (Parker et al., 2019). The costs of care increase without any guarantee of improved quality of life or preservation of life. The extraordinary costs of dementia provide a unique opportunity for APRNs and the interdisciplinary team to provide an intervention that works to integrate individualized ACP decisions into plans of care in order to avoid personally unwanted medical intervention.

APRNs have the knowledge and expertise to implement ACP as well as have meaningful conversations about clinical questions or concerns about the medical aspects regarding ACP. There is an opportunity for APRNs to collaborate with other members of the interdisciplinary healthcare team to create a holistic advance care planning intervention. APRNs and providers such as physician's assistants or physicians often are responsible for introducing and discussing ACP. However, in settings outside of primary care, other disciplines may be responsible for ACP discussions. At the designated PACE site, social workers are the professionals responsible for implementing and discussing ACP with participants and their caregivers. Social workers are adept at facilitating conversations that may be difficult, fostering crucial communication, and are competent at engaging in ACP implementation (Kwak et al., 2022). Social workers may have gaps in knowledge about clinical questions that may arise during an ACP conversation thus the need for collaboration between disciplines is important. The Doctor of Nursing Practice (DNP) prepared APRN is prepared to lead a multidisciplinary team approach to ACP for individuals with dementia. DNP prepared APRNs have education in not only advance pathophysiology, pharmacology, and physical health assessment but advanced preparation in quality improvement, business management, health policy, evidence-based practice, and collaboration across disciplines. Their leadership skills lend to being a key player in leading a team-based dementia-specific ACP intervention. Collaboration across disciplines would enhance the dementia-specific ACP intervention.

Problem Statement

The rate of documented dementia cases is expected to increase significantly in the next decade, impacting many individuals and their family members with this progressive, life-altering disease. Without advance care planning, cognitive decline causes those diagnosed with dementia or cognitive impairments to have limited opportunity to participate in their own decision-making process. Lack of engagement in decision-making conversations results in high rates of potentially unwanted invasive medical intervention and low levels of quality-of-life. Medical costs of these medical interventions increases financial burdens on individuals, their families, and taxpayers. Implementation of a dementia-specific advance care planning tool can help to decrease unnecessary suffering of individuals with dementia, provide support to their surrogate decision-makers, and decrease healthcare utilization costs.

Clinical Question

Does the implementation of a dementia-specific advance care planning tool help increase knowledge and decision-maker confidence, as well as decrease inappropriate healthcare utilization rates?

Review of the Literature

The purpose of this literature review was to assess the literature relevant to the topic of ACP implementation in individuals with dementia and/or their family caregivers. Literature regarding ACP targeted to surrogate decision-makers, impact of ACP on individuals with dementia, and challenges to implementing ACP, including dementia-specific ACP was analyzed.

Three databases were utilized including PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Proquest. The search was limited to publication dates from the last six years (2017-2022), peer reviewed, and published in English. Search terms included dementia, advance care planning or advance directive, quality of life, and dementia-specific. Each source was evaluated for relevance to the phenomenon of interest. If an abstract met required criteria, it was selected for a full-text read. A total of ten articles were found to support the review of literature. Articles included five systematic reviews, one was a qualitative study, three were interventional studies, and one was a longitudinal study.

Review and analysis of the evidence identified five themes. Themes included 1) barriers to advance care planning, 2) caregiver support and education, 3) advance care planning and quality of life, 4) the needs and roles of healthcare professionals, and 5) the lack of dementia-specific advance care planning. Each theme is presented below.

Barriers to Advance Care Planning

Seven out of the ten articles identified that there are multiple barriers and challenges to advance care planning with individuals with dementia (Bosisio et al., 2021; Fried et al., 2021; Geddis-Regan et al., 2020; Gotanda et al., 2022; Huang et al., 2020; Sellars et al., 2019; Wendrich van-Dael et al., 2020). One of the most commonly discussed barriers to ACP in individuals with dementia was that many individuals diagnosed with dementia and their caregivers do not understand the terminality of dementia (Bosisio et al., 2021; Fried et al., 2021; Gotanda et al., 2022; Huang et al., 2020). Often, especially soon after an individual is diagnosed, there is confusion regarding the progressive nature of dementia and that it is a terminal condition. Individuals with dementia and their family caregivers often do not understand that dementia will continue to progress at an unknown rate and result in continued decline which will often be the cause or contribution to their death. Due to this misunderstanding, individuals with dementia and their family caregivers often do not see the necessity to participate in ACP until there is significant cognitive decline.

Another barrier to ACP implementation is that individuals with dementia find it difficult to discuss end-of-life care choices with their families or do not wish to dwell on the inevitable (Bosisio et al., 2021; Fried et al., 2021; Geddis-Regan et al., 2020; Sellars et al., 2018; Wendrich van-Dael et al., 2020). Discussing death is never easy and it is even more difficult for individuals who know that at end-of-life they most likely will not be the same person that they are at present (Fried et al., 2021; Sellars et al. 2018). Several articles identified that, individuals with dementia voiced hesitancy in discussing ACP and end-of-life care options because they did not want to cause their loved ones premature distress (Fried et al., 2021; Sellars et al. 2018). They often said that they did not want to dwell on what may come or the end but rather savor the present and the time that they had being fully themselves (Fried et al., 2021; Sellars et al. 2018).

A third barrier to ACP completion was that individuals with dementia believed their loved ones would make their desired decisions without any paperwork or preparation (Fried et al., 2021). Individuals with dementia often believed that their loved ones would make the choices that they would make for themselves despite never having intentional ACP documents or conversations (Fried et al., 2021).

Lack of Support & Education for Surrogate Decision-Makers

The second theme identified was lack of support, education, and preparation for surrogate decision-makers (Bosisio et al., 2021; Fried et al., 2021; Geddis-Regan et al., 2020; Huang et al., 2020; Kim et al., 2020; Ma et al., 2021; Sellars et al., 2019). Surrogate decision-makers are often under-prepared and under-educated on caregiver role responsibilities. Without adequate planning, a surrogate decision-maker may have a limited understanding of what the individual with dementia’s choices may be and struggle with feelings of indecision or guilt (Fried et al., 2021; Sellars et al., 2019). When ACP was completed and/or the individuals with dementia had conversations about end-of-life care choices with their surrogate decision makers the level of anxiety, fear, and guilt decreased (Fried et al., 2021; Geddis-Regan et al., 2020; Kim et al., 2021; Ma et al., 2021; Sellars et al., 2019). Surrogate decision-makers reported increased confidence in their ability to make decisions on the behalf of the individual with dementia (Fried et al., 2021; Geddis-Regan et al., 2020; Kim et al., 2021; Ma et al., 2021; Sellars et al., 2019). When ACP is completed individuals with dementia experience higher levels of quality of life at end-of-life.

Advance Care Planning Promotes Quality of Life

Individuals with dementia who completed ACP experience higher levels of quality of life at end-of-life than their counterparts without ACP (Bosisio et al., 2021; Dixon et al., 2018; Gotanda et al., 2022; Huang et al., 2020; Sellars et al., 2019; Wendrich van-Dael et al., 2020). Individuals with dementia who have ACP had lower levels of healthcare utilization including hospitalization rates and emergency department visits (Dixon et al., 2018; Wendrich van-Dael et al., 2020). They also had lower rates of life-prolonging treatment and burdensome treatments like enteral feeding tubes (Dixon et al., 2018; Gotanda et al., 2022; Sellars et al., 2019). When ACP was completed, the care provided towards individuals with dementia at end-of-life was more comfort care orientated instead of life-sustaining.

ACP completion also helped to improve the relational quality of life for both the individual with dementia and their loved ones. Those with ACP in place experienced lower rates of decisional conflict among their family members (Bosisio et al., 2021; Dixon et al., 2018; Huang et al., 2020). There was also an increased concordance between the choices that the surrogate decision-maker made on behalf of the individual with dementia and the choices that they wished to have (Bosisio et al, 2021; Dixon et al., 2018; Wendrich van-Dael et al., 2020). Since quality of life is subjective to the individual, ensuring that their healthcare choices are being carried out is important (Dixon et al., 2018). The healthcare professional plays a major role in ACP completion and providing education about end-of-care choices so that individuals with dementia and their loved ones are informed decision-makers.

Healthcare Professionals' Roles & Needs

Nine out the ten articles analyzed in this literature review highlighted the importance of healthcare professionals in the completion and advocacy for ACP (Bosisio et al., 2021; Dixon et al., 2018; Fried et al., 2021; Geddis-Regan et al., 2020; Gotanda et al., 2022; Huang et al., 2020; Kim et al., 2021; Sellars et al., 2019; Wendrich van-Dael et al., 2020). Healthcare professionals have the critical role of having honest discussions regarding the importance of advance care planning for all of their patients but especially those diagnosed with dementia (Bosisio et al., 2021; Fried et al., 2021; Geddis-Regan et al., 2020; Gotanda et al., 2022; Huang et al., 2020; Kim et al., 2021; Sellars et al., 2018; Wendrich van-Dael et al., 2020). Primary care providers have a unique opportunity to introduce the concept of ACP to their patients and their family members. Due to the nature of their relationship, they are able to reinforce education about ACP with each subsequent visit. Primary care providers also are able to follow their patients with dementia throughout the progression of their disease allowing for continual education about the disease progression and interventions.

Advocacy for advance care planning with patients with dementia and their families is a crucial role of healthcare professionals. However, many healthcare professionals do not feel adequately prepared or educated to provide effective, competent advance care planning to their patients (Bosisio et al., 2021; Kim et al., 2021; Sellars et al., 2019; Wendrich van-Dael et al., 2020). As identified in the research, healthcare providers in these articles often express a desire to implement ACP with their patients but do not feel like they had an adequate training to do so in the most effective manner (Bosisio et al., 2021; Kim et al., 2021; Sellars et al., 2019;

Wendrich van-Dael et al., 2020). Providers verbalized frustration in their inability to support their patients and families in this crucial phase of care. The research also noted that many providers felt that there was an opportunity for increased education about dementia and the implementation of ACP (Bosisio et al., 2021; Kim et al., 2021; Sellars et al., 2019; Wendrich van-Dael et al., 2020).

Lack of Dementia-Specific Advance Care Planning

The limited availability and use of dementia-specific advance care planning tool was discussed in three of the ten articles reviewed (Fried et al., 2021; Ma et al., 2021; Sellars et al., 2018). In a qualitative study, the lack of dementia-specific advance care planning was a frustration to some individuals with dementia and their caregivers (Fried et al., 2021). The participants felt that the ACP tools available did not address the questions, concerns, or topics that were important to dementia end-of-life issues (Fried et al., 2021). The findings of these three articles highlighted that there was support for increased research and development of dementia-specific tools to be used during advance care planning discussions. Research supports that dementia-specific ACP tools would help foster ACP conversations between patients and their family members (Fried et al., 2021; Ma et al., 2021; Sellars et al., 2018). Some dementia-specific ACP tools have since been developed, such as the “Dementia Directive” and “The Dartmouth Dementia Directive” though research utilizing these tools remains limited (Dartmouth College, 2019; Gaster, 2017).

Future Research

Opportunity exists for additional research regarding advance care planning in individuals with dementia and their family members. Continued investigation around best practices for educating individuals with dementia and their family members about the progression of dementia and successful execution of advance care planning is essential. Further research about the emotional road of dementia and end-of-life for caregivers and decision-makers should be explored to provide support and guidance before end-of-life. Improving individual and family understanding of dementia and end-of-life care options could lead to increased quality of life at the end of life as reflected in the review. Investigation focusing on ACP discussions between the surrogate decision maker and the individual with dementia about end-of-life care choices would be beneficial to help support and resolve issues of burden and guilt.

The evidence from this review cumulates a need for continued research in the development and implementation of a dementia-specific advance care planning tool. A dementia-specific ACP tool would aim to increase education about the progression of dementia, end-of-life care choices, foster conversations about end-of-life between the individual with dementia and their surrogate decision-maker, and improve quality of life at end-of-life.

Organizational Assessment

Program of All-Inclusive Care for the Elderly (PACE) is a program funded by Medicare and Medicaid (Care Resources, 2021a). The program serves adults 55 years or older who qualify for increased nursing services and works to help keep individuals in their homes, support family caregivers, or assist with placement into nursing homes when needed (Care Resources, 2021a). PACE provides all-inclusive services including an interdisciplinary care team, prescriptions, home care, transportation, recreational activities, and a community center (Medicaid.gov, n.d.). While the program serves over 50,000 people across the United States, more than 2 million individuals qualify for PACE services (Robinson & Herr, 2019). A midwestern PACE site was used as the site for this pilot project. This PACE site serves 320 individuals in their various programs (Care Resources, 2021b). A SWOT analysis was performed to anticipate compatibility of the project and determine the strengths, weaknesses, opportunities, and threats of implementation in the PACE setting.

Strengths

Multiple strengths for implementing a dementia specific ACP tool at the PACE program site were identified. Each PACE center has a diverse interdisciplinary care team including primary care providers, therapy (physical, recreational, occupational and speech), nurses, social worker, dietician, home care liaison, drivers, personal care technicians, and center supervisor (Medicaid.gov, n.d.). There is a large focus on preventative medicine and PACE is recognized as a community resource for older adults with the support of many local organizations (Care Resources, 2021a; Medicaid.gov, n.d.; Medicare.gov, n.d.).

The project PACE site has been working on a quality improvement (QI) project to decrease emergency department (ED) visits and decrease inpatient admissions for its participants (Care Resources, 2021b). Members of the leadership team voiced excitement in the opportunity to pursue process improvement in their implementation of advance care planning. One of the nurse practitioners on staff worked with other PACE providers and the leadership team to foster excitement for the quality improvement project. There was immediate buy-in from many of the leadership team members including the PACE center manager. PACE is recognized in the community as a resource for older adults and they have partnerships with many local organizations to support their participants (Care Resources, 2021b).

Weaknesses

Communication and scheduling with surrogate decision-makers was an important aspect of the pilot project. Surrogate decision-makers are not present at the day center. Decision-makers often are difficult to contact and often work full-time creating scheduling difficulties. The same weaknesses existed for the two to three month follow up for decision-makers as well.

Opportunities

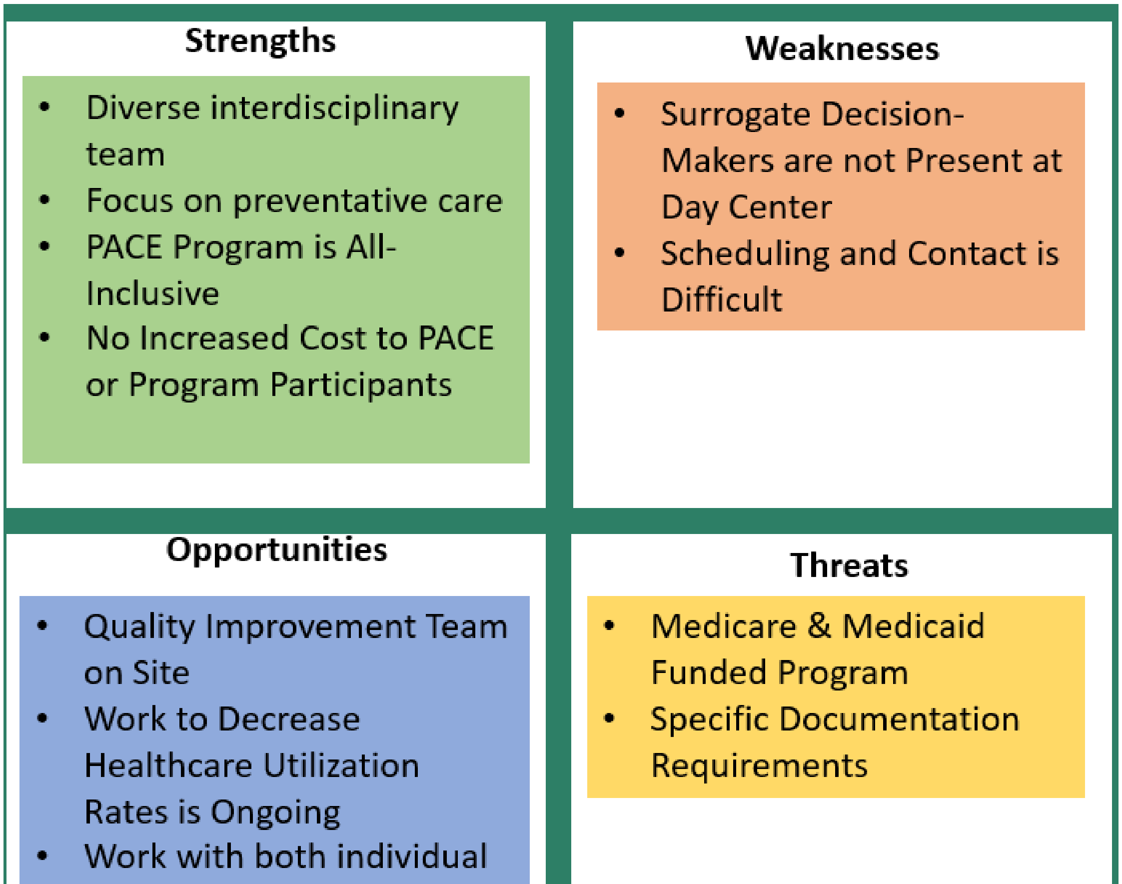
PACE has been working to reduce rates of unnecessary healthcare utilization. The goal of the dementia specific ACP tool project supported the PACE site's ongoing QI project to reduce healthcare utilization rates. Participants attend the center by themselves. ACP typically aims to include the individual's family caregiver or whoever would be the designated decision-maker at end-of-life. The social work team is in frequent contact with many caregivers. There is an opportunity to facilitate communication between the PACE participant, their caregiver(s), and the PACE interdisciplinary team regarding ACP.

Threats

PACE is funded by Medicare and Medicaid therefore is regulated by the government. There are very specific regulations for all documentation including every interaction between a participant of their caregivers. Specific documentation standards must be followed in order to meet Medicare and Medicaid standards.

Figure 1

Organizational Assessment



Strengths

- Diverse interdisciplinary team
- Focus on preventative care
- PACE Program is All-Inclusive
- No Increased Cost to PACE or Program Participants

Weaknesses

- Surrogate Decision-Makers are not Present at Day Center
- Scheduling and Contact is Difficult

Opportunities

- Quality Improvement Team on Site
- Work to Decrease Healthcare Utilization Rates is Ongoing
- Work with both individual

Threats

- Medicare & Medicaid Funded Program
- Specific Documentation Requirements

Theoretical Framework

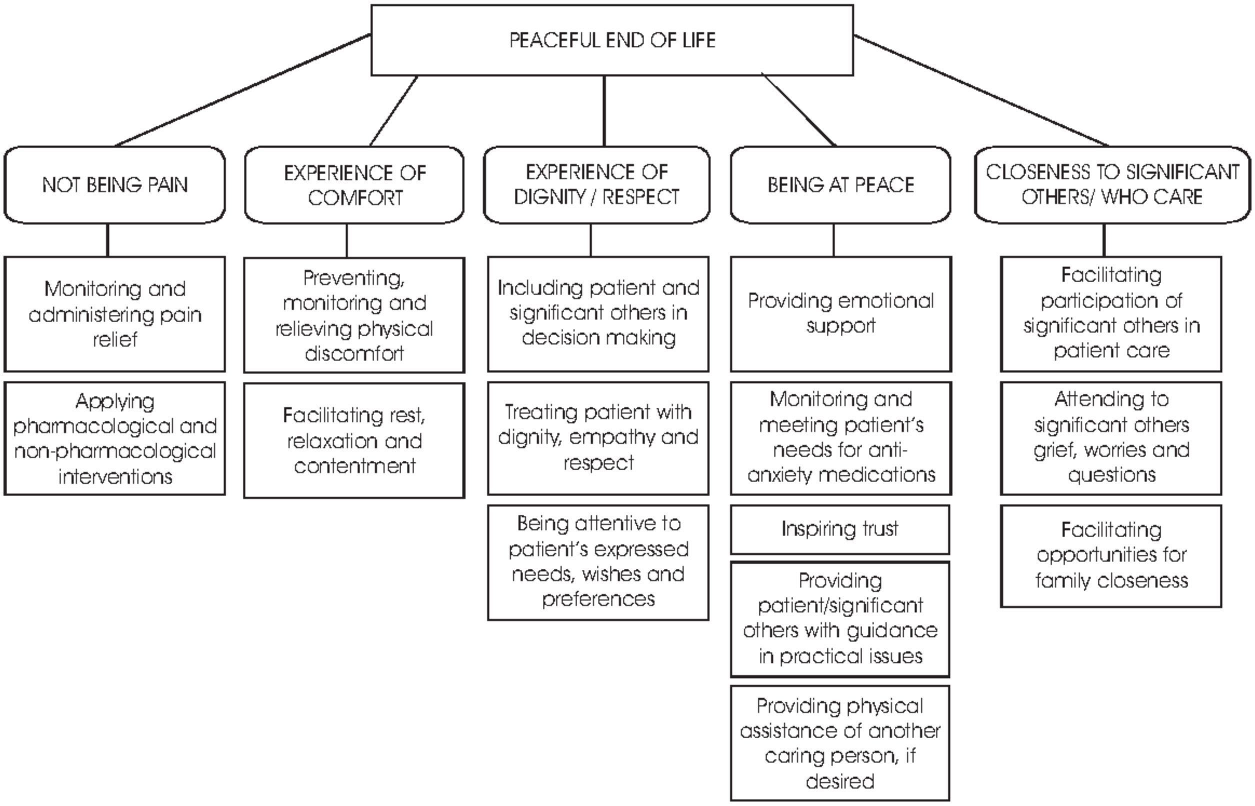
Peaceful End-of-Life Theory was developed by Ruland and Moore in 1998 after their work with terminally ill patients (McEwen &Wills, 2014). This model has five concepts that are standards of care for the individual at end-of-life (McEwen & Wills, 2014). The five concepts are: Not being in Pain, Experience of Comfort, Experience of Dignity/Respect, Being at Peace, and Closeness to Significant Others/Persons who Care (McEwen & Wills, 2014). The Peaceful End-of-Life Theory was used as a framework for this project. Each of the five standards of care concepts provided concepts to be included in the dementia-specific advance care planning tool and end-of-care decision education. For the project participants the ACP session helped to facilitate conversation about what it meant to each participant to be comfortable and without pain. The discussion also explored what it meant to be treated with respect and dignity throughout the progression of their disease. What being at peace meant to each participant was elicited through conversation about desire healthcare decisions. The importance of relationships in their care and the involvement of love ones in their decision-making was also discussed.

Part of the dementia-specific ACP intervention included education about the progression of dementia with the aim of increasing knowledge of the disease for both the individual with dementia and their surrogate decision-maker. The hope was that increased understanding of dementia would help both parties to be informed decision-makers and have conversations about care preferences for end-of-life. The ACP discussion also included what kind of medical interventions would be acceptable, and which would be unacceptable for the individual with dementia. For example, would the individual with dementia want an enteral feeding tube.

Discussion about care preferences between the individual with dementia and their surrogate decision-maker fosters peaceful end-of-life. The surrogate decision-maker should be included in as many of these conversations and the ACP intervention as possible. Surrogate decision-makers and caregivers are integral in providing the type of care and making the decisions that the individual with dementia would make on their own behalf. As explored in the literature review, surrogate decision-makers struggle with the burden of their role especially when they have no preparation or idea what choices their loved ones would want. Assisting the surrogate decision-maker and the individual with dementia to have these discussions would work to ensure peace at end-of-life and closeness to caregivers and loved ones.

Figure 2

Peaceful End-of-Life Theory



Conceptual Framework

Analysis of this quality process improvement project also used the Donabedian Model for Quality of Care to direct areas of analysis (National Health Service [NHS], 2021). The Donabedian Model assesses quality in three categories structure, process, and outcome (NHS, 2021). Utilization of the Donabedian model allowed for agreement between the DNP student leader and the multidisciplinary team about what important evaluation measures should be studied.

Structure Measures

Structure measures are attributes of the program or providers to provide services to program participants (NHS, 2021). The project PACE program has many attributes that were both beneficial to the participants that they serve and the goal of this project. The social work team at the PACE has experience in ACP implementation and works one-on-one with new enrollees. This means that the social work team's current process supported the dementia-specific ACP intervention process change. The decisions discussed during the ACP session were uploaded into the participant's electronic medical record (EHR). The primary care provider (PCP) is the key interdisciplinary team member in the creation and modification of the participants' plan of care. The PCP team is instrumental in working with the participants and their surrogate decision-makers to create plans of care that reflect the decisions in their ACP documents.

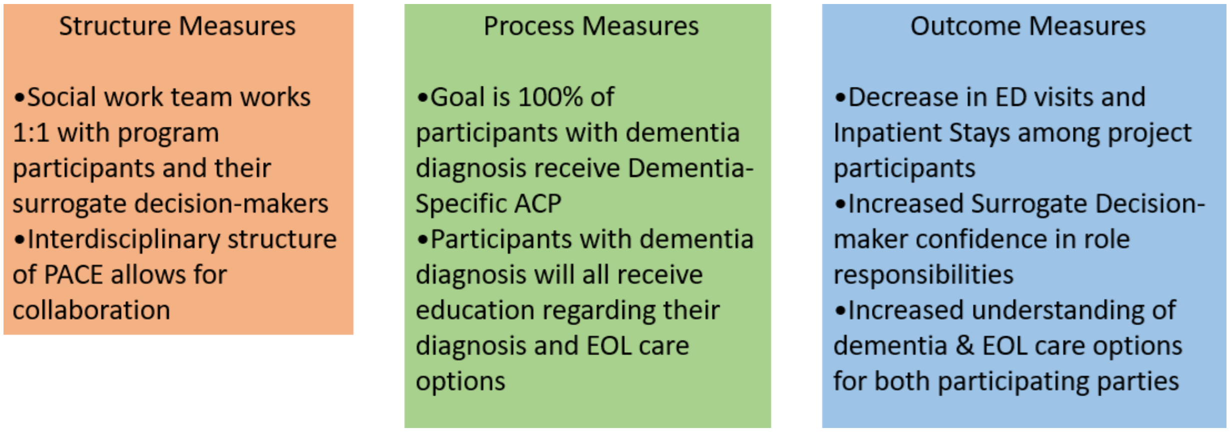
Process Measures

Process measures are attributes that demonstrate the ability of the program to achieve the desired outcomes and deliver services (NHS, 2021). New participants with dementia receive the dementia-specific ACP intervention upon completion of enrollment. During the ACP intervention each participant and their surrogate decision-maker received dementia-specific disease and end-of-life care option education.

Outcome measures specifically identify what outcomes and changes are being assessed as a result of the implemented project. This project assessed three outcome measures which include knowledge of dementia in individuals with dementia and their surrogate decision-makers, confidence of surrogate decision-makers, and healthcare utilization rates.

Figure 3

Donabedian Model



Structure Measures

- Social work team works 1:1 with program participants and their surrogate decision-makers
- Interdisciplinary structure of PACE allows for collaboration

Process Measures

- Goal is 100% of participants with dementia diagnosis receive Dementia-Specific ACP
- Participants with dementia diagnosis will all receive education regarding their diagnosis and EOL care options

Outcome Measures

- Decrease in ED visits and Inpatient Stays among project participants
- Increased Surrogate Decision-maker confidence in role responsibilities
- Increased understanding of dementia & EOL care options for both participating parties

Purpose Statement

The purpose of this project was to determine if the implementation of a dementia-specific advance care planning tool improved:

1. Participant and caregiver knowledge of the progression of dementia.
2. Participant and caregiver knowledge of end-of-life care options.
3. Caregiver confidence in decision-making responsibilities.
4. Healthcare utilization rates including emergency department visits and inpatient admissions.

Methods & Design

Ethical Considerations

Prior to project implementation, PACE provided a letter of consent followed by Institutional Review Board (IRB) review and approval at Detroit Mercy. The project required a full IRB review due to the vulnerability of individuals with dementia. The privacy and confidentiality of each participant was protected under the Health Insurance Portability and Accountability Act (HIPAA). Both parties, the individual with dementia and the surrogate decision-maker, consented to participate in the project. In the event that individual with dementia was not legally capable to give consent for being included in the project, consent was obtained from the legally designated surrogate decision-maker for both participating parties. Confidentiality of all participants was kept throughout the project. Consent and the completed dementia-specific ACP tool were uploaded to the PACE site EHR. Surveys were de-identified and kept in a limited access file. If at any point during the implementation process any participant no longer wished to continue to participate, they were allowed to withdraw from the project without fear of consequences.

Setting

This quality improvement project was performed at a midwestern PACE site. PACE serves individuals with physical and cognitive needs that would require these individuals to have higher levels of skilled care. However, because of the all-inclusive nature of the PACE program these individuals are able to stay in their homes or lower-level care facilities (ex. independent living) (Medicare.gov, n.d.). The project PACE site had 248 participants at the time of the project and enrolls eight to ten new participants every month. The majority of existing and new participants have a dementia or cognitive impairment diagnosis.

Participants

Participants included older adults, 55 years or older, who were new enrollees at the project PACE in the Midwest. Inclusion criteria included: 1) new participants with a pre-existing dementia or cognitive impairment diagnosis or a MOCA scale score of 19 or less, 2) an individual designated as their surrogate decision-maker or who may become their surrogate decision-maker, and 3) English speaking. This project provided the ACP intervention directed towards dyads consisting of the participant with dementia and their surrogate decision-maker. New enrollees were excluded from the project if: 1) they did not have a pre-existing dementia or cognitive impairment diagnosis or a MOCA scale score greater than 19, 2) individuals who did not speak English since the tools utilized were available in English only, and 3) if the new participant did not have an individual who was willing to be their surrogate decision-maker. Five months of new participants who qualified based on inclusion criteria were approached about receiving the dementia specific advance care planning intervention. The goal was to have 10-15 participant dyads included in this project.

Intervention

1. The multidisciplinary team consisting of the PCP and Social work teams were educated about the project process, assessment surveys, participant inclusion and exclusions criteria, and goals of the project.
2. The social work team and the project leader worked together to identify appropriate new enrollees to participate in the project based on the inclusion/exclusion criteria.
3. Baseline healthcare utilization rates for project participants (for emergency department visits and inpatient admissions) were be obtained for the four months preceding the beginning of the project.

4. Identified new participants and their surrogate decision-maker met with a member of the social work team and the project leader for an advance care planning session. Project inclusion was determined either via a pre-existing dementia or cognitive impairment diagnosis or by a MOCA score of 19 or less. The MOCA score was obtained during the new enrollee's initial clinic enrollment visit with the social work team.
    a. Instead of the standard ACP forms that PACE previously used, the participants in this project received a dementia-specific form.
    b. Before beginning the ACP session, the social worker and project leader obtained baseline data for the knowledge assessment and the confidence scale from the participant with dementia and their surrogate decision-maker.
    c. The social worker and project leader facilitated a conversation between the participant with dementia and their surrogate decision-maker guided by the dementia-specific ACP tool (see Appendix #1 "Dementia Directive" and Appendix #2 supplemental ACP form) (Gaster, 2017). They assisted both parties to discuss future care decisions and to complete the ACP tool for future use.
    d. After completing the ACP session(s) the social worker and project leader obtained immediate post-implementation survey data by having the individual with dementia and the surrogate decision-maker complete the knowledge assessment and the confidence scale surveys again.
    e. The social worker and project leader also had the participant and the surrogate decision-maker complete a brief qualitative questionnaire that provided feedback on the new dementia-specific ACP process. This was a one-time survey.
5. Implementation of the project continued until eleven dyads of new enrollment participants were completed.

6. At approximately three months post-implementation (for each dyad) the social work team and the project leader obtained three-month post-implementation survey data. The participant with dementia and their surrogate decision-maker completed the knowledge assessment and confidence scale for the final time.
7. Healthcare utilization rates were obtained for four months post-implementation for the project participants.

Data Collection & Tools

- Dementia Specific Advance Care Planning Tool: This project utilized a tool called "Dementia Directive" (see Appendix #1) (Gaster, 2017). This tool was created by a physician specializing in dementia care and it discusses specific needs of individuals with dementia and their surrogate decision-makers (Gaster, 2017). A supplement, created by the project leader, was used along with the "Dementia Directive" to specifically address questions that often arise during the care of an individual with dementia such as feeding tubes, fluid resuscitation, the use of vasopressors, etc. (see Appendix #2).
- Knowledge Assessment: A quantitative knowledge assessment was utilized to obtain baseline, immediate post-implementation, and three-month post-implementation data about dementia, ACP, and end-of-life care decisions from both the participant with dementia and their surrogate decision-maker (see Appendix #3). The project leader compared the data from baseline, immediate post-implementation, and three-month post-implementation to see if the ACP intervention led to a statistical difference.
- Confidence Scale Assessment: A quantitative confidence scale assessment was utilized to obtain surrogate decision-maker confidence in their ability to perform the role of decision-maker and advocate for the participant with dementia (see Appendix #4). This scale was obtained at baseline, immediate post-implementation, and three-months post-

implementation. The author compared the data from baseline, immediate post-implementation, and three-month post-implementation to see if the ACP intervention led to a statistical difference.

- Advance Care Planning Experience Questionnaire: A brief qualitative questionnaire was utilized to gain insight about the dementia-specific ACP experience (see Appendix #5). This short questionnaire provided both the participant with dementia and the surrogate decision-maker the opportunity to share thoughts about the process and how they believe the process will impact them. The questionnaire was collected once immediately post-implementation. The questionnaires were analyzed for themes to help continue improving the dementia-specific ACP process and understand the personal impact the process has.
- Healthcare Utilization Rates: Care Resources PACE actively tracks and records all healthcare utilization data including emergency department visits and inpatient admissions. Four months of baseline pre-implementation healthcare utilization data and four-month post-implementation data were obtained via EHR chart review.

Social Work Feedback Survey

In order to ensure that the dementia-specific ACP tool and process fit the needs of the PACE participants and the social work team, a post-implementation survey was sent to elicit feedback. The post-implementation survey was open to every member of the social work team.

Evaluation Methods

Three outcome measures were assessed in this project. The objective and how each was assessed are discussed below.

- The participant with dementia will have statistically significant increase in knowledge of dementia and end-of-life care decisions by the three month follow up after the multi-disciplinary led dementia-specific ACP tool implementation.

- The surrogate decision-maker will have a statistically significant increase in knowledge of dementia and end-of-life care decisions by the three month follow up after the multi-disciplinary led dementia-specific ACP tool implementation.
    - A knowledge assessment was administered before implementation and immediately after implementation.
    - Three-months post-implementation the knowledge assessment was re-administered.
    - The participant's knowledge and the surrogate decision-maker's knowledge was assessed separately and pre and post assessment data was compared. The analysis helped to determine the impact that the dementia-specific ACP intervention had on both parties' understanding of dementia and the end-of-life care options that are available.
- Surrogate decision-makers will have a statistically significant increase in confidence scores by the three month follow up after the implementation of the multi-disciplinary led dementia-specific ACP tool.
    - Surrogate decision-maker confidence was assessed before the ACP intervention and immediately after implementation using a Likert scale-based confidence assessment.
    - The same confidence assessment was used two to three months post implementation to re-evaluate decision-maker confidence.
    - The final score for both pre and post confidence assessment was compared to analyze the effectiveness of the ACP intervention for surrogate decision-maker confidence.

- Healthcare utilization rates among the participants who received the dementia-specific ACP intervention will fall below the benchmark of less than 0.12 for ED visits per 1000 days and less than 0.06 inpatient stays per 1000 days after the implementation of the dementia-specific ACP tool at the three month follow up mark.
    - Data for four months before implementation was collected to obtain a baseline rate of healthcare utilization for all project participants.
    - Healthcare utilization data was then be collected for four months post ACP implementation and analyzed to identify if there was a decrease in healthcare utilization rates after the intervention.
- Advance Care Planning Experience Questionnaire was completed by the participant with dementia and the surrogate decision-maker together. It was collected after the initial ACP session with the social work team.

Data Analysis

Pre-implementation data was compared to the immediate post-implementation data collected after the dementia-specific ACP session. Non-parametric analytics, performed with SPSS, were used to analyze the data due to the small sample size. Wilcoxon rank sum test was utilized to analyze the knowledge assessment score for both the participants with cognitive deficits and the surrogate decision-maker. Surrogate decision-maker confidence assessment scores were analyzed using Wilcoxon rank sum test as well.

Intellectus Statistics was used to perform non-parametric analytics for the three data collection points. Friedman’s test was performed to analyze the participant with cognitive deficit’s knowledge assessment score at pre-implementation, immediate post-implementation, and three months post-implementation. Friedman’s was also utilized to analyze surrogate decision-maker knowledge and confidence assessment scores from the same three data collection points.

Chart review was performed on the project sample participants. A total combined ED and inpatient admission rate was obtained for four months pre-implementation and four months post-implementation. The total healthcare utilization rate was compared pre- and post-implementation.

Results

Participant Demographics

There were eleven dyads consisting of an individual with dementia, or a cognitive impairment diagnosis and their chosen surrogate decision-maker were included in the project. The participants were all newly enrolled into the project PACE site from February 2023- July 2023. All the participants with dementia/cognitive impairment included in the project were female. There were newly enrolled male participants that qualified to be part of the project but they did not wish to participate or they did not have an individual willing to participate as their surrogate decision-maker. The majority of the included individuals with dementia/cognitive impairment were 70-79 years in age (Figure 4). Approximately half of the participants were Caucasian and the other half African American (Figure 5). Three of the individuals had a dementia diagnosis and the other eight individuals had a cognitive impairment ranging in MOCA score of 9-19 (Figure 6). The majority of the surrogate decision-makers involved in the project were adult children of the participants with dementia/cognitive impairment (Figure 7).

Figure 4

Age of Participants with Dementia/Cognitive Impairment

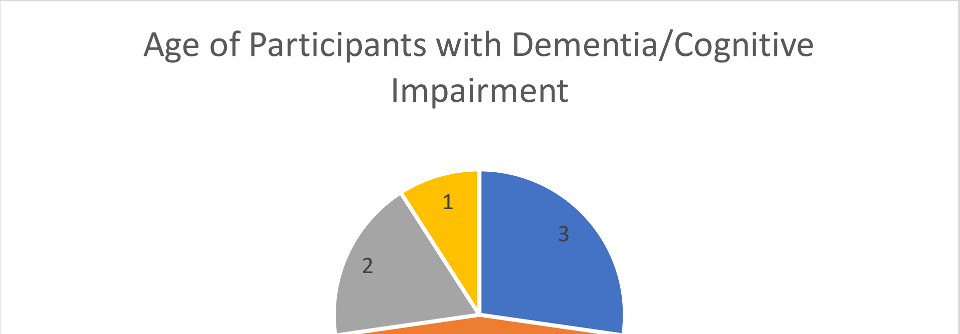


Figure 5

Ethnicity of Participants with Dementia/Cognitive Impairment

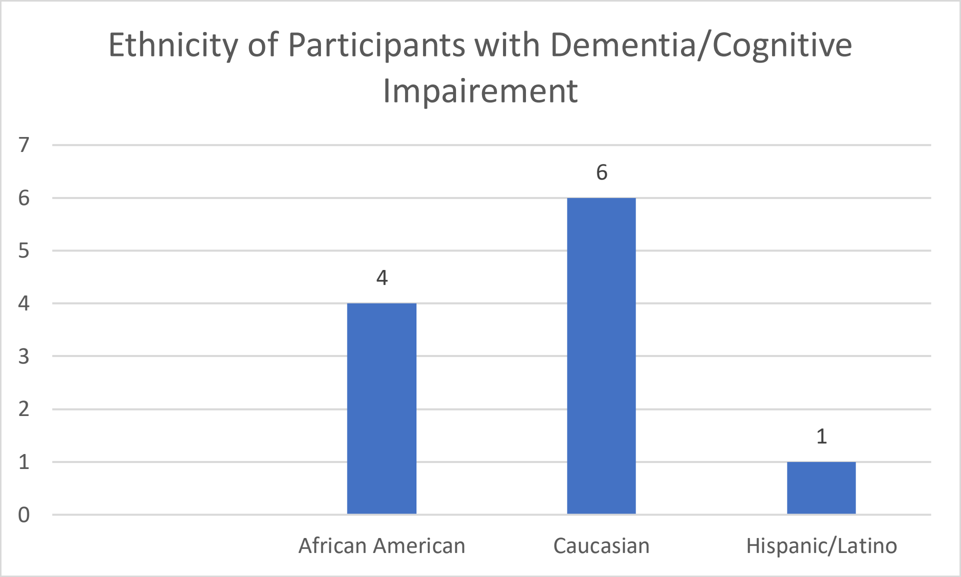


Figure 6

Diagnosis of Participants with Dementia or Cognitive Impairment

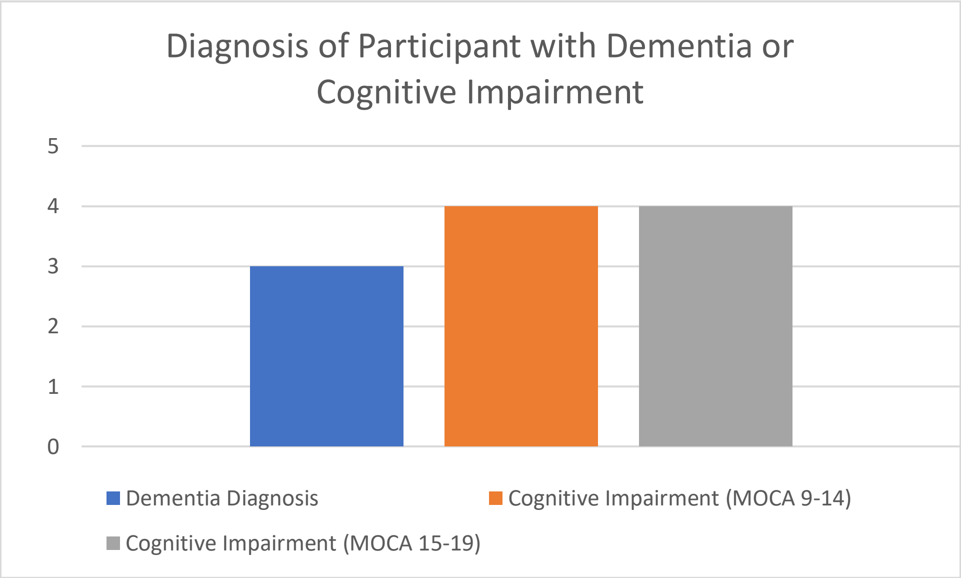
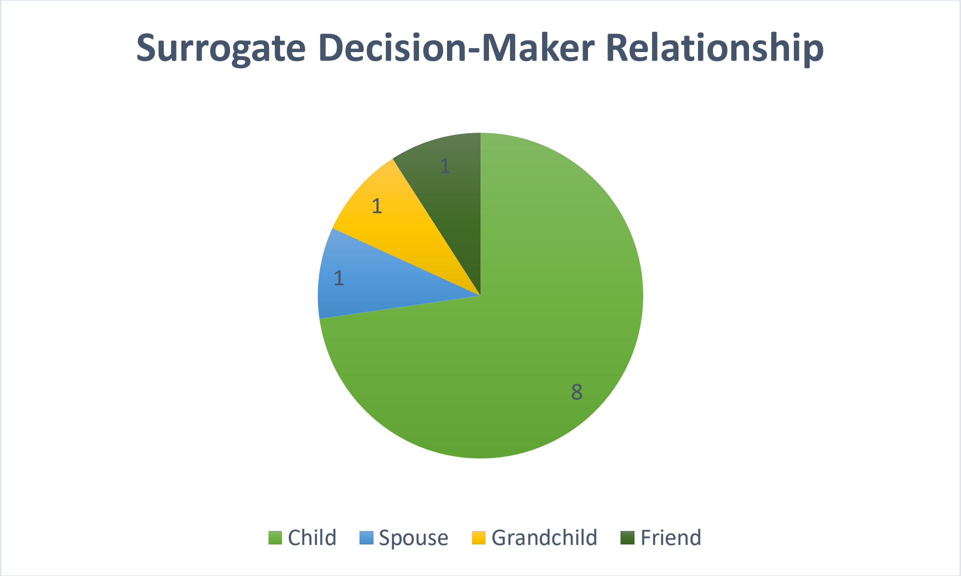


Figure 7

Surrogate Decision-Maker Relationship



Data Results

Participant with Dementia/Cognitive Impairment Knowledge Assessment

The participants with dementia had an average pre-implementation knowledge assessment score of 76.6 % as compared to an average immediate post-implementation score of 75.9%. Wilcoxon sum rank test was performed to determine if the participants with dementia knowledge improved as a result of the ACP session. Statistical analysis revealed *p*= 0.809 indicating there was not statistically significant improvement in the participants with dementia knowledge after the ACP session.

Friedman's test was performed to compare the participants with dementia knowledge assessment score between pre-implementation, immediate post-implementation, and three months post-implementation follow up. Statistical analysis revealed p=0.886 indicating there was not statistically significant improvement of the participants with dementia knowledge score at any of the three data collection points. Some participants did demonstrate a considerable improvement in their knowledge score though not enough to achieve statistical significance.

Surrogate Decision-Maker Knowledge Assessment

Surrogate decision-makers had an average pre-implementation knowledge score of 89.6% as compared to an average immediate post-implementation knowledge score of 95.4%. Wilcoxon sum rank test was performed to determine if the surrogate decision-makers knowledge improved as a result of the ACP session. Statistical analysis revealed p=0.026 indicating that there was statistically significant improvement in knowledge scores in surrogate decision-makers after the ACP session.

Friedman's test was performed to compare the surrogate decision-makers knowledge assessment score between pre-implementation, immediate post-implementation, and three months post-implementation follow up. Statistical analysis revealed p=0.018 indicating a statistically significant improvement in surrogate decision-makers knowledge across all three data collection points. Surrogate decision-makers had increased knowledge after the ACP session and sustained their knowledge at three months follow up.

Surrogate Decision-Maker Confidence Score

Surrogate decision-makers had an average pre-implementation confidence score of 78.9% as compared to an average immediate post-implementation score of 92.0%. Wilcoxon sum rank test was performed to determine if the surrogate decision-makers confidence improved after the ACP session. Statistical analysis revealed p= 0.017 indicating that there was statistically significant improvement in confidence scores in surrogate decision-makers after the ACP session.

Friedman’s test was performed to compare the surrogate decision-makers confidence assessment score between pre-implementation, immediate post-implementation, and three months post-implementation follow up. Statistical analysis revealed $p=0.005$ indicating a statistically significant improvement in surrogate decision-makers confidence across all three data collection points. Surrogate decision-makers had increased confidence after the ACP session and sustained their confidence at three months follow up.

Healthcare Utilization Rates

Chart review was completed for the 11 participants from the project sample. Inpatient admissions and ED visits were manually recorded for each participant from the project sample for the four pre-implementation months (February-May 2023) and four post-implementation (June-September 2023). A combined inpatient admission and ED visit rate was obtained for both pre-implementation and post-implementation. The pre-implementation healthcare utilization total was 11 inpatient admissions and ED visits. The post-implementation healthcare utilization total was nine inpatient admissions and ED visits. Four of the post-implementation visits can be attributed to one study participant who signed on to hospice and then passed away during the post-implementation period.

Qualitative Results

To better understand both the participant with dementia and the surrogate decision-maker’s thoughts on the dementia-specific ACP process, a qualitative questionnaire was completed at the end of the ACP session. The questionnaire asked three questions aimed at determining if the ACP session helped facilitate conversation between the dyad members, increase understanding about options for care, and empower future decision-making. Dyads agreed that the dementia specific ACP process was beneficial to them with 90.9% answering positively to all three questions.

Three themes were identified from the qualitative questionnaire. The three themes were identified facilitating conversation, improved understanding of care options and resources, and empowered decision-making. Both members of the dyads felt that the ACP session improved conversation between the participant with dementia and the surrogate decision-maker. They also felt that they felt they had better access to resources and more informed for future decision-making.

Social Work Feedback Survey Results

A post-implementation survey was administered to the social work team to assess what aspects of the tool or the dementia-specific ACP process could or should be modified for the future. Four social workers completed the survey. All four survey respondents felt that the dementia-specific ACP tool was a good or strong fit for their participant population. Respondents were asked what they liked about the ACP tool. The social workers appreciated that the tool provided education for the individual with cognitive deficits and their surrogate decision-makers about the progression or dementia and what kind of care and choices are available. They also reported that they like that the ACP tool allowed their participants with cognitive deficits to be more specific about the type of care they would want throughout the progression of their disease and therefore helped their surrogate decision-makers to understand their wishes as well.

The respondents reported that with the inclusion of the data collection surveys the time required for implementation was quite lengthy. Other suggestions included the modification of some of the tool’s language to be more empathetic and to include more questions specific to mental health needs. To help prepare the dementia-specific ACP tool for future use at the project PACE site, respondents also added that having the tool included in the new participant enrollment process would be helpful and including information about completing healthcare Designated Power of Attorney (DPOA) documentation should be included in the process as well. Feedback from the survey was included in the presentation of the project results to the social work team.

Discussion

The individuals with cognitive deficits had varying levels of engagement with the ACP conversation. This is likely related to their stage of cognitive decline ranging from early, mild stages to late-stage, severe disease. Varying level of engagement likely also contributed to the statistically insignificant findings of the participant with cognitive deficit in relation to the limited improvement in knowledge of their disease state and progression. Some individuals with dementia showed evidence of learning but not enough to have a statistically significant knowledge assessment outcome. The individuals who showed evidence of learning should not be discounted. Rather, it is important to note that the individuals who showed the highest level of learning or maintenance of learning were those in the earlier stages of their cognitive deficit. This outcome reflects the findings of the literature that discussed the challenges of engaging individuals with advanced stage cognitive deficit in the ACP conversation, but supports dementia-specific ACP implementation with individuals in the earlier stages of their disease process.

Surrogate decision-makers had increased knowledge and confidence assessment scores after the dementia-specific ACP session. Pre-implementation data showed that many decision-makers were unaware of what kind of decisions their loved one would want in the future. Again, this reflects the findings discussed from the literature that most decision-makers feel underprepared for their future role. Dementia-specific ACP allowed the decision-makers to gain clarity regarding their loved one’s preferences and ask questions to both the healthcare professionals administering the tool and their loved one.

PACE programs are their own insurance company. They are responsible for all medical costs of their participants. PACE has a process that their participants are asked to follow when needing or wanting to use healthcare outside of the PACE interdisciplinary team. Program participants are asked to call the triage nurse before going to the ED with the exception of life-threatening incidents such as a fall/chest pain/possible stroke/etc. The triage nurse then recommends either to go to the ED or sets up follow up for the program participant with the appropriate interdisciplinary healthcare team member.

There were multiple reasons why project participants visited the ED before project implementation including chest pain, weakness, falls, respiratory distress, cognitive impairment, acute and chronic pain. After implementation reasons included acute/chronic pain, deconditioning, chest pain, constipation, fatigue, bowel ischemia, falls, bells palsy, hypertension and acute confusion. Care Resources tracks and monitors all ED visits and inpatient admissions. Their goal is to decrease their total healthcare utilization rates including ED visits and inpatient stays by using their multidisciplinary team and chain of care as much as possible to control costs. After project implementation there was one project participant who accounted for four of the ED visits due to progression of her metastatic malignancy. This one outlier could have skewed the healthcare utilization results. A longer longitudinal study examining the effect of early dementia-specific ACP on healthcare utilization and the financial outcomes would be benficial. With two fewer inpatient stays or ED visits PACE saved an estimated $4064-$11,966 in Medicare costs based on research conducted by Duncan et al. and a study by United Healthcare (Duncan et al., 2019; Parker et al., 2019).

The dementia-specific ACP sessions revealed that many individuals with cognitive deficits would like to avoid life-sustaining medical interventions in the advanced stages of their disease. These decisions were documented so that they may be reflected in their individualized plans of care. These conversations supported the work of reducing overall healthcare utilization rates at PACE. By including ACP decisions in project participants' plans of care, unwanted healthcare intervention can be avoided and therefore help to decrease the total rate of utilization. The literature review found that individuals with dementia who had ACP in place had lower rates of life-sustaining interventions which was reflected in the PACE study as well.

Sustainability Plan

To sustain the work started through the dementia-specific ACP quality improvement project, all tools, materials, and findings were shared with both the PACE social work and PCP team. The findings of the project were shared with each team with time to ask questions and clarify next steps for the process. The social work team will take over the dementia-specific ACP process and incorporate the tool into their enrollment process for new PACE participants. They also plan to revisit the ACP of PACE participants who were enrolled prior to the project's start. Their goal is that every PACE participant with a dementia diagnosis, cognitive impairment diagnosis, or a qualifying MOCA score participate in the dementia-specific ACP process.

The PCP team at PACE was also informed of the study findings and the goals for continued improvement. The PCP team will be responsible for revisiting each PACE participant's ACP and ensure that their plan of care matches their documented decisions. Each PACE participant's ACP will be re-evaluated at the six month and annual visit with both their PCP and their social work case worker. The goal is that the participants' plan of care aligns with their preferences for care throughout the progression of their disease.

Limitations

Three limitations were noted. A small sample size was included in this pilot project. Only 11 dyads were included for the first half of the project and 10 participants with a cognitive deficit completed the two to three month follow up related to a participant passing away between implementation and follow up. Only nine surrogate decision-makers completed the two to three month follow up related to the participant who passed away and one surrogate decision-maker who could not be contacted for follow up.

The participants with cognitive deficits had varying levels of cognitive decline. There were varying levels of ability to engage in the ACP session and to discuss desired future care decisions. The results of the participants with cognitive deficits may not be generalizable to all individuals diagnosed with dementia or cognitive impairments due to the various degrees of cognitive decline.

Minimal qualitative feedback was obtained during the immediate session follow up. The questions on the qualitative survey should have offered more open-ended questions to elicit more in-depth responses. The participants with the cognitive deficit were all at varying stages of cognitive decline. This meant that there was more difficult for some participants to actively participate in the ACP discussion and data collection.

Implications for Practice

APRNs are well-suited to lead an interdisciplinary team approach to advance care planning especially for older adults with dementia. Collaboration across healthcare disciplines in the delivery of ACP works to decrease gaps in implementation. Teamwork between social workers, APRNs, and PCPs ensures that eligible participants are identified for dementia-specific ACP, receive the ACP intervention, and that continued follow up occurs. Surrogate decision-makers lack education and preparation for their role as advocate and decision-maker. However, dementia-specific ACP increases surrogate decision-maker knowledge of dementia and confidence in their ability to perform role of advocate and decision-maker. Individuals diagnosed with a cognitive deficit begin losing their ability to fully participate in ACP conversations and so ACP should be implemented as soon after diagnosis as possible. Only female individuals with dementia participated in this quality improvement project. There is a need to increase implementation of dementia-specific ACP and education with males diagnosed with cognitive deficits. Ensuring the completion of dementia-specific ACP may also reduce rates of non-emergent healthcare utilization. Reduction of healthcare utilization can decrease healthcare costs for both the individual and taxpayers. The multi-disciplinary team at PACE allows for dementia-specific ACP implementation and integration of individual ACP decisions into personalized plans of care.

Conclusions

Dementia-specific ACP ensures that individuals diagnosed with dementia are able to decide what is acceptable versus unacceptable care at each stage of their disease. The dementia-specific ACP process also helps to create clarity and confidence for future decision-makers on what is important to their loved ones. Dementia-specific ACP has the potential to reduce healthcare utilization secondary to avoiding ED visits and inpatient stays when these are deemed unacceptable by an individual’s ACP documentation. Collaboration between disciplines can facilitate the ACP process and ensure that the decisions made by the individual with cognitive deficits are reflected in their plan of care.

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Appendix #1

“Dementia Directive” Advance Care Planning Tool

What If I Had Dementia?

Planning for the future

Alzheimer’s disease is one of the most common problems people face in their 70’s and 80’s. One of the most important things you can do is tell people who would be taking care of you what medical care you think you would want if you were to develop worsening dementia.

What is dementia? Over many years, people with Alzheimer’s (and other forms of dementia) lose the ability to understand what is going on around them. In later stages, people with dementia no longer recognize people they know. They need help from others with their own basic body functions. At times they might still enjoy some experiences. At other times they can become angry and confused.

There is no cure for dementia. Gradually people lose the ability to speak, eat, and walk. Eventually people die from dementia, often from dementia-related pneumonia. This process can take anywhere from 5 years to 20 years.

One of the most important questions to consider is: what kind of medical care do you think you would want if you were to develop worsening dementia?

Why it is important to express your wishes. People with advancing dementia lose the ability to make decisions for themselves. Their families need to make medical decisions for them. Giving family members guidance about what type of care you would want can help ease the burden of their decision making and help you feel more secure that you will receive the care that you would want.

Some people may not want to give this type of guidance, but would rather trust their families to make decisions. For those people, this Directive may not be helpful. However, many people do want to provide some guidance for their family, even if it is hard to know exactly what your future situation might be.

What kinds of guidance can you give? You can say, ahead of time, what you would want the focus of your medical care to be. At what point would you still want everything done to keep you alive longer? At what point might you want only hospice-type care focused mainly on treating your symptoms and keeping you comfortable?

Stage 1 -- Mild dementia

With mild dementia, people may often lose the ability to remember what just happened to them. Routine tasks become difficult, such as cooking. Some tasks can become more dangerous, such as driving.
If you were to be at this stage of dementia what medical care would you want?

Select **one** of the 3 main goals of care listed below to express your wishes. Choose the goal of care that best describes what you would want if you had Mild Dementia.
If I have mild dementia then I would want the main goal for my care to be:

☐ **To live for as long as I can**. I would want full efforts to prolong my life, including efforts to restart my heart if it stops beating.

☐ **To receive treatments to prolong my life, but** if my heart stops beating or I can't breathe on my own, then I would not want my heart shocked to restart it and I would not want to be put on a breathing machine. **(DNR and Do Not Intubate)** Instead, if my heart stops or I can't breathe on my own, allow me to die peacefully.
Why you might choose this goal: If your mind were already not working well due to dementia, and something suddenly happened which stopped your heart or made you unable to breath on your own, the chances are high that even if you survived the ICU, your brain would be more damaged. So some might say, "If I would likely be worse off if I survived, then I would prefer to die peacefully."

☐ **To receive comfort-focused care only.** (Including DNR and Do Not Intubate)
I would only want medical care to relieve symptoms such as pain, anxiety, or breathlessness. I would not want care to keep me alive longer. It would be important to me to avoid sending me to a hospital or ER, unless that was the only way to keep me more comfortable, because trips to the hospital when someone has dementia can be quite traumatic.

Stage 2 -- Moderate dementia

In moderate dementia, communication becomes very limited. People lose the ability to understand what is going on around them. People require daily full-time assistance with dressing and often toileting. They can sometimes become quite confused and agitated and paranoid. Some people appear to be content much of the time.
If you were at this stage of dementia what level of medical care would you want?
Select **one** of the 3 main goals of care listed below to express your wishes. Choose the goal of care that best describes what you would want if you had Moderate Dementia.
If I have moderate dementia then I would want the main goal for my care to be:

☐ **To live for as long as I can**. I would want full efforts to prolong my life, including efforts to restart my heart if it stops beating.

☐ **To receive treatments to prolong my life, but** if my heart stops beating or I can't breathe on my own, then I would not want my heart shocked to restart it and I would not want to be put on a breathing machine. **(DNR and Do Not Intubate)** Instead, if my heart stops or I can't breathe on my own, allow me to die peacefully.
Why you might choose this goal: If your mind were already not working well due to dementia, and something suddenly happened which stopped your heart or made you unable to breath on your own, the chances are high that even if you survived the ICU, your brain would be more damaged. So some might say, "If I would likely be worse off if I survived, then I would prefer to die peacefully."

☐ **To receive comfort-focused care only.** (Including DNR and Do Not Intubate)
I would only want medical care to relieve symptoms such as pain, anxiety, or breathlessness. I would not want care to keep me alive longer. It would be important to me to avoid sending me to a hospital or ER, unless that was the only way to keep me more comfortable, because trips to the hospital when someone has dementia can be quite traumatic.

Stage 3 -- Severe dementia

In severe dementia, people are no longer able to recognize loved ones and family members. Some people with severe dementia may be calm and serene much of the time, but many go through periods of agitation. They can be awake through the night. They can be angry, disruptive, and yelling. People need 24-hour help with all daily activities, including bathing and assistance with all basic body functions.
Select **one** of the 3 main goals of care below you'd want if you had Severe Dementia.
If I have severe dementia then I would want the main goal for my care to be:

☐ **To live for as long as I can**. I would want full efforts to prolong my life, including efforts to restart my heart if it stops beating.

☐ **To receive treatments to prolong my life, but** if my heart stops beating or I can't breathe on my own, then I would not want my heart shocked to restart it and I would not want to be put on a breathing machine. **(DNR and Do Not Intubate)** Instead, if my heart stops or I can't breathe on my own, allow me to die peacefully.
Why you might choose this goal: If your mind were already not working well due to dementia, and something suddenly happened which stopped your heart or made you unable to breath on your own, the chances are high that even if you survived the ICU, your brain would be more damaged. So some might say, "If I would likely be worse off if I survived, then I would prefer to die peacefully."

☐ **To receive comfort-focused care only.** (Including DNR and Do Not Intubate)
I would only want medical care to relieve symptoms such as pain, anxiety, or breathlessness. I would not want care to keep me alive longer. It would be important to me to avoid sending me to a hospital or ER, unless that was the only way to keep me more comfortable, because trips to the hospital when someone has dementia can be quite traumatic.

Appendix #2

Supplemental Advance Care Planning Tool

Dementia-Specific Advance Care Planning: Supplemental Form

1. If I were to lose the ability to eat safely or the desire to eat I:

   ☐ **Would** want a feeding tube (through my nose or into my abdomen) to provide nutrition.

   ☐ **WOULD NOT** want a feeding tube placed.

2. If my blood pressure was to become dangerously low or dangerously high I:

   ☐ **Would** want to receive intravenous medications in the ICU to manage my blood pressure.

   ☐ **WOULD NOT** want to receive intravenous medications in the ICU to manage my blood pressure.

3. If I was acutely ill and my provider felt that I need fluid resuscitation through an IV I:

   ☐ **Would** want to receive IV fluids per my provider.

   ☐ **WOULD NOT** want to receive IV fluids per my provider.

4. If my blood levels became low to the point that I required a blood or blood product transfusion I:

   ☐ **Would** want to receive a blood or blood product transfusion.

   ☐ **WOULD NOT** want to receive a blood or blood product transfusion.

Appendix #3

Knowledge Assessment Survey

Dementia and Advance Care Planning: Knowledge Assessment

1. Dementia is a disease that can be cured.
    a. True b. False
2. Dementia is a disease that a person will have forever.
    a. True b. False
3. People who have dementia often have memory loss and lose the ability to talk about their wishes as their dementia gets worse.
    a. True b. False
4. People with dementia will always be able to eat normally.
    a. True b. False
5. People with dementia will always be able to talk to their loved ones normally.
    a. True b. False
6. People with dementia may someday not be able to recognize their loved ones.
    a. True b. False
7. People with dementia can prepare for the future by discussing their healthcare decisions with their loved ones and a trusted healthcare provider.
    a. True b. False
8. Advance Care Planning is a document that clearly talks about the person with dementia's healthcare decisions.
    a. True b. False
9. Advance Care Planning is important to prepare before the person with dementia loses their ability to talk about their wishes.
    a. True b. False

10. Advance Care Planning forces people to make healthcare decisions that they don’t actually want.
    a. True b. False
11. By preparing Advance Care Planning, people with dementia can make decisions about what kind of end-of-life care they want or do not want.
    a. True b. False
12. People with dementia’s loved ones always know what kind of decisions they would want so you don’t have to talk about their dementia getting worse.
    a. True b. False
13. End-of-Life care can include hospice care.
    a. True b. False
14. Hospice care helps to make sure that a person is comfortable and does not have unwanted medical tests or procedures.
    a. True b. False

Appendix #4

Surrogate Decision-Maker Confidence Assessment

1. How confident are you that you know your loved one's healthcare decisions in the event they lose the ability to tell you themselves?

No Confidence	Little Confidence	Some Confidence	Confidence	High Confidence
1	**2**	**3**	**4**	**5**

2. How confident are you that you know if and when your loved one would want their code status to be changed to "Do Not Resuscitate" (DNR)?

No Confidence	Little Confidence	Some Confidence	Confidence	High Confidence
1	**2**	**3**	**4**	**5**

3. How confident are you that you know if your loved one would want to be put on a ventilator (breathing machine) in the event they can no longer breather on their own?

No Confidence	Little Confidence	Some Confidence	Confidence	High Confidence
1	**2**	**3**	**4**	**5**

4. How confident are you that you know if your loved one would like to have a feeding tube in the event that they no longer can eat on their own?

No Confidence	Little Confidence	Some Confidence	Confidence	High Confidence
1	**2**	**3**	**4**	**5**

5. How confident are you that you know what kind of care (palliative care, hospice care, etc.) your loved one would want at the end of their life?

No Confidence	Little Confidence	Some Confidence	Confidence	High Confidence
1	**2**	**3**	**4**	**5**

Appendix #5

Advance Care Planning Experience Qualitative Questionnaire

Dementia Advance Care Planning Session: Feedback

1. Do you feel that this advance care planning helped you and your loved one to talk about your wishes for the future?

2. Do you feel that you have a better understanding of your options for care and options for end-of-life after advance care planning?

3. After this advance care planning session, do you feel more prepared and empowered to make healthcare decisions for yourself or your loved one?